

**EXPLORING A CHILD'S DEVELOPMENTAL DIAGNOSIS: AN
INTERPRETIVE DESCRIPTION OF PARENTS' EXPERIENCES IN
NORTHERN BRITISH COLUMBIA**

by

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ABSTRACT

Background: Full parental understanding of a child's diagnosis of a developmental disability is critical to be able to ensure the best health outcome for their child. Yet factors that parents perceive as influencing their comprehension during the final diagnostic meeting have not been well identified. **Method:** As part of a qualitative study using interpretive description, 17 parents were interviewed on the basis of their having been referred to, and for having received a child's developmental diagnosis from a Complex Developmental Behavioural multidisciplinary team located in northern British Columbia. Semi-structured interviews focused on the factors that played a role in facilitating or impeding the parents' understanding of their child's diagnosis, and on the identification of factors that influenced the way in which the child's clinical recommendations were pursued. The interviews were recorded and transcribed. Data analysis was informed by Braun and Clarke's six phases of thematic analysis. **Results:** Three overarching themes with twelve subthemes emerged from parents' reported experiences of receiving their child's developmental diagnosis. The three overarching themes and twelve subthemes included (a) clinical encounter (including the subthemes structural considerations, professional diversity and new insights, questions regarding the assessment process, validation, and expectations); (b) the manner of the delivery of the diagnosis (impact—emotional and impact on parenting practices, professionalism, professional language, and quantity of information); (c) Where do we go from here? (post disclosure, the final evaluation report, and recommendations). The parents' accounts established and clarified the positive and negative parental determinants that aided or challenged their ability to understand their child's developmental diagnosis and identified the influence this had when it came to implementing the clinical recommendations.

Conclusions: Parents reported several factors played a role in facilitating or impeding their ability to comprehend their child's diagnosis. The risks and benefits associated with the child's recommendations extend beyond the medical exchange that occurred at the family disclosure meeting. The parents' narratives provided insight into a complex phenomenon.

TABLE OF CONTENTS

Abstract.....	ii
Table of Contents	iv
List of Tables	vii
Acknowledgements	viii
Dedication	ix
Chapter 1 Introduction.....	1
Informing this Research.....	1
Clinical Problem	3
Purpose of the Research.....	5
Research Question	5
Disciplinary Framework—Theoretical Location.....	6
Assumptions	8
Definition of Terms	8
Summary.....	11
Chapter 2 Literature Review	13
Shifts in Professional Practice	14
Formal Diagnostic Process	19
Gender	21
Length of Diagnostic Assessment	23
Multidisciplinary Team	25
Professional Communication and Parental Prerequisites	27
Communication Techniques	32
Formal Education.....	35
Mnemonic Approaches	38
Efficacy of Guidelines	41
Parental Experience and Impact	42
Concepts of Cultural Excellence	49

Cultural Safety	50
Cultural Competence	53
Cross-Cultural Practice	54
Summary	57
Chapter 3 Disciplinary Framework and Methodological Approach	59
Social Work Discipline.....	59
Practice Wisdom.....	61
Social Work and Epistemology	62
Social Constructionism.....	63
Research Design	65
Ethical Considerations	70
Confidentiality	71
Role of the Researcher.....	73
Recruitment Strategies.....	74
Details of Data Collection	77
Interview Protocol	78
Interview Procedures	79
Data Analysis.....	80
Verification Strategies	84
Peer Review	87
Member Checking	87
Reflexivity	88
Summary.....	90
Chapter 4 Findings	91
Introduction.....	91
Snapshot of Data Analysis.....	92
The Participants	93
Overall Parental Experiences of their Child’s Developmental Diagnosis.....	95
Overarching Theme 1: Clinical Encounters	95
Subtheme 1: Structural Considerations	97
Subtheme 2: Professional Diversity and New Insights	108

Subtheme 3: Questions Regarding the Assessment Process	116
Subtheme 4: Validation	121
Subtheme 5: Expectations	125
Overarching Theme 2: The Manner of the Delivery of the Diagnosis	129
Subtheme 1: Impact (Emotional Impact)	130
Impact on Parenting Practices	134
Subtheme 2: Professionalism	137
Subtheme 3: Professional Language	139
Subtheme 4: Quantity of Information.....	141
Overarching Theme 3: Where Do We Go From Here?	144
Subtheme 1: Post Disclosure	144
Subtheme 2: The Final Evaluation Report	147
Subtheme 3: Recommendations	150
Summary.....	156
Chapter 5 Discussion	158
Clinical Encounters.....	159
The Manner of the Delivery of the Diagnosis	163
Where Do We Go From Here?	169
Summary.....	172
Practice Considerations	173
Limitations of the Study	178
Future Research	178
Conclusion	179
Reflections	181
References.....	183
Appendix A: Interview guide.....	205
Appendix B: Information Letter and Consent Form	207
Appendix C: Member Checking Letter	211
Appendix D: Ethics Board Approval	212

LIST OF TABLES

Table 1	<i>Demographics of Participants in Terms of Regional Location, Gender, Ethnicity, and Biological or Adoptive Parent</i>	94
Table 2	<i>Themes and Sub-themes Arising from the Interviews</i>	156
Table 3	<i>Protective Factors that Facilitate and Risk Factors that Impede Parental Understanding.....</i>	168
Table 4	<i>Protective Factors that Facilitate and Risk Factors that Influenced Parents' Implementation of Clinical Recommendations</i>	172
Table 5	<i>Practice Considerations for Delivering a Child's Developmental Diagnosis with Parents</i>	177

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DEDICATION

I dedicate this dissertation to my son, Matthew Stubley. My son was one of the major motivators for my pursuit of a PhD. I wanted to ensure that I was able to provide a quality life for my son in all areas of his life. At times, balancing a PhD and parenting posed a challenge but, given that I co-parent with his father, I was able to manage. I began my PhD journey when my son was 2 years old—and he now is 9 years old.

Chapter 1 Introduction

This dissertation, explored the experiences of parents that received a comprehensive diagnostic assessment of their child by one of the Complex Developmental Behavioural Conditions (CDBC) multidisciplinary teams located across northern British Columbia. The parental experience of understanding a child's diagnostic assessment is not well documented in the literature. Although it is not appropriate to form generalizations from the data depicted in my study, this important research allows for the generation of new ideas and can inform clinical practice and create innovative practice techniques when delivering diagnostic findings, which, in turn, may potentially improve outcomes for children and families. My chosen methodology of "interpretive description draws upon the philosophical structure of applied disciplinary knowledge for its interior logic and design decisions" (Thorne, 2013, p. 295). Chapter 1 includes my personal and disciplinary knowledge that capitalizes on the angle of vision that the discipline of social work brings to an applied methodological approach in a healthcare setting. In addition, the purpose of my research, the significance of the study, the guidance of social work epistemology and its limitations; outlines the research questions and provides definitions of terms and an outline of chapters that follow.

Informing this Research

For the past decade, I have worked in a variety of clinical capacities where I interacted with children and families in different settings. I had countless conversations with families who endured frustration and conflict regarding their level of understanding of what was shared by a professional that was involved in some capacity in their life. It was noted by the parent that the professional's style of delivery (communication) often left the parent in a

state of confusion, as there was an apparent lack of insight into what the parent understood about their particular situation. My professional role as a Senior Practice Analyst (quality assurance) with the Ministry of Children and Family Development provided the opportunity to gain clinical wisdom into the professional interactions with families in the practice of child welfare. I was often perplexed by the discrepancies in the understandings held, on the one hand by the social worker and on the other hand, by the parents. Interviews with child protection social workers and families showed that parents lacked an understanding of the content that was being delivered by the social worker. Statements of helplessness and expressions of misunderstanding were not uncommon to hear from the family (parent). Parents reported that the involvement of the child welfare system triggered anxiety and stress, which, in turn, clouded their ability to fully understand the message being delivered.

On a personal level, I was diagnosed with cancer in January 2007. I experienced the challenges involved when I first heard my diagnosis and was faced with trying to make sense of the disease and the unique treatment journey associated with my particular type of cancer. There was no doubt that the professional delivery of my diagnosis coupled with the anxiety of hearing bad news impacted my ability to fully comprehend the diagnosis. My professional practice discipline—social work—coupled with my personal experience has fuelled my interest in exploring this clinical problem in a different context—a health setting. Through this research journey, my goal was to expand the understanding of this experiential phenomenon and provide practice considerations for health professionals tasked with the delivery of a diagnosis. Specifically, the parental experiences of hearing a child's developmental diagnosis by a multidisciplinary team (health professionals) that specializes in comprehensive diagnostic assessments. Insight from the parent's perspective produced

clinical strategies for clinicians to enhance parental understanding within the delivery of a child's diagnostic assessment.

Clinical Problem

Approximately 16% of children experience a developmental issue in the course of their childhood (Levy, 2011; WHO, 2001) and it has been reported that there appears to be a recent spike in the incidence of neurodevelopmental disorders in children resulting in emotional and behavioural problems (Blanchard, Gurka, & Blackman, 2006; Brauner & Stephens, 2006; Fombonne, 2009). Consequently, families often embark on a professional journey to receive a developmental diagnostic assessment for their child. Providing a clinical diagnostic assessment for children and youth with complex developmental and behavioural disabilities—and securing the involvement and support needed for and from their families—is often a complex task. Hence, in the area of autism, Chudley et al. (2005) strongly recommend that a neurodevelopmental diagnosis be performed by a multidisciplinary team of health professionals given the intricacies associated with clinical impairment.

There is no doubt that the clinical diagnostic disclosure is a pivotal time for parents (Tattersall & Young, 2006) as it provides information about their child and allows families to make informed decisions about the various domains of their child's life. The manner in which health professionals communicate a child's developmental diagnosis has been shown to influence the parent in a number of ways. The disclosure of the clinical diagnostic assessment has a dramatic effect on how and whether parents accept and manage their child's developmental diagnosis (Taanila, 2002). Furthermore, depending on the way in which the information is professionally disclosed, the emotional effect on the parents can be mediated

in ways that influence the parents' views of their child, either positively or negatively (Bartolo, 2002).

A common theme throughout the related literature is a widespread dissatisfaction on the part of parents with respect to the way their child's developmental diagnosis was professionally communicated (Cunningham, Morgan, & McGucken, 1984; Edelstein & Strydom, 1981; Liptak et al., 2006; McKay & Hensey, 1990; O'Sullivan, Mahoney, & Robinson, 1992; Pearson, Simms, Ainsworth, & Hill, 1999; Quine & Pahl, 1987; Sloper & Turner, 1993). Parental satisfaction is an important determinant for their child's plan and future well-being (Bartolo, 2002).

Parents who received devastating news in a blunt manner about their children's health reported that the news gave rise to feelings of denial, blame, grief, confusion, anger, and pain (Cottrell & Summers, 1990). However, if it is executed skillfully, the professional delivery of the diagnostic assessment findings can facilitate parental understanding of their child's needs (Bartolo, 2002). Several researchers examined various perspectives during and after the comprehensive diagnostic assessment process. However, very little has been published on the determinants of parental understanding in the context of delivering a child's developmental diagnosis and the influence this has on the parent's ability to implement the clinical recommendations. This poses a concern given that parental adherence to clinical recommendations is crucial to positive outcomes for children (Hock, Kinsman, & Ortaglia, 2015). This apparent gap in clinical practice knowledge provides the foundational rationale for my research and the study aims.

Purpose of the Research

The goal of my research was to examine and explore the experience of parents who received a comprehensive developmental diagnostic assessment for the purpose of informing clinical practice and future research, and guidelines designed to improve the professional delivery of final diagnostic assessments, all intended to improve health outcomes for children and families.

Research Question

The overarching research question of this study is: What is the experience of parents who received a comprehensive diagnostic assessment by one of the Complex Developmental Behavioural Conditions (CDBC) multidisciplinary teams across northern British Columbia?

The specific aims of this question were to:

1. reveal factors that played a role in facilitating or impeding the parents' understanding of their child's developmental diagnostic assessment, and
2. identify factors that influenced the implementation of the child's clinical recommendations.

My research explored the experiences of parents who received a comprehensive diagnostic assessment of their child by one of the CDBC multidisciplinary teams in northern British Columbia. The CDBC teams are situated within a larger healthcare system—Northern Health—that serves residents across northern British Columbia. Northern British Columbia covers a large geographical area encompassing a number of rural areas which include families from diverse cultures. Across the northern region seventeen parents participated in my research. The families that received a diagnostic assessment of their child from their respective CDBC multidisciplinary team were residents of Prince George, Quesnel, Vanderhoof, and Burns Lake.

Specifically, my study revealed factors that played a role in facilitating or impeding parental understanding of their child's clinical diagnostic assessment disclosed at the final family meeting and identified factors that influenced the way in which the clinical recommendations were implemented following the delivery of the diagnosis.

Disciplinary Framework—Theoretical Location

The conventional qualitative approaches to inquiry (phenomenology, grounded theory, narrative, ethnography, case study) dictate that a study must be firmly positioned within a theoretical framework (Thorne, 2014). It was common for nursing scholars to subscribe to one of the aforementioned qualitative approaches despite concerns related to the theoretical constraints associated with the specified methodological choice (Morse, 1989; Thorne, 2008). Thorne, Stephens, and Truant (2016) claimed that the adherence to an external theoretical framework compromised the logical integrity of a nursing enterprise, as the findings generated had minimal impact on the application to practice. As such, interpretive description was conceived and recognized as an applied qualitative methodology

derived from nursing epistemology that borrows the best technique from conventional social science methods in the absence of the external theoretical constraint (Thorne, 2013). Thorne et al. (2016) argue that the “intellectual underpinnings of an applied discipline can provide an effective framework where qualitative technique can be aligned” (p. 452).

In preparation for writing my dissertation, I read a wide range of scholarly books and professional discipline publications, which prompted a great deal of critical reflection and confusion as I located a theoretical framework that aligned best with my research ideas—both academically and professionally. I achieved a great sense of clarity and methodological direction when I became engaged in the application of interpretive description. Upon examination, it was clear that this methodology was well suited for a clinical setting that sought to generate knowledge relevant for a particular context. For example, Hunt (2009) conducted an inquiry into the moral experiences of clinicians performing humanitarian work by way of interpretive description. In addition, Buissink-Smith and McIntosh (1999) executed an interpretive description design in the area of tourism and hospitality.

A number of theoretical approaches would have described the complexities involved in my study. However, it was my aim to move beyond description of the parental experiences and absorb the intricate factors that played a vital role in shaping the parental experiences—providing insight that informed professional practice in a health context. Based on the similarities of practice between the two applied disciplines of social work and nursing in a healthcare setting (Holliman, Dziegielewska, & Teare, 2003), I recognized the profound effect that my discipline knowledge played in offering a solid framework that guided my applied qualitative inquiry. In Chapter 3, I demonstrate a clear and logical

pathway describing social work's disciplinary epistemology, influenced by social constructionism, to defend and justify my methodological integrity.

Assumptions

Interpretive description “explicitly recognises and capitalises on the researcher as the instrument” (Thorne, 2008, p. 64). In other words, the researcher's chosen procedures and the rationale that drives the research trajectory play a significant role in moulding the inherent features of one's inquiry (Thorne, 2008). The following assumptions were made in reference to my study:

1. Parents of children who received a developmental diagnosis by one of the multidisciplinary teams in northern British Columbia shared what they believed to be the most pertinent and relevant information related to their experience.
2. Parents of children who went through the comprehensive diagnostic assessment process willingly participated in my study as they were genuinely interested in sharing their experiences to enhance the delivery style of the multidisciplinary team to ultimately ensure that future families exit the family meeting with a solid understanding of their child's diagnostic finding.
3. Receiving their child's diagnosis by way of a multidisciplinary team provided the parents with a broader understanding of their child's overall functioning, which lead to a shift in parental practices.

Definition of Terms

The operational definitions for the terms used in this study are as follows:

Bad News: Bad news has recently been defined in the medical literature as “pertaining to situations where there is either a feeling of no hope, a threat to a person’s mental or physical well-being, a risk of upsetting a traditional lifestyle, or where a message is given which conveys to an individual fewer choices in his or her life” (Bor, Miller, Goldman, & Scher, 1993). Ptacek and Eberhardt (1996) define bad news as news that “results in a cognitive, behavioral or emotional deficit in the person receiving the news that persists for some time after the news is received” (p. 496). Martis and Westhues (2013) suggest that other possible distinctions of bad news would transpire if health researchers investigated this topic in numerous nations, ethnicities, and professional settings.

Complex Developmental Behavioural Conditions: Children and youth who have significant difficulties in multiple areas of function including development and learning, mental health, and adaptive and social skills. The common diagnoses delivered to families by the CDBC teams include but are not limited to the following: Fetal Alcohol Spectrum Disorder (FASD), Attention Deficit Hyperactivity Disorder (ADHD), Intellectual Disability, Learning Disability, Depression, impairments in motor control, and other developmental disorders. In principle, children and youth who have biomarkers such as substance exposure, dysmorphic features, and growth retardation, as well as significant difficulties in multiple areas of function, including development and learning, mental health, and adaptive and social skills (Northern Health a, n.d.).

Family Meeting (final disclosure): Upon completion of the comprehensive assessment, the multidisciplinary team meets with the family to explain results,

provide diagnoses, make recommendations, and answer questions (Northern Health a, n.d.).

Multidisciplinary Assessment Team: A team that completes a comprehensive diagnostic assessment and is comprised of the following professionals: a pediatrician, who is a medical doctor trained to diagnose and manage the special needs of children and adolescents; a psychologist, who assesses a child's strengths and weaknesses across a number of developmental areas such as cognitive abilities, academic achievement, attention, memory, planning, problem solving, personal care, social skills, and mental health concerns; a speech language pathologist, who assesses a child's ability to understand spoken language, to speak to others using words, sentences, explanations, and narrative reporting, to use appropriate gestures, body language and facial expressions, and to manage the communication demands of social situations; and an occupational therapist, who evaluates a child's fine motor skills, hand-eye coordination, and functioning in daily life (Northern Health a, n.d.).

Parent/Parenthood: An individual who begets and/or brings forth an offspring (father, mother); a person who raises and cares for a child; the state of being a mother or father ("Parent," 2008).

Patient- and Family-Centred Care (PFCC): Patient- and family-centred care is an approach to the planning, delivery, and evaluation of healthcare that is grounded in mutually beneficial partnerships among healthcare providers, patients, and families. It redefines the relationships in healthcare. Patient- and family-centred practitioners recognize the vital role that families play in ensuring the health and well-being of

infants, children, adolescents, and family members of all ages. They acknowledge that emotional, social, and developmental supports are integral components of healthcare. They promote the health and well-being of individuals and families and restore dignity and control to them. Patient- and family-centred care is an approach to healthcare that shapes policies, programs, facility design, and staff day-to-day interactions. It leads to better health outcomes, wiser allocation of resources, and greater patient and family satisfaction (Institute for Patient- and Family-Centered Care, n.d.).

Written Report: Subsequent to the family meeting, the family receives a report that highlights the assessment results and diagnoses and outlines recommendations for interventions unique to the child.

Summary

Chapter 1 provided a brief introduction to my research study, which included my personal experience, coupled with my former career in child welfare practice. Subsequent reading of the academic literature allowed me to frame the research problem, purpose, significance, theoretical framework, and the overall research questions.

Chapter 2 provides a review of the literature as it relates to parental experiences of receiving a child's diagnosis. In Chapter 3, I describe the intellectual underpinnings of social work knowledge base and the influence of social constructionism as an effective disciplinary framework coupled with the applied health research methodology executed for my research. In Chapter 4 I discuss the findings generated by the research, and in Chapter 5 I discuss the interpretation and relevance of the research with respect to the experiences of parents whose children received a comprehensive diagnostic assessment by way of one of the CDBC

multidisciplinary teams. In Chapter 5 I also discuss how the received diagnosis influenced the parents' implementation of the recommendations that followed the diagnosis. In Chapter 5 I also consider future directions for research.

Chapter 2 Literature Review

For many individuals, becoming a parent and raising a family is a lifelong aspiration. Despite the common role that parents share in society, the notion of parenting, according to Hoghughi and Speight (1998), is nonetheless challenging to delineate. They write that “to parent” is an active verb denoting positive activities undertaken by parent figures with respect to children: “Although the noun ‘parent’ usually implies a natural or biological parent, it should be stressed that ‘good enough’ and indeed ‘super’ parenting can be delivered by non-biological parent figures” (Hoghughi & Speight, 1998, p. 294). In the absence of any complications, raising a child can be a difficult but rewarding task. The chance that a child may develop a disease or encounter developmental delays heightens the challenge of child rearing. Research looking at parenting a child with a disability shows that stress is considerably higher for these parents compared to the normal stress felt by parents with typically developed children (Ritzema & Sladeczek, 2011).

There are many reasons why people seek a medical explanation for developmental disabilities, and questions are often related to identifying whether the disability has been caused by an infection or is the outcome of other health-related complications. Gillman, Heyman, and Swain (2000) found that parents of children with disabilities sought a diagnosis on the basis of their belief that an assessment of their child’s symptoms would induce treatment, intervention, and social support, which would in turn prompt an enriched life for both the child and the family.

In this chapter, I will consider a variety of factors associated with the delivery of a child’s developmental diagnosis within the medical setting, including shifts in professional practice, the diagnostic process, the role of the multidisciplinary teams, professional

communication and parental perquisites, communication techniques, formal education, mnemonic approaches, efficacy of guidelines, parental experiences, impact of a child's diagnosis on parents, concepts of cultural excellence, followed by a summary.

Shifts in Professional Practice

Individuals with disabilities have been detested, excluded, and victimized in our society for many centuries (Mackelprang & Salsgiver, 1996). Public reaction towards individuals with a disability was often contingent on cultural belief systems. For example, ancient tribes believed that people with disabilities were possessed by evil spirits (Albrecht, 1992). Mackelprang and Salsgiver (1996) relate instances where disabled individuals were subject to extremely intrusive measures in the attempt to eradicate the devil from their soul. They also note that in the past, society viewed a child with a disability as an imperfection, an impediment to a flawless world.

Historically, according to Ferguson (2002), professional perspectives aligned with the views of society in general—medical professionals were shocked when a child was born with a disability, and this, in their eyes, negated all other aspects of the child; practitioners saw disability not only as permanent but also as a catastrophic outcome. Casstevens (2010) noted that the symptoms of a disease were the main focus—to the exclusion of all other perspectives. Engel (1977) identified this way of looking at disorders as the “biomedical model” given its basis in solely biological factors to the exclusion of the social, behavioural, and psychological aspects of disease (p. 130). Similarly, Engel (1980) notes that this model also gave no consideration to the patient's qualities as an individual or the role that family and culture play in the life of the individual. One historic outcome of this, is that parents took measures to conceal their disabled child by either secluding them in their home or

placing them in an institution, actions that were often influenced by the recommendation of the professionals involved in their child's diagnosis (Mackelprang & Salsgiver, 1996).

Ferguson (2002) notes that, in the early 1900s, the moral blame for most childhood disabilities was assigned to the parents (Ferguson, 2002). In the 1970s, a mother giving birth to a disabled child was often riddled with guilt and shame (Hedderly, Baird, & McConachie, 2003). As a result, mothers were known to question all the actions they took in the course of the pregnancy as well as any practices they felt might have contributed to their child's disability. As time progressed, a number of parents described their experiences of having a child with a disability as constructive, as the families grew and adapted in positive ways. For example, coping strategies were developed, there was stronger congruence among family members, and families blossomed in the realm of their religious beliefs (Ferguson, 2002). In addition, in recent discoveries regarding the plasticity of the brain, neuroscience has come to recognize the importance of psychological and social influences in the life of an individual (Froggett & Richards, 2002).

The narrow historical scope associated with the biomedical model has prompted many researchers to formulate new paradigms and clinical approaches that clinicians can use during the professional-client encounter. Specifically, at the practical level the biopsychosocial model (Engel, 1980) and the patient- and family-centred care (PFCC) approaches (Institute of Medicine, 2001) are two pathways that respect and value the role a patient's personal journey plays in the development of a diagnosis (Borrell-Carrió, Suchman, & Epstein, 2004).

In recent years, there have been various strategic initiatives implemented at the several levels of government focused on leading change to better meet the needs of families

and children with developmental disabilities. For example, at the national level in 2007, Canada became a signatory to the UN Convention on the Rights of Persons with Disabilities, an international treaty that recognizes and works to protect the rights of individuals with disabilities, and in 2010, Canada ratified the Convention (Collin, 2012). At the international level, the World Health Organization (WHO) (2001) published the International Classification of Functioning, Disability and Health (ICF), a document that superseded the 1980 classification of “impairment” and “handicaps.” In 2012, Canada joined countries around the world in marking the 20th anniversary of the International Day of Persons with Disabilities. Furthermore, in 2001 the American Institute of Medicine (IOM) identified “Family- and Patient-Centered Care” (FPCC) as one of the six pillars upholding the delivery of quality care.

In recent years, many healthcare organizations nationally and internationally have implemented the PFCC approach with the intention of providing the most efficient healthcare services. For example, Northern Health in Prince George, BC noted in their 2015/16-2017/18 service plan that the organization is committed to ongoing quality improvement by way of incorporating PFCC (Northern Health c, n.d.). This approach is seen as a holistic practice, one that, according to Boykins (2014), encompasses a patient’s cultural traditions, personal preferences, needs, and beliefs. PFCC has been identified as a system of care that embodies a number of features to promote quality care and positive outcomes for both the child and the family (Lewin, Skea, Entwistle, Zwarenstein, & Dick, 2001; Oates, Weston, & Jordan, 2000). These include: (a) shared control of the consultation, decisions about interventions or management of the health problems with the patient, and/or (b) a focus in the

consultation on the patient as a whole person who has individual preferences situated within social contexts (Lewin et al., 2001, p. 4).

In February of 2012, the American Academy of Pediatrics released a policy statement entitled “Patient- and Family-Centered Care and the Pediatrician’s Role” (Institute, 2012). The policy statement declared the importance of incorporating PFCC in clinical decision-making in order to encourage patients and their families to collaborate with healthcare professionals and/or healthcare team members in all aspects of care and allowing them to participate at the level they choose. These progressive shifts have challenged the historical underpinnings of the medical model and offer an alternative to the restrictive dominant medical model. These shifts are reflected in the changing discourse in healthcare where, for example, the PFCC framework emphasizes that the professional focus should be on the individual’s experiences with illnesses and/or disability (MacKean, Thurston, & Scott, 2005). Where traditionally, according to Teutsch (2003), the client-provider relationship in the clinical setting was authoritarian and did not generally take into account the client’s perspective, communication by medical practitioners has shifted from this authoritative model to a collaborative shared decision-making model (Légaré & Witteman, 2013).

Kisler and McConachie (2010) argue for combining the medical model with one of social inclusion when presenting a diagnosis and emphasize that this is fundamental so that professionals can support families effectively. According to Smith and Carey (2013), the PFCC approach expects professionals to use their clinical skills to engage the patient and family in the development of a plan, an approach that is especially important in healthcare settings that involve the care of a child. Ziring et al. (1999) question whether this reflects the recognition that, with more children facing persistent and escalating complex developmental

problems, there is a necessity to bridge the gap between the traditional medical model and the child healthcare providers and families. Lawlor and Mattingly (1998) emphasize that a PFCC approach is the best way to address these gaps and the most appropriate practice modality in child healthcare settings.

Davis, Schoenbaum, and Audet (2005) note that there is overall agreement among professionals about what PFCC means, but that little is known about the qualities or characteristics of this kind of care that families consider valuable. They propose that “superb access to care” should be one of the core characteristics of quality care, allowing patients and their families to experience “ease of making an appointment; [the] ability . . . to select the day and time of their appointment themselves; timely appointments, and short waiting time in the office” (Davis, Schoenbaum, & Audet, 2005, p. 954). Mead and Bower (2000) note that over the last three decades, a great deal of research has encouraged a PFCC approach in the medical setting, and Smith and Carey (2013) confirm that many professionals have chosen to adopt the PFCC planning strategies for clients with complex needs in the hope of improving their quality of life.

Clinical Practice Approach

The Institute for Patient- and Family-Centered Care, an American health organization, is based on the understanding that a child’s family provides the primary source of care and support for the child. This approach to care recognizes that the perspectives and information that families, children, and young adults themselves provide are essential components of high-quality clinical decision-making, and that patients and family are integral partners with the healthcare team.

According to the Institute of Medicine (IOM), patient- and family-centred care (PFCC) occurs in partnership with practitioners, patients, and their families in order to ensure that decisions are respectful of the wants, needs, values, and preferences of the patient, and that patient values guide all clinical decisions (Institute of Medicine, 2001). From this point forward, I use the term patient-centred care interchangeably with patient- and family-centred care, given that they share the same goals and have the same implications for individuals and families (Entwistle & Watt, 2013). Both approaches share crucial elements for the delivery of high-quality care by professionals in healthcare (Institute of Medicine, 2001). Liptak et al. (2006) emphasize that family-centred care has frequently been identified as a core feature of healthcare for children and that it sets the stage for the delivery of high-quality healthcare services to children and their families. They note that, when PFCC was implemented in the process of healthcare practice, parents not only felt heard but also believed that they were able to obtain relevant information needed to participate fully in shared decision-making that served the interests of their children (Liptak et al., 2006). Fostering a family-professional partnership is a necessary component of healthcare, especially when provided to children with complex developmental behavioural conditions.

Formal Diagnostic Process

The overall purpose of the diagnostic process is to allow the development of tangible recommendations to enhance the lives of the individuals in question, their families and their community (Chudley et al., 2005). Parents may be informed of the diagnosis of their child's disability at different junctures in the course of raising their child. This information may come to light during the prenatal development period, at birth, or during the emergent periods at various stages of the child's development (Harnett, Tierney, & Guerin, 2009). The settings

in which the diagnosis of a child's disability is provided can differ a great deal; the delivery of the news may occur in a hospital, a community health services setting, a disability environment, a healthcare clinic, or the family home (Harnett et al., 2009). The news of a child's disability may be unforeseen, or it may be the outcome of a number of planned assessments or tests (Harnett et al., 2009). In most cases, parental concern for the well-being of their child, combined with the uncertainty about how to best support their child, typically motivates a parent to seek out a formal assessment and diagnosis.

Siklos and Kerns (2007) conducted a study by way of questionnaires regarding the diagnostic experience of parents with children who have autism—82% of parents in their study found the diagnostic process stressful. Parents described the diagnostic process as time-consuming, with long waitlists and delays between clinical meetings (Mulligan, MacCulloch, Good, & Nicholas, 2012; Siklos & Kerns, 2007). Nonetheless, Tattersall and Young (2006) found the diagnostic period to be an important process for parents and Todd and Jones (2003) found that parents can often provide detailed and vivid accounts years after the diagnostic experience had passed, signifying the central importance of this process. Shevell and Shevell (2013) use the metaphor of a key to describe the process of being given a diagnosis—a “key fitting into a lock, a diagnosis opens the door for future provisions of care” (p. 230). Most often the evaluation is an ongoing process that requires numerous encounters facilitated by a multidisciplinary team of professionals.

Different healthcare specialists often use a variety of terms for the diagnostic process, where terms such as evaluation, assessment, identification, and diagnosis can mean much the same thing. Klein et al. (2011) summarize the process this way: “The diagnostic assessment is a comprehensive process where an interdisciplinary team of professionals share

information regarding the child's diagnosis, functioning level (e.g., language abilities, self-care independence, play skills, problem-solving abilities), intervention strategies, and available resources with families" (p. 121). A diagnosis is the culmination of complex testing, interviews, analysis of findings, preparation of the diagnosis, and formulation of recommendations.

Gender

Graungaard and Skov (2007) found that the gender of the parent present when a diagnosis was to be given appeared to influence the way in which the diagnosis was translated to the parent and what kind of information was deemed to be vital. For example, men wanted a more logical avenue to allow them to comprehend and cope with the news, often asking for a thorough written report. Starke and Möller (2002) found that mothers who questioned the diagnosis were more likely to seek information from another source. Graungaard and Skov (2007) also found a gender difference in the way mothers and fathers imagined the future:

Fathers tended to need a longer future perspective and a firmer idea of what the future might bring. Mothers were more likely to concentrate their mental energy on caring for the baby, breastfeeding and other normal parenting duties, as well as mentally strengthening the child with their energy. (p. 301).

Research findings show that approximately half of the parents in a number of studies were informed of their child's diagnosis as a couple (Pearson, Simms, Ainsworth, & Hill, 1999). Furthermore, parents preferred to be together when receiving the diagnosis and insisted that this be the appropriate practice unless there were important reasons for having

the news delivered when separate (Paul, Cerda, Correa, & Lizama, 2013). The practice of delivering a diagnosis to both parents is not a recent one. Dembinski and Mauser (1977) confirmed 40 years ago that parents valued the presence of their partner, noting “that joint parental responsibility for a child may reduce the possibility of family discord, distortion of information, and increase the understanding and acceptance of the child” (p. 582).

Additionally, numerous studies have shown that mothers do not like to hear the news for the first time from their spouse or partner. Skotko, Capone, and Kishnani (2009) found that when a parent heard the news from a partner, it created an unfair burden on the partner, who may already be carrying a sense of guilt, stress, and anxiety over the situation.

Interestingly, Hasnat and Graves (2000) found no relationship “between overall satisfaction and any of the variables relating to the people present at the disclosure interview” (p. 34) and Sloper and Turner (1993) reported similar findings. Despite these contradictory findings, it nonetheless seems imperative to ask the family who they would like to have present during the family meeting to provide emotional support (MacKean et al., 2005). In any case, the invitation to have parents allow family, friends, or any other person they deem significant is consistent with the philosophy of PFCC (Lindeke, Leonard, Presler, & Garwick, 2002). In a completely different health context—yet related to the delivery of a diagnosis, Ramos (2014) found that, in cases where an HIV diagnosis was to be given, patients expressed a preference for hearing the news directly from their physician and were not necessarily interested in having other professionals or even meaningful others present during the session. In keeping with these findings, Pearson et al. (1999) emphasize that more planning is required to guarantee that parents and patients alike have a choice about who

attends the family meeting and/or professional encounter when a health diagnosis is delivered.

Length of Diagnostic Assessment

The duration of time involved from the commencement of the comprehensive diagnostic assessment to the delivery of the final diagnosis is a common theme expressed throughout the literature (Hubermann, Boychuck, Shevell, & Majnemer, 2015; Zuckerman, Lindly, & Sinche, 2015). In some instances, certain disabilities can be diagnosed at the outset. Down syndrome, for example, is based on distinctive physical features which are obvious at birth and parents are notified on the day of delivery or shortly thereafter (Skotko et al., 2009). For the most part, however, findings show that there is often a significant delay between the first diagnostic visit and the formal delivery of the diagnostic results. Shevell and Shevell (2013) add the caveat that one of the most serious outcomes associated with a delay in a diagnosis is the deterioration of parental confidence in the multidisciplinary team. Keenan, Dillenburger, Doherty, Byrne, and Gallagher (2010) found that “between the first referral and the diagnosis an average of 16 months elapsed” before a formal diagnosis was established (p. 393). Crane, Chester, Goddard, Henry, and Hill (2015) found that parents in the UK face a delay of 3.5 years from the first contact with the health professional until the receipt of the formal diagnosis. And yet, concerned families want access to information and services immediately in order to achieve the best outcomes for their children. This is entirely in keeping with research which shows that early intervention for children with complex developmental disabilities and/or cognitive and general developmental delays increases the likelihood of positive outcomes for the child and family (Guralnick, 2005; Guralnick & Bricker, 1987; Smith, Groen, & Wynn, 2000). Early intervention has been recognized for its

benefits and improved outcomes in a variety of neurodevelopmental disabilities for many years (Merriam & Majnemer, 1998). Waiting a long time for a child's diagnosis has implications for the child given that the optimal time to implement early interventions may have passed depending on the age of the child (Kelly, Ghalaeieny, & Devitt, 2012), and delays can hinder the implementation of effective support and appropriate intervention strategies (Webb, Jones, Kelly, & Dawson, 2014).

Such delays may also prompt parents to seek information from other less reliable sources—such as lay professionals, family, friends, and the Internet—prior to receiving the formal diagnostic assessment, which may result in them having formed misconceptions based on flawed sources, which in turn may influence how they receive the formal diagnosis (Klein et al., 2001). Professionals need to be aware of how families assimilate the final diagnostic assessment in light of other sources of information gathered in the meanwhile (Klein et al., 2011). At the same time, it should be noted that this kind of seeking for information is also indicative of problem solving, a process which has been reliably linked to positive effects when it comes to coping with a child with a disability (Taanila, Syrjälä, Kokkonen, & Järvelin, 2002).

The duration of time that one may wait in receiving a final diagnosis is not uncommon, nor is it unique to this sector of the healthcare system. For example, a study conducted in a setting that involved receiving the diagnosis of cancer found that parents experienced a significant delay between their first professional encounter and receiving the final diagnostic results (Eiser, Parkyn, Havermans, & McNinch, 1994). It is no surprise that the long process following the initial recognition by parents of unusual behaviour in their child to the child's final diagnosis will cause parents to experience anger, anxiety, and

confusion in the process (Mulligan et al., 2012). According to Shevell and Shevell (2013), a deferral of a diagnosis involves missed opportunities that can weaken the results, given the widespread understanding that “early intervention, no matter the underlying diagnosis, does beneficially improve outcome” (p. 230).

The findings regarding delays, and the implications of such delays, point to the importance of a multidisciplinary team when it comes to conducting assessments, and to timing and organizing the communication of the developmental diagnosis.

Multidisciplinary Team

Members of a clinical multidisciplinary team (MDT) are among the many professionals who are tasked with the delivery of a child’s developmental diagnosis—and all will acknowledge the difficulties inherent in such a disheartening action. Today, a greater number of professionals who provide services to children and families with disabilities have implemented some form of the multidisciplinary team model (Berman, Miller, Rosen, & Bicchieri, 2000). MDT allows that each team member will contribute to the overall diversity of expertise as a way of increasing “the effectiveness of decision making and meeting clients’ needs in a more holistic fashion” (Housley, 2003, p. 76).

Hinshaw and Deleon (1995) remind us that the healthcare system is multidimensional, and no one discipline or area of expertise can deliver the quality of comprehensive assistance that families need in order to address the complex needs of some children. Research indicates that multidisciplinary teams are crucial to the development of a coordinated assessment that will contribute to fostering and preserving the health of society, while at the same time developing services that are effective and of sound quality (Xyrichis & Lowton, 2008). In light of the benefits of multidisciplinary teams in the delivery of

healthcare, the World Health Organization has developed a number of documents that reinforce the understanding that healthcare providers across various disciplines are more effective when working together (World Health Organization, 2006). On an international level, according to Hudson (2014) Scotland, Northern Ireland, Wales, and England have, since 2002, each developed healthcare models that indicate a shift towards amalgamated prototypes of service delivery, indicating a growing understanding that service providers must work in partnership within health, education, and social policy to provide quality care to the children and families affected by a developmental disorder.

Multidisciplinary teamwork has existed for several decades within healthcare as a means to address the multiple needs of diverse populations. Research indicates that the diagnosis and treatment of various complex developmental behaviour and health conditions marked by multiple comorbidities are best addressed by a multidisciplinary approach (Chudley et al., 2005, Hudson, 2014; Lamb et al., 2014). Nijhuis et al. (2007) emphasize that, in these situations, both the child and the family require a comprehensive treatment plan which should be informed and developed by a team of professionals from various disciplines who must work closely together. Similarly, Davidson et al. (2007) point out that a multidisciplinary team must work directly with the child and the parents in order to keep them informed and to have them actively involved in the clinical decision making.

Research indicates that, when multidisciplinary teams incorporate patient-centred information into their decision making and couple this with biomedical information, quality decisions are attained (Lanceley, Savage, Menon, & Jacobs, 2008). Multidisciplinary teams usually include developmental pediatricians, psychologists, speech-language pathologists, occupational therapists, and social workers, all of whom aid in the delivery of the diagnosis

(Klein et al., 2011). One of the hallmarks of an efficient team is the ability to communicate effectively with one another and, most importantly, to communicate effectively with the child and family. Effective communication between patients, families and physicians is the foundation for a meaningful relationship and, most important, it creates an avenue to shared decision-making (Mack, Feudtner, & Hinds, 2011). Shared decision-making is seen as the “pinnacle” of PFCC framework (Barry & Edgman-Levitan, p. 780, 2012).

Professional Communication and Parental Prerequisites

The rapid evolution of the healthcare system has prompted the scholarly investigation of communication practices as they occur between physicians and their patients in medical settings (Ong, De Haes, Hoos, & Lammes, 1995; Pahal, & Li, 2006). As a general physician or a member of a multidisciplinary team, it is important to consider how information about the diagnosis, prognosis, and treatment options will be conveyed to the family. Deploying positive communication styles and providing meaningful knowledge empowers families to take an active, participative role in partnering with medical professionals. Studies conducted in medical environments demonstrate that satisfied patients are more likely to engage in the medical diagnostic process, achieve higher levels of compliance with treatment recommendations, experience improved signs of ailment control, and act in a manner that ultimately leads to positive outcomes for the mental and physical health of the patient and the family (DiMatteo, Haskard-Zolnierrek, & Marin, 2012; DiMatteo, Prince, & Taranta, 1979; Doyle, Lennox, & Bell, 2013; Hall, Milburn & Epstein, 1993; McLaughlin, 2005; Roter, Hall, & Aoki, 2002; Irish & Hall, 1995; Price et al., 2014). In other words, the quality of the interaction has shown to be a positive link to the individual’s ability to follow through with treatment plans and recommendations (Charon, Greene, & Adelman, 1994; Singh, Naik, Rao,

& Petersen, 2008; Stewart, 1995). Similarly, the ways in which the delivery of a child's disability diagnosis is delivered can have an immense effect on the parents' ability to follow through with their child's clinical recommendations (Ahmed, McCaffery, & Aslani, 2013).

Building relationships and including parents in all aspects of the assessment process is seen as a positive indicator of future success for the child and the family (Graungaard & Skov, 2007). Inclusion fosters the advancement of parents' understanding of their child's disability and cultivates agreement between parents and professionals regarding what supports and services are meaningful (Glaun, Cole, & Reddihough, 1998). This type of communicative interaction is congruent with the pillars of FPCC, noted above (Barry & Edgman-Levitan, 2012; Hutchfield, 1999).

As a cautionary note, engaging in PFCC does not mean that the professional relinquishes their control to the family, but rather that they discover mutual territory when it comes to understanding the child's diagnosis and the needs of the family (Laine & Davidoff, 1996). Higgs, McAllister, and Sefton (2005) note that effective communication is achieved when the intended message of the sender has been heard by the person involved (receiver), and together they accomplish a shared understanding. Nissenbaum, Tollefson, and Reese (2002) propose a model along these lines—the conference and collaboration model—understood to be an effective option for delivering a diagnosis because the parents are both involved in the process. Additional techniques and models will be discussed later in this chapter.

Medical and health professionals should be honest, compassionate, and able to convey hope when delivering a diagnosis. The purpose of adopting this posture is to provide some positivity, allowing physicians and professionals to encourage parents to become

effective partners in their child's journey. Uys (2010) indicates that this style of delivering serious news will have a positive impact on how the family copes with the diagnosis, and Klein et al. (2011) show that adequate information during the delivery of the diagnosis is associated with higher parental satisfaction. Physicians who practise a PFCC communication style tend to allow time for the discussion of psychosocial issues rather than limiting their focus to the technical aspects of illness and treatment.

At the same time, Roter, Hall, and Aoki (2002) proposed that the way in which medical professionals use specialized language, or medical jargon (which often obscured the possibility of understanding) may contribute to the lack of follow-through on the part of the parents when it comes to implementing the clinical recommendations. It is important that professionals are cognizant of the language they use when communicating with families in order to circumvent the complexity of the message—the content must be adapted to suit the particular needs of the parents and the context in which they find themselves (such as cultural and educational background, income, and social standing). In fact, Szwajcer, Macdonald, and Kvern (2014) proposed that a health literacy training program should be incorporated into the Canadian family medicine curriculum. Jenkins and Fallowfield (2002) reminded us that personal beliefs are complex understandings—based on social, emotional, and behavioural factors—misinterpretation can easily happen in the course of communicating complicated information. Quine and Rutter (1994) reported that inadequate communication tended to foster non-compliance with the clinical recommendations, and Price, McNeilly, and Surgenor (2006) emphasized that the use of medical terminology must be rephrased in simple layman's terms when conveying a diagnosis to a patient, or to the family of a patient.

Similarly, negative or even remotely negative comments have the potential to be damaging to the self-esteem of the parent. For example, Harnett et al. (2009) found that when influential professionals conveyed an absence of hope at a time when parents were particularly susceptible, the effect on the ability of parents to cope would have “negative, self-fulfilling outcomes and limit the developmental opportunities that will be provided for the child” (p. 37).

The literature reviewed shows that parents look for particular professional attributes and behaviours when receiving their child’s final developmental diagnosis: they wish to be told as soon as possible, in privacy, in a direct but sympathetic manner; they want an opportunity to discuss the diagnosis in detail; and they want additional time to work out their feelings about the experience (Quine & Rutter, 1994; Skotko, 2005; Strauss, Sharp, Lorch, & Kachalia, 1995). For example, Martins and Carvalho (2013) found that 77.8% of patients who received bad news preferred an “empathic professional” to deliver the diagnosis. Skotko et al. (2009) found that parents wanted to hear the news immediately, even in cases where the diagnosis was not yet confirmed. Chiarello, Effgen, and Levinson (1992) found that parents appreciated professionals who were personal, communicated effectively, demonstrated commitment, understanding, and compassion, promoted equality, and valued the family. Mansell and Morris (2004) found that parents wanted practical support and more time following the disclosure of the diagnosis in order to absorb the information post-disclosure and that they wanted to request a follow-up appointment to ask meaningful questions.

Often, despite best efforts to take precautions when imparting information about the results of a diagnosis, the process happens very quickly and the practitioners involved do not

have the luxury of a follow-up appointment or repeated visits with the family (Nissenbaum, Tollefson, & Reese, 2002). Shevell and Shevell (2013) emphasize that, where there is the sense that a family has not fully comprehended the information given, a follow-up meeting should be scheduled soon after the meeting. A number of research findings indicate the value of a follow-up meeting shortly after the diagnosis has been conveyed and emphasize the importance of the presence of the same professionals who provided the diagnosis to the family (Kisler & McConachie, 2010; Sloper & Turner, 1993).

According to Levetown (2008), the ways in which patients and families assimilate information fall into two areas of learning—the cognitive and affective domains. Cognitive requirements have to do with “the need to know and understand,” and affective requirements have to do with “the emotional need to feel known and understood” (Levetown, 2008, p. 1442). Levetown (2008) is essentially describing one of the most basic of all human needs—the need to understand and be understood.

Diagnostic evaluation reports or written information are often provided to parents and clients during their clinical meeting. With respect to cognitive learning, a study conducted by Waisman et al. (2003) in a pediatric emergency discharge setting found that parents responded better to formal, written post-discharge care instructions (information sheets) than they did to the verbally transmitted emergency diagnosis. Likewise, Brogan and Knussen (2003) conducted a study involving 126 parents regarding their overall satisfaction with the disclosure of their child’s disability and the results showed that parents rated higher satisfaction when given written information coupled with the opportunity to ask questions. In contrast, Klein et al. (2011) found that, following the diagnostic disclosure session or final meeting with the health practitioner, when parents are given a summary report outlining the

diagnosis, they are not yet prepared to act upon written instructions. At the same time, Cranwell and Miller (1987) point out that “it may be too great a task for any one document to provide information to give indications of appropriate teaching approaches, techniques and materials, and to present a comprehensive picture to parents” (p. 27).

In keeping with such findings, a number of practitioners are now recording their clinical sessions so that patients and family members who have difficulty recalling or understanding the information presented to them will have another opportunity to hear it at a time of their choosing (Eden, Black, MacKinlay, & Emery, 1994; Price, McNeilly, & Surgenor, 2006). This kind of proactive intervention works well for practitioners who often do not have the time for follow-up sessions with families after they have presented their diagnosis. It is evident that the delivery of a diagnosis is an important task, and if it is not managed with professional integrity and skill, the outcomes for children and families can be less than desirable.

Communication Techniques

It seems reasonable to propose that effective communication skills are essential to the delivery of exceptional services by the healthcare profession. The competent delivery of the diagnosis is instrumental in bringing parents to a place of understanding, and this, in turn, will better ensure their follow-through with the treatment recommendations for their child. Research indicates that when the diagnostic finding is conveyed in a skilled, professional, and sensitive manner, the information conveyed is more likely to help the parents understand their child’s needs and allow them to plan for the well-being of their child by way of future interventions (Cottrell & Summers, 1990). Despite such research findings, a recent analysis

by Vail et al. (2011) reported that attending physicians do not use PFCC approach when breaking bad news.

Bartolo (2002) advocates communication techniques that are grounded in the philosophy of the PFCC approach. He recommends three negotiating frameworks that can be adopted to communicate a diagnosis with families, all of which are positive, thorough, and have demonstrated good outcomes: (a) a parent-friendly framework, (b) defocusing the bad news, and (c) a hopeful-formulation frame. Similarly, Shea (1993) offers suggestions for an interpretative conference that includes “setting goals for the conference, stating the diagnosis and anticipating the family to react emotionally to the diagnosis” (p. 31). Shea also stresses the importance of the physical setting, the use of language, and a discussion of the child’s future.

The relational diagnosis model proposed by Rigazio-DiGilio (2000) addresses the “intrapersonal perspective” (p. 1018) of communicating a diagnosis. Relational diagnosis considers each individual as part of the family, which filters into the larger social structure of a community. This approach recognizes that each situation is unique due to the distinctiveness of each family’s dynamics. The relational diagnosis model stresses the importance of the “larger sociocultural context, sees each client’s uniqueness and reality as tantamount, and provides highly specific procedures that facilitate clinicians and clients to co-create therapeutic environments” (Arciniega & Newlon, 1999, p. 452). Another research study made several critical recommendations which included revealing the results at the earliest opportunity, providing an opening for a follow-up meeting, offering ample information in a transparent, non-jargon format, and conducting the family meeting in a compassionate and truthful manner (Sloper & Turner, 1993).

Fallowfield (1993) describes three ways of giving bad news: the first is blunt and insensitive and accepts that patients will be upset; the second is kind and sad, but devoid of positive support, encouragement, or optimism; and the third is understanding and positive with a lot of flexibility, reassurance, and empathy (Fallowfield, 1993, p. 6). The literature makes it clear that the third approach produces better outcomes for children and families. Other related literature shows similar results, where empathetic understanding and sincerity were important for health professionals to communicate. Harnett et al. (2009) emphasize the importance of delivering a child's diagnosis with "positive, realistic and hopeful communication" (p. 257). The authors present findings from their three-phase research project that aimed to determine the most effective form of communication for patient-practitioner interaction. Based on their findings, the authors present the following guidelines for effective diagnosis communication:

Family-centered disclosure.

Respect for child and family.

Sensitive and empathetic communication.

Appropriate, accurate information.

Positive realistic messages of hope.

Team approach planning.

Focused and supported implementation of best practice. (Harnett et al., 2009, p. 260.)

These findings are not necessarily new given that parents and families have been expressing the same desires for nearly four decades. Essentially, patients have reported that overall satisfaction is achieved when physicians show respect in the way they conduct themselves (Doyle & Ware, 1977).

Formal Education

Many physicians feel uneasy and unprepared when it comes to conveying poor results, despite the fact that they do this on a regular basis (Dosanjh, Barnes, & Bhandari, 2001). Breaking bad news is an extremely difficult and challenging process for the healthcare professional (Price et al., 2006). Many internship and university programs do not include formal instruction on ways in which bad news can be better delivered (Hebert, Butera, Castillo, & Mega, 2009; Reed et al., 2015). Finocchio, Bailiff, Grant, and O'Neil (1995) indicate that graduates from medical school have not received the necessary core communication competencies, leaving them unprepared to be effective at communicating. Dosanjh et al. (2001) argue that the old-style medical education is “ineffective in teaching clinical communication” (p. 204). Similarly, a study conducted with clinical oncologists showed that only 6% of the oncologists were exposed to curriculum related to conveying bad news; hence, they rated their ability to perform in this area as very low (Hebert et al., 2009). Sadly, another study reported that only 27% of residents felt competent in giving bad news to parents of a sick child (Rider, Volkan, & Hafler, 2008).

Over the course of a professional health career, clinicians likely have had to disclose bad news to patients and families with some frequency—an experience widely known to be a source of significant stress for many healthcare professionals (Baile et al., 2000). For both novice and experienced healthcare professionals, the learning process for the delivery of bad news is via mentorship of preceptors and, sadly, through trial and error. Many physicians struggle to achieve competence in delivering bad news (Sweeny, Shepperd, & Han, 2013). Reed et al. (2015) acknowledge the difficulty, emphasize a professional and tactful approach, and propose that breaking bad news is a teachable skill. In addition, Hedderly et al. (2003)

report that similar training is needed for the many other professional practitioners who make up multidisciplinary teams. One study investigated the practicality of social workers as evaluators of residents delivery of bad news during patient encounters, and both professional groups shared feedback related to this approach—results highlighted that the residents value the expertise of social workers in delivery of bad news, and the teaching of such a difficult skill (Min, Spear-Ellinwood, Berman, Nisson, & Rhodes, 2016).

Davis et al. (2005) propose that “patient-centered vision would define quality as providing the care that the patient needs in the manner the patient desires at the time the patient desires” (p. 953). One way to cultivate a responsive healthcare system requires the canvassing of the patient’s overall experience with their primary caregiver (Davis et al., 2005; Joos, Hickman, & Borders, 1993). Audet, Doty, Shamasdin, and Shoenbaum (2005) note that only 36% of primary physicians routinely receive patient survey information, and less than 50% of those take this feedback into account and incorporate it into their practice—despite the IOM recommendation of the inclusion of PFCC in 2001.

Harrison and Walling (2010) question whether future professional practitioners can acquire practical competency in this complex realm, even if proficient training is provided, due to the multiple factors involved when delivering bad news. On the same note, Wouda and van de Wiel (2013) express skepticism about whether medical students can actually gain “expertise in professional communication” during their medical training (p. 51). They recommend that “curriculum designers should reflect on the amount of time and effort they want to spend on the teaching of clinical communication and to determine the level of communication competency they find realistic to achieve within these limitations” (p. 51). In

contrast, as noted above, Reed et al. (2015), in their study conducted with pediatric residents, found that residents can be taught to break bad news to parents and families.

A number of studies concerned with looking at the way a child's diagnosis was communicated showed that the greater emphasis was on the prognosis and that the communication process contained more intense emotional content than similar situations where a diagnosis was being given to an adult (Harrison & Walling, 2010). Levetown (2008) found that there was a lack of emphasis on interpersonal skills in pediatric training, with the result that little consideration was given to emotions, relationships, and continuity of care.

During certain periods, the physician's title and attitude were possibly influenced by some of the residual passé philosophies that once were prominent in the traditional medical environment—the belief that the medical physician was the expert to the exclusion of other sources of collateral (patient) (Casstevens, 2010). In fact, Ruffolo, Kuhn, and Evans (2006) note that “through their training, professionals develop an area of specialization that places them in the role of an expert” (p. 40). Consequently, professionals may convey an attitude of superiority which can stand in the way of forming a positive relationship with their client and take away from their client's ability to have some control, leaving them to feel as if they are not able to participate in their care (Ruffolo, Kuhn, & Evans, 2006). At the same time, research shows that while physicians think that it is critical to involve patients and families in the decision-making process, over half of the physicians failed to do so—noting some of the residual impact of past philosophies (Finocchio et al., 1995). In addition, Finocchio et al. (1995) indicated that the past medical training of their subjects left them ill equipped to engage in this kind of collaborative process. The researchers advocate for improvements in the education and training of medical practitioners.

In their review of the research, Libert et al. (2001) found that students reported that training was helpful, but that research indicates a lack of transfer from theory to practice. Nonetheless, a decade later, Barth and Lannon (2011) argue that communication can be taught and that an emphasis on communication skills has become a vital component of the training for medical practitioners. Furthermore, content that deals with breaking bad news has been incorporated into medical pedagogy in undergraduate and postgraduate curricula in North America (Wakefield, Cocksedge, & Boggis, 2006).

Mnemonic Approaches

Baile et al. (2000) notes that the process of disclosing unfavourable clinical information to patients can be seen as similar to other medical procedures that require the execution of a stepwise plan. Given the importance of being able to communicate difficult news to individuals and their families a number of modalities, or specific techniques for communicating, are identified in the research literature. Approaches that incorporate a mnemonic (i.e., a pattern of letters which stand for a concept or action and serve to trigger memory) have been shown to be effective, in this case mnemonics that are useful for reminding a practitioner of baselines to ensure that key issues are addressed.

The two mnemonics used extensively by healthcare practitioners to aid them in delivering bad news to patients with chronic conditions or illnesses are S.P.I.K.E.S. (S = setup, P = perception, I = invitation, K = knowledge, E = empathize, S = summarize and strategize), and A.B.C.D.E. (A = advance preparation, B = build a therapeutic environment/relationship, C = communicate well, D = deal with patient's and family reactions, E = encourage and validate emotions).

The S.P.I.K.E.S. protocol for the disclosure of an illness or disability is a method that can be used by a multidisciplinary team. It refers to a step-by-step process that was initially created for patients who were diagnosed with cancer but has also been used in numerous other settings to assist a range of healthcare specialists deliver bad news to patients and/or their families. With respect to the first step, setup, a team member will arrange to meet with the parents for an interview. This meeting should ensure privacy and involve the input of any significant others identified by the family. Above all, the time allotted for this meeting should not be constrained, and interruptions should be avoided or explained if expected.

In the second step, perception, the practitioner will assess the parents' perception, or understanding of the situation in which they find themselves. Understanding what the parents do or do not know will allow the practitioner to tailor a response that suits the parents' level of knowledge on the matter and reduce additional unwanted and unnecessary stress. The third step, invitation, refers to point in the meeting where the practitioner asks the parents whether they would like more information. The fourth step, knowledge, refers to giving additional information which will incorporate a forewarning prior to giving bad news. During the fifth step, empathize, the practitioner's role is meant to shift from being informative to being empathic and supportive by responding to the parents' reactions with compassion and caring. In the sixth and final step, summarize, the goal is to outline a strategy for dealing with the diagnosis and to summarize what has occurred in the course of the meeting by reviewing the main points, outlining a plan, and scheduling another meeting (Baile et al., 2000).

The A.B.C.D.E mnemonic technique is similar to the S.P.I.K.E.S. sequence but is condensed into five steps. Step A refers to advance preparation, which involves

incorporating what the practitioner imagines the parents may already know and taking the time to prepare the delivery of this information privately and ahead of time (Rabow & McPhee, 1999). Step B, building, refers to creating a therapeutic environment and building a relationship with the parents—in a safe and private space and an atmosphere that feels warm and welcoming. Step C, communicate well, refers to incorporating some key communication strategies to assist in the delivery of the diagnosis, such as being direct, avoiding the use of euphemisms or jargon, allowing time for silence, and repeating information as necessary (Rabow & McPhee, 1999). Step D, deal, reminds the practitioner to deal with parental reactions in a professional and empathic manner, and step E, encouraging reminds the practitioner to provide encouragement and validate the emotional responses of the parents. This last crucial step reminds the practitioner to ensure that all questions are answered and assess whether the parents have absorbed as much of the information as possible in the course of this first meeting.

In 2004, the Ireland Health Services National Partnership Forum gave support to the National Federation of Voluntary Bodies to develop national best practice guidelines for how families are informed of their child's disability (Informing Families Committee, 2007). The ensuing research study *Informing Families of Their Child's Disability*, which was conducted in 2007, generated eight guidelines that were identified as vital for informing a family of their child's diagnosis: (1) the setting/location and the people present at disclosure; (2) communication; (3) information and support; (4) culture and language; (5) training, education and support for professionals; (6) organization and planning; (7) referral; and (8) dissemination. It was recommended that, when delivering the diagnosis, professionals must communicate with honesty, empathy, sensitivity, respect, compassion, and understanding

(Informing Families Committee, 2007). The study emphasized that it is critical that the diagnosis include positive and realistic messages embedded with hope.

Efficacy of Guidelines

Guidelines have been developed on the subject of “how to discuss the diagnosis of neurodevelopmental disability with the family” (Kisler & McConachie, 2010). Research studies have been generated outlining practice standards intended to strengthen and enhance practice (Cottrell & Summers, 1990). However, Eggly et al. (2006) disputed the accomplishment of various guidelines that are published to assist professionals in communicating bad news to patients. They argue that the fundamental problem with the guidelines was that the style used during the delivery process dictates a prescribed sequence, regardless of the nature of the medical practice. Ultimately, the authors argue that the delivery does not always occur in a linear or chronological fashion due to a host of factors that are unique to each individual, family, and/or situation. Martis and Westhues (2013) concur, indicating that “the level of knowledge, sensitivity, and skill required for clinical interactions differs according to disease type, its severity, consequences, and the psychosocial characteristics of persons involved in the situation” (p. 3). Barclay, Blackhall, and Tulskey (2007) point out that these methods are widely used in healthcare and pedagogy but the evidence regarding them is ambiguous.

Fallowfield and Jenkins (2004) support the fundamental principles of these strategies, which appear to them as practical and well-intended. According to these authors, professionals need to strike a balance between elevating hopefulness and creating unrealistic expectations. Similarly, Harnett et al. (2009) point out that professionals may face legal challenges when offering hope, inadvertently prompting a family to engage in wishful

thinking—something to take into consideration in the training of future practitioners.

Another criticism of the guidelines has to do with accountability. A number of sources point out that there is no audit process to verify the level of adherence by practitioners to the guidelines in a practice setting (Kisler & McConachie, 2010). As a case in point, McConachie (1991) indicated some years ago that a great deal of work was needed to incorporate the guidelines into practice, especially when it comes to child development teams. McConachie emphasized the value of ensuring that the guidelines continue to be incorporated through times of employee changes and departures. Kisler and McConachie (2010), in their retrospective review of parental satisfaction subsequent to the introduction of such guidelines, determined that longstanding compliance is hard to ensure in the face of employee turnover.

Fallowfield and Jenkins (2004) argue that there is scant evidence linking the incorporation of guidelines to improved outcomes for individuals, given that there is no way to measure patient outcomes. The authors further emphasize that the hallmarks of solid professional preparation are sound pedagogical principles combined with evidence-based research and an active quality assurance function (Fallowfield & Jenkins, 2004).

Parental Experience and Impact

At the heart of the process by which a diagnosis is delivered is the necessity to enhance the knowledge and coping abilities of the family and lessen the impact of devastating news (Boyd, 2001). Klein et al. (2011) acknowledge that research shows that when a family is given the diagnosis of a child's disability it will have an emotional effect on the parents. Sloper and Turner (1993) also found that "the disclosure of a child's neurodevelopmental disability is recognized as a 'crisis event' for the parents as the

information successfully destroys previously held dreams despite internal doubts and concerns” (p. 816). Similarly, research shows that a diagnosed disability of the child affects parents in both negative and positive ways (Beck, Daly, Hastings, & Stevenson, 2004; Boström, Broberg, & Hwang, 2010; Hastings & Taunt 2002). Studies show that the diagnosis can not only be traumatic for parents but can interfere with their ability to bond with their child (Fitzpatrick, Graham, Durieux-Smith, Angus, & Coyle, 2007). Shevell and Shevell (2013) point out that on first hearing the words “developmentally delayed” or similar words to that effect, a parent’s dream of having a normal child may shatter as it becomes clear that the child may not achieve appropriate developmental milestones. Similarly, Schuengel et al. (2009) noted that a sudden and drastic change occurs in the way in which parents think about their children, often resulting in grief as they consider losing a perfect child. On the other hand, Klein et al. (2011) reported that families who are inclined to hope are able to develop a new vision of their child and come to see a clear trajectory forward.

Quine and Pahl (1987) found that some parents responded to the final diagnosis with relief after the uncertainty of a lengthy journey of tests. Similarly, Dembinski and Mauser (1977) confirmed that, when parents were informed of their child’s learning disability, they experienced a feeling of acceptance and relief.

Shevell and Shevell (2013) point out that having a disability confirmed will change parents’ expectations; it will generate new challenges which may seem impossible to overcome—challenges which will change family dynamics. They emphasize the significance of the child’s family environment and note that it will have a powerful outcome on a child’s disability. Parents are trying to understand the meaning of the new information and imagine the future, both for their child and for their family (Graungaard & Skov, 2007).

The child's family is seen as the most influential factor when it comes to managing a disability, and the family dynamic is fundamental to shaping a positive or negative experience for the child (Bronfenbrenner, 1986).

Graungaard and Skov (2007) argue that the disclosure process significantly shapes the emotional reaction of the parents. Their qualitative examination of 16 families in relation to the impact of the diagnosis found that parents placed a significant value on the initial contact with professionals. Their findings showed that there was a strong correlation between the ability of parents to cope with their child's diagnosis and the nature of the diagnostic process (Graungaard & Skov, 2007).

Research shows that the manner in which the child's disability is disclosed shapes the way in which parents adjust to their child's circumstance, and this may, in turn, influence the treatment of the child in the early stages following the disclosure (Chiu et al. 2014; Cottrell & Summers, 1990; Graungaard & Skov, 2007; J. Ptacek & Eberhardt, 1996). Research also shows that parental dissatisfaction with the disclosure process is correlated to an increased level of depression in a parent in the future, as well as the long-term impact on a parent's ability to cope (Baird, McConachie, & Scrutton, 2000; Taanila et al., 2002). Shevell and Shevell (2013) emphasize that, without a doubt, the process of disclosure will have an impact on the way parents will adjust and the kind of management techniques they will develop, factors which are essential to fostering the best interests of a child. They point out that this process "is critically important, as the parents are the essential drivers and partners of their child's health care" (Shevell & Shevell, 2013).

Klein et al. (2011) conducted an exploratory and descriptive qualitative research study which focused on the parental experience of the diagnostic delivery where six out of

the nine (66%) dyads in the study reported their experiences as emotional and anxiety provoking. One mother stated, “I didn’t know what they wanted and that’s what caused me such frustration and such angst” (p. 125). The researchers also noted that parents expressed their wishes to hear the particulars of the diagnosis but found the experience overpowering and likely to create a weepy atmosphere.

Graungaard and Skov (2007) caution that such an emotional reaction is occasionally misjudged in the sense that it may prompt the health professional to limit the information shared during the diagnosis. Crane et al. (2015) note that “it was predicted that overall satisfaction ratings would be greatest among the parents who rated the provision of information received at diagnosis highly,” which suggests that it would be advantageous to take a break at this point in the clinical interaction and reconvene without sacrificing the required information that the parents’ need and desire (p. 3). This study also showed that 66% of parents were satisfied with the professional behaviour when they felt fully informed of their child’s diagnosis. This percentage is higher than the finding reported by Jones, Goddard, Hill, Henry, and Crane (2014), which showed that only 47% of parents were satisfied with the manner in which the diagnostic results were presented. From a quality assurance perspective, these percentages show a low level of satisfaction overall, which confirms the need for appropriate communication strategies to be built into the formal education and training of professional health practitioners.

A number of studies highlight the observation that disability disclosure fosters a period of change for the parents, in ways similar to the phases identified in bereavement (Cunningham, Morgan, & McGucken, 1984). A study conducted by Quine and Pahl (1987) describes the initial emotional reaction of parents as one of overwhelming shock, where 64%

felt “stunned, confused or numb” (p. 233). Kisler and McConachie (2010) note that models based on those helping families adjust to bereavement have been developed to help families adapt in the period following a challenging diagnosis for their child.

A number of sources also indicate that the trauma experienced by parents upon learning about their child’s disability can jeopardize their interpretation of the information they receive (Bartolo, 2002; Quine & Pahl, 1986; Seideman & Kleine, 1995). Klein et al. (2011) observed that there is a likelihood that parents may feel overwhelmed and unable to digest the information in the period immediately after the news has been delivered, and Shevell and Shevell (2013) observed that it is not uncommon for parents to leave the initial meeting retaining very little of what was explained. A study conducted by Morse (2011) revealed that parents experienced a feeling that they could not hear anything, which made understanding medical information difficult. Morse’s subjects reported that, although they could hear the physician’s voice, they had no ability to register the words, never mind being able to synthesize meaning. Morse found that hearing bad news had an impact on cognitive functioning to the extent that it became a challenge for people to fully comprehend what was being said. She notes that comprehending, knowing, and understanding are slow processes and change cannot come about until the information is fully integrated.

Eiser et al. (1994) found that when parents are provided complex, detailed information during an emotionally saturated period, complications may arise because their ability to absorb the information is impaired, which in turn results in greater difficulty recalling the period during when the diagnosis was made. A similar parental experience was observed in a different healthcare discipline in relation to the delivery of a medical diagnosis. Kessel, Roth, Moody, and Levy (2013) also found this to be the case in a pediatric oncology

setting where parents described the time of first hearing a diagnosis of cancer as a “blur” and acknowledged that “retaining information becomes difficult and overwhelming” (p. 393).

A number of studies indicate that parents want an opportunity not only to express their feelings but also to ask questions during the family meeting (Garwick, Patterson, Bennett, & Blum, 1995; Krahn, Hallum, & Kime, 1993; Krauss-Mars & Lachman, 1994; Ptacek & Eberhardt, 1996). Parents also reported that they did not know what questions to ask during the family meeting as they did not understand and were reluctant to reveal their lack of knowledge (Eiser et al., 1994). Similarly, parents felt that they were imposing on the professionals when they asked questions (Dembinski & Mauser, 1977). Skotko (2005) found that if mothers felt that they were not given an opportunity to ask more about their child’s condition, they experienced a great deal of anxiety and stress which contributed to a negative outlook on the child’s future.

Parents also revealed, in a qualitative study by Graungaard and Skov (2007), that the parents were upset by the contrast between their own perceptions about their child and the doctor’s assessment of their child. This study showed that parents tended to focus on their child’s strengths whereas the doctor’s characterization of the child was framed in terms of disability and deficit. Hence, parents saw these assessments as flawed and believed that their child was being devalued in the process. One might ask whether such discrepancies between physicians’ views and parents’ views are related to the inability of the physician to change his or her style of delivery because they are operating within the traditional medical paradigm. Ponte et al. (2003) noted that the inability of practitioners to change their practice approach conflicts with the tenets of PFCC. It is no surprise that hearing difficult news

provokes anxiety, but the degree of distress may be amplified if the perceptions of doctor and patient do not coincide (Ptacek & Eberhardt, 1996).

A study by Clarke and Fletcher (2005) found that many parents realized that they had to be advocates for their child and that “they cared more for their child and their child’s well-being than the health care team” (p. 119). The parents in their study felt they needed to be assertive, persistent, and aggressive, at times believing that it was necessary to intervene. These differences in interpretation (between physicians and parents) may influence both the way in which the diagnostic summary is conveyed and the way in which parents describe the delivery of the content.

The question remains whether it is even possible to achieve patient satisfaction when less than desirable news is being delivered. Cunningham et al. (1984) considered whether disappointment was unavoidable on hearing bad news and whether negative parental reactions would then be directed towards the bearer of bad news. They developed a model based on previous feedback by parents with respect to their experience with having received bad news. The model was tested on a control group of parents who had received a diagnosis and had nonetheless expressed 100% satisfaction, allowing the authors to conclude that “dissatisfaction is not inevitable” (p. 39). Research indicates that parental satisfaction is contingent on several factors including the manner of the delivery of the news, the timing, the age of the child, the quality of information, the support offered post-diagnosis, and the stress felt during the diagnostic process, all combined with the attributes and internal resilience of the parents (Crane et al., 2015; Hasnat & Graves, 2000; Howlin & Moore, 1997; Hubermann et al., 2015).

Apart from the physiological and emotional response to a diagnosis, there were other considerations that factor into a parent's response, including economic, social, and cultural identity, as well as knowledge and previous experiences (Korsch, Gozzi, & Francis, 1968, p. 855). While all of these factors played a role in the individual response to a diagnosis, the proficiency with which the healthcare professional conveyed the diagnosis was ranked as one of the most influential factors overall.

To summarize, there has been a considerable amount of criticism that identified the unsympathetic and blunt manner in which health practitioners delivered news, an unfortunate reality, given that the disclosure process can be a therapeutic turning point for the parents if exercised effectively (Bartolo, 2002). As discussed above, research has established a link between parental satisfaction with the way a diagnosis was delivered and the associated outcomes for both the child and the family. It appears that the opportunity to promote a better long-term outcome is compromised or lost if this moment of disclosure is not managed with more consideration. At the same time, the opportunity for exerting a positive influence at this point cannot be overstated. As Choi, Lee, and Yoo (2011) noted, by providing the diagnosis in a positive manner, professionals can help parents develop an optimistic outlook about their child's future.

Concepts of Cultural Excellence

The increasing cultural, racial, and ethnic diversity in our society will ideally compel educational institutions to prepare skillful and respectful physicians and professionals who will discuss the relevance and importance of the individual's diversity in their clinical practice (Tervalon & Murray-Garcia, 1998). The reasons why families may not follow through with treatment recommendations may also be linked to the dynamic between the

family and the professional. It is possible to have a mismatch between the parent and the professionals that may influence the follow-through with recommendations. According to Borkan and Neher (1990), the relationship between parents and professionals can be strained by different sociocultural disparities including the professional's lack of cultural knowledge regarding the family's health philosophies and life experiences, and the professional's inadvertent and unintentional practices of discrimination and unfair treatment on the basis of the family's social class. This adds another layer of complexity between the family and the professional, reinforcing the importance of cultural excellence in clinical practice.

According to Acer (2012), the definition of "culture" is under continuous and serious debate (p. 361). One factor contributing to the debate may be the fact that social researchers examine culture from diverse viewpoints, creating differences in meaning and leading to various ways of understanding the concept (McFee & Degge, 1980). In the final section of this chapter, I explain the various models of culture and the intended application of these models when providing services to diverse cultural groups.

Cultural Safety

The conceptual framework for cultural safety originated in Aotearoa/New Zealand in the 1980s and reflects the Maori people's dissatisfaction with structural inequities within the healthcare system. This framework recognizes the interconnectedness between the four quadrants of health: physical, mental, spiritual, and emotional (Kirmayer, 2012). The term "cultural safety" is attributed to Irihapeti Ramsden, a Maori nurse leader (Cox & Taua, 2012). Ramsden sought to apply cultural safety as a critical lens from which to examine the interactions between Maori people and settler culture healthcare providers, while drawing attention to the power imbalances between the two groups (Smye, Josewski, & Kendall,

2010). Ramsden's definition centres on self-awareness and social positioning as these concepts relate to the professional within the context of the professional relationship (Cox & Taua, 2012).

The theory of cultural safety is shaped by the diversity of milieus in which it is applied, while advancing a common objective of promoting equality in health outcomes. The theoretical origins of cultural safety are rooted in "historical, economic, and social contexts" (Gerlach, 2012, p. 152) that impact health-related conditions and services. Furthermore, cultural safety is concerned with recognizing the social, economic, and political position of specific populations within the social order. Cultural safety seeks to position health-related concerns of Indigenous peoples within the context of the harmful impact of colonial influences (Gerlach, 2012).

Efforts to introduce a Canadian perspective on cultural safety have led to various professional entities proposing more locally rooted points of view on the definition of cultural safety. The National Aboriginal Health Organization (NAHO) recognized the value and applicability of the cultural safety framework in guiding the delivery of culturally responsive and culturally appropriate health services. Cultural safety fosters competencies within the professional sector that serve to enhance patient encounters through improved sensitivity and understanding of social, political, linguistic, economic, and spiritual issues (Kirmayer, 2012). The Indigenous Physicians Association of Canada (IPAC) and the Association of Faculties of Medicine of Canada (AFMC) have defined cultural safety as a position in which the professional incorporates a practice of self-reflection in order to advance therapeutic encounters with Indigenous peoples. The Aboriginal Nurses Association of Canada (ANAC) asserts that cultural safety is a comprehensive term that accounts for the

social, political, and historical context, as well as issues of racism, discrimination, and prejudice. ANAC furthers the scope of cultural safety to include an action component, in which inequalities are actively challenged, and a component of reflection, in which acknowledgement is given to the inherent cultural qualities of all individuals (Baba, 2013).

ANAC published *A Framework for First Nation, Inuit and Metis Nursing* in 2009. The purpose of the model is to impact “curriculum, faculty members and Aboriginal and non-Aboriginal students” in nursing education programs across Canada (Hart-Waselceesikaw, 2009, p. 5). The competency model included application of “program supports, safe learning environments, engagement and collaboration with First Nation, Inuit and Metis communities” (Hart-Waselceesikaw, 2009, p. 5). The model emphasized postcolonial understanding, communication, inclusivity, and respect (Baba, 2013).

Another important Canadian contribution to our understanding of cultural safety is offered by the Competencies for Indigenous Public Health, Evaluation, and Research (CIPHER) project. CIPHER, a partnership between the University of Victoria and Aboriginal scholars around the world, was created to advance public health competencies that support Aboriginal healthcare. The partnership endorses a conceptualization of cultural safety that acknowledges historical factors that contributed to hostilities between settler and Aboriginal cultures, the influence of colonialism on systemic issues, and their subsequent impact on the delivery of services in the healthcare sector (Baba & Reading, 2012). The notion of cultural safety has led to the development of culturally safe practices that seek to protect the cultural identity and traditions of those accessing services. These practices treat culture as more than perceived cultural norms and propose that it is rather a sociopolitical paradigm that is best understood through the history and experiences of service users. Culturally safe practitioners

have an obligation to not simply recognize or be aware of each patient's cultural belief systems and practices, but also to be vigilant about not applying standard assumptions about an individual or group's cultural needs (Woods, 2010). Cultural safety presents as a process that fosters professional competency within a cultural framework (Woods, 2010).

Cultural Competence

Scholars have documented a number of definitions of cultural competence. Pesquera, Yoder, and Lynk (2008) described cultural competence as "raising self-awareness and increasing knowledge about populations that provide encounters, understanding cultural and health beliefs of different groups" (p. 118). Sue (1998) stated that "one is culturally competent when one possesses the cultural knowledge and skills of a particular culture to deliver effective interventions to members of that culture" (p. 441). Sue and Torino (2005) explain that "cultural competence is the ability to engage in actions or create conditions that maximize the optimal development of the client and client systems" (p. 8).

Efforts to support the implementation and evaluation of culturally competent practices within the healthcare profession have led to the development and adoption of cultural competency paradigms. Campinha-Bacote, a champion for culturally competent practice, has developed two models, "The Process of Cultural Competence in the Delivery of Health Care Service" and "A Biblically Based Model of Cultural Competence in the Delivery of Health Care" (Silvestri, 2012, p. 17). Campinha-Bacote (2007) defines cultural competence as a continuous process that supports the professional's capacity to work effectively within the patient's cultural context (Campinha-Bacote, 2011). He identifies four levels of cultural competence: unconscious in competence, conscious incompetence, conscious competence, and unconscious competence. Campinha-Bacote argues that the

professional ought to view the process of adopting cultural competency as a continuous, circular progression in which she or he seeks to become culturally competent rather than presume cultural competency as a goal to be achieved or a state of being. Both models exhibit five key constructs: cultural awareness, cultural skill, cultural knowledge, cultural encounters, and cultural desire. In the Biblically Based Model of Cultural Competence in the Delivery of Health Care, the key constructs are supported through the integration of biblical virtues, including but not limited to love, caring, temperance, practical wisdom, understanding, compassion, intellectual honesty, and humility (Silvestri, 2012).

According to Williams (2006), cultural competency reflects the theoretical influences of positivism, constructivism, critical theory, and postmodernism (Lum, 2010). In addition, Rothman (2008) suggests that culturally competent practice must show evidence of an important skill set that includes “engagement, trust, and relationship-building; assessment; need definition and contracting; intervention; evaluation and termination; utilization of cultural resources; and advocacy” (Lum, 2010, p. 22). The ultimate goal of culturally competent care is to provide quality healthcare that meets the needs of the individual regardless of his or her cultural background.

Cross-Cultural Practice

Our cultural background influences the type of life experiences we have and thus our assumptions about the world and ways of defining reality (Lee & Greene, 1999). Some professionals lack insight into and awareness of their own culture and the effects it has on the therapeutic encounter (Acer, 2012). For this reason, it is especially important for professionals to work in concert with Aboriginal families and other ethnic groups to understand their own personal culture and the culture of others (Acer, 2012). Greenwood

(2005) asserts, “If Aboriginal children are to become well and healthy adults who meaningfully contribute to their communities and broader society, it is imperative that they are well versed in the fundamental values of their histories and cultures” (p. 554). To thrive in cross-cultural situations and respond effectively to diverse cultures, professionals require greater awareness of their own unique cultural patterns and to be less ethnocentric, less judgmental, more flexible and empathic, and better equipped with an intellectual understanding of others (McFee, 1986).

Knowledge about the distinctive attributes of each cultural group has been encouraged in the development of competent cross-cultural practice (Sue, Arredondo, & McDavis, 1992). Chau (1990) proposes that the rapid growth of ethnic diversity requires the development of a model to educate social work students for effective practice in cross-cultural contexts. Chau identifies two perspectives that influence the learning of cross-cultural practice: cultural pluralism and cultural ethnocentrism, concepts which students must be familiar with in order to deliver effective interventions within a cross-cultural setting. Briefly, cultural pluralism refers to a minority group surrounded by a larger society that allows the minority group to maintain its cultural identities, values, and practices—characteristics that are respected and accepted by the wider community. By contrast, cultural ethnocentrism is the tendency to believe that one’s own cultural group is of prime importance and to judge the values and standards of other cultures based on those of one’s own culture (Chau, 1990).

Chau (1990) recommends the use of a “value continuum of cultural pluralism and ethnocentrism as the basis to teach cross-cultural practice” (p. 126). The utilization of this continuum is intended to strengthen students’ abilities to respect and accept cultural

anomalies and the assets intrinsic in the differences, and to understand and embrace individual differences. Chau (1990) explains that “it also provides a conceptual means for students to develop clinical judgment as to when it is appropriate to reinforce the client’s culturally patterned behavior or problem-solving method and when to encourage adoption of culturally different solutions” (p. 126). It is no surprise that, in the absence of this knowledge, practitioners from different cultural backgrounds encounter difficulties in their professional interactions when their worldviews and assumptions about the world differ from the worldview of their clients. Lee and Greene (1999) state that any cross-cultural encounter ought to be viewed as an educational process on the part of both parties. Acquiring clear ideas about how to co-construct reality in an authentic and respectful manner provides the foundation for a successful, professional, cross-cultural helping endeavour. Gaining competence in cross-cultural practice with Aboriginal families demands a deep awareness of one’s own professional values and biases—an awareness which is more likely to lead to the empowerment of human differences.

Research studies note that the context in which the communication occurs might constrain the application of the methods, as professionals need to be cognizant of cultural, religious, or ethical perspectives. For example, Cunningham et al. (1994) emphasize the importance of being culturally sensitive, and Yeung and Kam (2008) point out that in the setting of cross-cultural meetings “autonomy should not always be considered the most important factor, but must be balanced against other values such as loyalty, integrity, solidarity, and compassion” (p. 535).

Similarly, Levetown (2008) stresses that “it is a good idea to be aware of the general cultural norms and taboos of the dominant subcultures attending the practice” (p. 1447).

Levetown explains that it is generally safer to ask family members directly about their cultural etiquette for communicating than to make assumptions. She elaborates, noting that some cultural groups tend to be “passive with authority figures” and may not ask questions for clarification, or worse may have a language barrier of which the professional is unaware (p. 1447). These cross-cultural settings may well necessitate additional training that emphasizes awareness and respect for the cultural diversity given that different cultural groups will experience and cope with tragedy differently. The implementation of cultural sensitivity training is possible in many of the aforementioned frameworks.

Summary

The shifts in professional practice discussed here are progressive and are welcomed by many. However, appropriate training within organizations and at tertiary institutions requires that existing curricula be amended in order to better reflect current practice trends in keeping with the principles underlying patient- and family-centred care (PFCC). Ideally, changes in training curricula will encourage professional practitioners to be both more culturally sensitive and more effective communicators, given that research indicates the importance of both to producing a better health outcome for children following the delivery of a challenging diagnosis. Changes in communication strategies and increased cultural awareness also have the potential to have a more positive impact on the experiences of parents when faced with bad news, which in turn will make them more able and more equipped to follow through on the clinical recommendations that come with a diagnosis.

There appears to be a gap in the literature with respect to the parental understanding of a child’s developmental diagnosis and the implications this has for carrying out the recommendations for the child’s well-being. It was clear from the research evidence that

parents were often perplexed and bewildered for a host of reasons. One of the aims of my study was to explore parents' experiences of their child's developmental diagnosis and what role their understanding played in following through with the recommendations set out by the multidisciplinary teams.

The following chapter provides an outline of the methodology used to explore the experience of parents upon hearing their child's developmental diagnosis. The intent of the chapter is to describe the disciplinary framework, study design, sample, participant selection, data collection, privacy, confidentiality, and trustworthiness of the study.

Chapter 3 Disciplinary Framework and Methodological Approach

This chapter describes the logic of my disciplinary framework and the rationale for my chosen methodology “interpretive description”—it defines the internal logic of the social work discipline and the influence of social constructionism as it offers a theoretical framework that guided my study. My role as the researcher, recruitment strategies, ethical considerations, data collection methods, data analysis, and verification strategies are discussed. It is important to note that the use of the pronoun “I” in my dissertation is congruent with my chosen qualitative framework—interpretive description. Webb (1992) writes that the “use of the first person is required in keeping with the epistemologies of the research and in the pursuit of reflexivity” (p. 747). He emphasizes that the first person standpoint is pivotal to qualitative inquiry given that the role of the researcher influences, guides, and impacts both the course of the research and the conclusions reached.

Social Work Discipline

Social work practice is broad in nature and scope, as human behaviour is complex and individuals encounter various challenges throughout the lifespan. Social work practitioners draw upon a wide array of theories, frameworks, perspectives, and modalities to provide a thorough assessment related to the various challenges humans face at the micro, mezzo, and macro levels. Regardless of context, a quality assessment is an important skill within social work practice as it leads to effective interventions (Heinonen & Spearman, 2010; Regehr & Glancy, 2014; Sheafor & Horejsi, 2012). The International Federation of Social Workers depicts social work practice as follows:

Social work is a practice-based profession and an academic discipline that promotes social change and development, social cohesion, and the empowerment and liberation

of people. Principles of social justice, human rights, collective responsibility and respect for diversities are central to social work. Underpinned by theories of social work, social sciences, humanities and indigenous knowledge, social work engages people and structures to address life challenges and enhance wellbeing. (Hare, 2004 p. 3).

The disciplinary framework “person in environment” distinguishes the social work profession from other related human service professions as other disciplines predominantly focus on a single dimension of the person (Sheafor & Horejsi, 2012). The perspective “person in environment” rests on the notion that the social worker focuses on several interrelated dimensions of the person (biological, emotional, social, familial) in conjunction with various aspects of their environment (economic, physical, family) (Heinonen & Spearman, 2010; Saleebey, 2013; Sheafor & Horejsi, 2012). Given the multiple levels of influence that contribute to a particular issue, it is not possible to identify a single practice modality and/or theory that could adequately address the plethora of nuances and issues that configure the distinct human situation. As such, social workers build professional competency by weaving a variety of theories, ethical knowledge, practice wisdom, perspectives, and frameworks in an attempt to fully understand and assist the individual or family to adapt to and manoeuvre challenges in relation to their situation. Sheafor and Horejsi (2012) describes this blend as “one’s theoretical orientation to practice” (p. 35). Within the context of my research study, I borrowed relevant sources of knowledge from my disciplinary epistemology, which framed my research study and encouraged a thoughtful, reflexive use of my orientation to practice to generate findings that were relevant to a clinical setting (Thorne, Stephens, & Truant, 2016).

Practice Wisdom

Social work practice is facilitated through the application of social work core values, ethical and philosophical principles, theories, and practice skills (CASW, 2008) that help shape the knowledge base for social work practice. Social work is scientific but not in the sense of a pure science, as it is an applied professional science (Sheafor & Horejsi, 2012). Among the many ways of knowing there is one particular form of knowledge coined “practice wisdom.” In essence, practice wisdom is “derived from the worker’s personal observations and the collective experiences from several generations of social workers who informally share their understanding with colleagues” (Sheafor & Horejsi, 2012, p. 30). Chu and Tsui (2008) claim it is “the knowledge acquired from direct practice experience and not from the direct formal application” (p. 49). In fact, other scholars promote the exploration of practice wisdom or tacit knowledge as a new epistemology of applied practice research (Millstein, 1993; Rosen & Zeira, 2000; Scott, 1990).

The reliance on practice wisdom was one of the tenets of the disciplinary knowledge framing my applied research study—transferring knowledge obtained in one context (child welfare) to a different environment (clinical setting) to inform practice (Fook, Ryan, & Hawkins, 2000) would contribute to the generation of knowledge. In short, I witnessed the destruction and confusion that families faced when a child protection social worker communicated the required actions to protect their child and/or children. Within this tangled web of experiences, parental misunderstanding sometimes occurred, resulting in tragic outcomes. To make sense of a similar phenomenon in a new context, my practice wisdom provided a viable standpoint on my rationale for exploring parental experiences of a child’s developmental diagnosis communicated by a multidisciplinary team.

As a child welfare social worker, I was responsible for making professional judgments and decisions about child safety, family functioning, risk factors, and overall needs of the family with the central emphasis placed on the best interest of the child. My professional role granted me a unique entry into the most private areas of parents' and children's lives. It was vital, therefore, that I was able to justify the decisions I made at the various stages of assessment and intervention. Family situations were both complex and extraordinary, as the situations often involved several social issues such as domestic violence, substance misuse, mental health issues, and poverty. My assessments were based on a series of professional casework activities, drawing from various sources of knowledge in an attempt to explain why a certain action resulted in a particular behaviour. It became evident that social work is not a pure science and ideas had to be adapted or abandoned in light of changing circumstances and new information garnered through the ongoing engagement between the social worker and the family. Each child, parent, and situation warranted a different practice approach that was designed to suit the circumstance of that particular family unit. As such, the efficacy of evidence that came from the client's point of view (practice-based evidence) rather than from the determination of the practitioner often resulted in the best intervention.

Social Work and Epistemology

According to Willis (2007), epistemology is "concerned with what we know about reality (however that is defined) and how we know it is real." Epistemology is about knowledge or simply "the theory of knowledge" (Willis, 2007, p. 10). Who knows more about a person's situation than the person experiencing the reality? Supporting this question is a guiding social work principle which states: "the social worker should consider clients as

experts in their own life” (Sheafor & Horejsi, 2014, p. 53). Too often, social workers and other helping professionals rely too much on theoretical orientations of human functioning and negate to elicit the client’s understanding of the situation (Sheafor & Horejsi, 2014; Hepworth, Rooney, Rooney, & Strom-Gottfried, 2016). Wilson (2008) asks, “What part of this reality is worth finding out more about . . . what is ethical to do in order to gain this knowledge, and what can this knowledge be used for?” (p. 34). As noted earlier, the knowledge generated from my research was intended to advance clinical practice to improve health outcomes for children and families who receive services from the CDBC clinical teams in the near future. The skill of social work practice lies in practice models designed to explore the client’s perspective—the relationship between the social worker and the client is one of collaboration and mutual expertise. In essence, subjective and experiential knowledge is fundamental to social work practice as it is co-constructed between the social worker and the client—social work is collaborative and explorative.

In the realm of human complexity, it is important to conceptualize all sources of knowledge as tentative, as judgments based on the best information available at a given point in time can be scrutinized and refuted in the light of new information or evidence to the contrary (Trevithick, 2008). The knowledge base of social work—whether abstract, action-based or intuitive—ought to be viewed in a manner that complements the variations of knowledge versus what particular source of information trumps the other.

Social Constructionism

The intellectual underpinnings of the social work profession share a number of common features within social constructionism. What does this mean in the context of my research? My research was guided by the internal logic of the social work discipline and

social constructionism, which provided a way of examining multiple angles of vision on the factors that played a role in the parental understanding of a child's developmental diagnosis. Social constructionism is based on the assumption that all meaning in the world is connected to a social understanding of the process. Social constructionism allows research to proceed with the assumption that reality is socially constructed, which gives value to the context in which the individual makes sense of his or her world (Creswell, 2003). A constructionist perspective emphasizes that meaning is not constructed exclusively by the person but rather is socially constructed (Barkway, 2001; Thorne, 2008). Hoffman (1990) sets out her understanding of social construction theory this way:

The theory posits an evolving set of meanings that emerge unendingly from interactions between people. These meanings are not skull-bound and may not exist inside what we think of as an individual "mind." They are part of a general flow of constantly changing narratives. Thus the theory bypasses the fixity of the model of biologically based cognition, claiming instead that the development of concepts is a fluid process, socially derived. (p. 2)

Rather than pursuing a singular truth such as one "right way" to do something, social work seeks to uncover truth-claims and draw upon multiple ways of knowing and evidence to determine the best way to intervene within a particular context. A unique element of constructivism is the significance of the dialogue between the researcher and the participant, where a deeper meaning can be unleashed (Ponterotto, 2005). Relevant theories, prior knowledge, and experience brought to a clinical interaction are valuable and inform that interaction, and it is in the collaborative nature of the social worker-client interaction that an iterative process of knowledge development occurs. As a consequence of my personal health

diagnosis (cancer) coupled with my professional career as a social worker, I was able to engage in a dialogue that recognized first-hand the complexities families face when receiving a diagnosis. In essence, it was the collaborative dialogue (researcher and participants) that co-constructed the interpretation of the research findings (Ponterotto, 2005).

How people explain their lives, the world they inhabit, and their interaction with others can vary greatly and lead to fundamental differences in the way they perceive events and the understanding and meaning they assign to experiences (Trevithick, 2008). For example, there was no single or predictable way that parents described their experience; rather, their description was unique to a variety of experiences leading from the shaping of their beliefs, hopes, past experiences, support system, and their overall situation. They added richness to why and how delivered messages further facilitated or complicated an already challenging adaptation process during a crucial developmental stage of parenting.

In sum, my research disciplinary framework coupled with a social constructionist perspective rooted in a subjectivist epistemology is congruent with interpretive description—applied research design (Thorne, 2008). Parental experiences were viewed in the context of a complex healthcare system to develop clinical approaches that accurately reflected tangible ways clinicians can effectively provide quality care.

Research Design

The purpose of my study was to examine the experiences of parents who received a diagnostic assessment and recommendations by way of one of the CDBC clinical multidisciplinary teams situated across northern British Columbia. The small body of relevant research on this topic approaches it from various angles and examines different stages of the diagnostic process. However, questions remain in relation to the parental

understanding of a child's diagnostic assessment subsequent to the professional clinical delivery and how this influenced the parent's implementation of their child's clinical recommendations. In the previous section, I outlined an intellectual structure that served as the theoretical foundation upon which I made design decisions about my research inquiry. Social work's disciplinary epistemology and internal logic structure formed the scaffolding influenced by social constructionism and guided loosely by systems theory. This structure achieved the generation of practical options for enhancing the practice of delivering a child's developmental diagnosis and supported the rationale for explicit supportive resources beyond the diagnostic disclosure. Using social work's disciplinary epistemology as the theoretical scaffolding within which to frame this study required a methodology that provided opportunities for description, interpretation, and pragmatic action (Thorne, 2008). As such, my study drew on an interpretive method of research that addressed a particular experience in a clinical setting from the perspective of the service recipients (parents).

The research design that governed my study was a specific qualitative method of inquiry known as interpretive description (Thorne, Kirkham, & MacDonald-Emes, 1997). Interpretive description has roots in several academic disciplines such as sociology, anthropology, and psychology. Within these specialties, specific dominant qualitative methodologies (grounded theory, ethnography, and phenomenology) are often selected to guide one's methodological trajectory (Thorne, 2008; Thorne et al., 1997). Qualitative scholars who have examined various aspects of healthcare often subscribed to one of the aforementioned qualitative approaches—despite concerns related to the incongruence associated with the specified methodological choice (Morse 1989; Thorne, 2008). As a result of this incompatibility, several nursing scholars who researched clinical aspects of healthcare

service delivery felt that the traditional qualitative approaches were not an appropriate fit and jeopardized the rigour of the study (Thorne et al., 1997). Hence, they voiced the need for a different methodological approach that fostered the creation of specific types of applied research knowledge (Thorne, 2008). Interpretive description was conceived and has gained popularity as a useful method for generating new insights in clinical settings (Thorne, 2008; Thorne et al., 1997). Thorne et al. (1997) described interpretive description as a non-categorical methodological approach to develop clinical understanding with a core emphasis placed on generating knowledge that informs clinical practice.

Selecting a research methodology to best fit the research question is important because the research design forms the framework for data collection and analysis (Migiro & Oseko, 2010; Willis, 2007). As with most research studies, the research question guides the research methodology (Patton, 2005). After I reviewed and researched the features and parameters associated with qualitative research methodologies—hermeneutic phenomenology in particular—it was evident that interpretive description presented the best framework to explore subjective experiences in a clinical context that not only had relevance for clinicians who communicate a diagnostic finding but the health implications for children and families. Furthermore, interpretive description recognizes that the “clinical mind tends not to be satisfied with “pure” description, but rather seeks to discover associations, relationships and patterns within the phenomenon that has been described” (Thorne, 2008 p. 50). My research highlighted professional factors that facilitated or impeded parental understanding in the context of a clinical multidisciplinary team delivering a child’s diagnostic finding. The literature review, theoretical alliances, social work’s disciplinary epistemology, and my own positioning of ideas and experiences in relation to understanding

a child's developmental diagnosis provided a theoretical scaffold which framed my study. Theoretical scaffolding is the term employed to indicate the foregrounding and scholarly positioning within a study (Thorne, 2008). My theoretical scaffolding was anchored within a qualitative methodological design—known as interpretive description (Thorne, 2008).

Interpretive description is based on a logic model design that supports the generation of applied discipline knowledge that ought to be executed in a coherent manner creating meaningful findings (Thorne, 2008). In other words, interpretive description does not adhere to a prescriptive set of rules that dictates one's research trajectory (Thorne, 2008). However, the clinical context and the discipline shape the lens through which the data is collected and analysed. Thorne (2008) explains, “as a method for generating knowledge pertaining to clinically derived phenomena interpretive description explicitly locates itself within the applied disciplinary domain” (p. 68). My research cuts across several applied discipline domains, as the comprehensive diagnostic assessments that families received were informed by a multidisciplinary assessment which may or may not have included the following healthcare professionals: pediatrician, psychologist, social worker, speech language pathologist, and/or occupational therapist. Given the various healthcare professionals at play in this clinical context, my research involved the breadth of several disciplines that are recognised by the School of Health Sciences. For example, Health Sciences is “interdisciplinary in nature with the intent of addressing the needs of health science researchers and professionals” in the delivery of healthcare to improve health issues in northern, remote, and First Nations communities (UNBC, 2016). The quality of a clinical encounter in a healthcare setting is of paramount importance as it plays a role in one's health outcomes. My research sought to generate insight from the parental perception to inform

clinical practice where healthcare clinicians on multidisciplinary teams deliver a child's developmental diagnosis—to improve health outcomes for children and families in a northern, remote community. Interpretive description has a pragmatic focus in which the findings generated are relevant to clinical practice and have application potential (Thorne, 2008). Thorne (2008) explained:

We desperately need new knowledge pertaining to the subject of experiential, tactic, and patterned aspects of human health experience—not so that we can advance theorizing, but so that we have sufficient contextual understanding to guide future decisions that will apply evidence to the lives of real people. (p. 36)

Interpretive description moves past major description and allows for meanings and explanations to be generated, thus enhancing clinical understanding (Thorne, 2008).

Interpretive description is consistent with my ontological and epistemological stance for this study, hence it offered the most compatible approach to forming an understanding of the individual and shared experiences of the parents—as interpretive description seeks to understand shared experiences while also taking into consideration the variation between individual experiences (Hunt, 2009; Thorne et al., 1997; Thorne, Kirkham, & O'Flynn-Magee, 2004; Thorne, 2008).

My research was informed by the literature review, theoretical alliances, social work disciplinary epistemology, and my own positioning of ideas and experiences in relation to parental understanding of a child's developmental diagnosis (Thorne, 2008b, 2013a).

According to Corey, Corey, and Callanan (2003), ethics refers to a set of moral principles, rules, or standards governing a person or a professional discipline. The following ethical framework was implemented during the course of my research project.

Ethical Considerations

Before beginning my research study, approval was granted by the University of Northern British Columbia Research Ethics Board and the Northern Health Research Review Committee (see Appendix). Batchelor and Briggs (1994) note that, in cases where researchers undertake studies in the absence of an ethical framework, they render themselves ill-equipped to manage the unpredictable nature of qualitative research. As with any research involving human subjects, ethical considerations are primary, and I made sure to follow all ethical guidelines from the outset of my research through to the end. I adhered to the principles of due diligence and full disclosure throughout in order to ensure that my participants were fully informed and understood that to which they had consented (Banner & Zimmer, 2012). I also referred to the four guidelines characterizing various codes of ethics pertaining to the protection of human research subjects, as outlined in Christians (2005): (a) informed consent, (b) avoidance of deception, (c) privacy and confidentiality, and (d) accuracy (p. 144). Prior to the face-to-face interviews, I sent the informed consent and information sheets to the participants via email for their review so they could ask questions about the research and think about whether they truly wanted to participate. I let the participants know that at any time during the interview process, they could ask to stop the interview or choose not to continue without penalty.

Morse, Barrett, Mayan, Olson, and Spiers (2008) look at the way qualitative researchers conceptualize the inherent risks in qualitative interviews. They point out that risk is not absent once the participant signs the consent form, and they note that a risk assessment should not be confused with being a one-time event but rather is necessary throughout the research interview. I took care to ensure that, at all times, my participants' well-being was

paramount. As such, during the interview, I frequently asked my participants how they were feeling to ensure there were no areas of emotional distress, and I also paid attention to their non-verbal cues. As noted above, participants were reassured in advance that they could notify the researcher, either by email or by telephone, if they decided to withdraw from the study, and they would not be required to explain their reasons. In the event that a participant decided to withdraw following data collection, I agreed ahead of time to destroy the data immediately on receiving notification. No participants withdrew from my research study.

Confidentiality

Privacy and confidentiality were addressed in the consent form and verbally reiterated to the participant before the interview. I informed my participants that I was legally obligated to report any information relating to child or elder abuse, and if I had any reason to believe that the participant would cause serious harm to another person I would make a report to the appropriate authorities. Neither action was warranted on the basis of any of my interviews. To maintain the anonymity of the participants, I assigned each participant a pseudonym, in keeping with the standards set out by Orb, Eisenhauer, and Wynaden (2001). I assured each participant that information shared during interviews would remain confidential and explained that I, the researcher, would be the only person with access to their name and contact information. Although I used a professional transcriptionist to transcribe each interview, the transcriber only knew the participants by their pseudonym. The transcriber was asked to sign a Transcriber Confidentiality Agreement (Appendix); I reviewed the terms of this agreement with the transcriber and emphasized the importance of confidentiality.

Equally important to me were the emotions that I expected would be triggered by the topic, given the likelihood of painful memories associated with hearing the delivery of a child's developmental disability. This occurred during two of my interviews. I saw my primary obligation as being responsive to the participant's vulnerability and rights. In both cases, I stopped the interview and assessed the best interests of my participants, an assessment which was conducted jointly, allowing the participants to drive the shared decision making. And in both cases, the participants repeatedly assured me that they wanted to continue with the interview. I also offered to refer the participants to counselling, and I provided a written note with contact information for the appropriate providers. Prior to the participant leaving the interview and/or the premises, I ascertained whether the participant had fully regained composure and left in relatively good emotional shape. In both cases, I debriefed with my supervisor and used my journal to document the experience, in part to ensure that I remained grounded and did not participate in countertransference.

I stored the digital copies of the interview data on my computer at UNBC, which I use for professional purposes and which is linked to a secure server with password and anti-virus protection. I have stored the hard copies of the data in a locked cabinet in a locked office, also at UNBC. On completion of my PhD, all audio recordings will be destroyed, and any remaining paper copies will be shredded. The electronic file containing analysed data will be stored for five years on the UNBC server under my account, at which point the electronic file will be deleted.

I believe that I had a certain advantage with respect to the complexities of conducting ethical research, given my familiarity with my own professional code of ethics and my ability to translate those guidelines into my research project. As a social worker, I abide by the

British Columbia Association of Social Workers Code of Ethics, which is comprised of eleven principles. The first principle ultimately guided my research: “A social worker shall maintain the best interest of the client as the primary professional obligation” (British Columbia Association of Social Workers, n.d.).

Role of the Researcher

One of the hallmarks of qualitative research relates to the concept that the researcher is the instrument (Guba & Lincoln, 1981). Interpretive description accepts the theoretical and practical knowledge that a researcher brings to their research study. In fact, Thorne (2008) expresses the importance of the researcher locating him or herself within the research. In other words, what kind of “intellectual integrity” contributed to the development of the researcher’s area of interest (Thorne, 2008, p. 69)? Interpretive description assumes that the researcher has an affiliation to an applied discipline, which aligned with my scholarly pursuit, coupled with my previous professional role as a practitioner in an organizational setting.

There were a number of factors that influenced my research area before I embarked on this particular study. Initially, my curiosity was piqued by my PhD faculty advisor’s ideas and concerns about how families experienced the process of receiving a comprehensive diagnostic assessment by way of the CDBC multidisciplinary team. This clinical interest, coupled with my professional expertise in child welfare practice, motivated me to explore this human experience within the healthcare system. As a former professional child protection social worker, I witnessed the destructive consequences that families and children faced when a parent lacked an understanding of the service recommendations that were deemed necessary to protect their children. My professional role as a Senior Practice Analyst

(quality assurance) with the Ministry of Children and Family Development provided the opportunity to gain insight into an ongoing problem that appeared to exist in professional practice. My research question morphed out of my personal and professional relationship to the subject area. Parental understanding of a child's diagnostic finding was fundamental in order to provide optimal care to the child. In essence, a solid understanding enables the parent to connect the child to the most appropriate services devised by the clinical multidisciplinary team.

My approach with my participants was to learn as much as I could by way of open and honest dialogue. I wholeheartedly endorse the notion that the participants were experts of their experiences, and that there were multiple truths. I was aware that decisions I made at each stage of the research trajectory were influenced by my world view. Furthermore, my professional training equipped me with a number of skills fundamental to working with diverse populations, such as relationship-building, active listening, interviewing, and engagement—all of which I deployed in my role as a researcher. My professional experience conducting interviews bolstered my confidence when it came to collecting interview data. A number of scholars have looked at interview process in the context of qualitative inquiry, and several enumerate what they consider to be fundamental skills central to performing a quality interview. The majority of these have been incorporated in the Code of Ethics for the Canadian Association of Social Workers (2005) and informed the way in which I conducted my doctoral research.

Recruitment Strategies

Recruiting individuals for the purposes of research can be achieved in various ways. Sampling is one way of selecting individuals from the general population. When it comes to

sampling, there are important differences between the strategies used in qualitative and quantitative research: the rationale behind the logic, the strategies employed, and the purpose of sampling varies significantly (Mayan, 2009; Patton, 2005). My review of the literature indicated that a purposive sampling technique would be most appropriate for this study given the methodology I chose to use (Maxwell, 2005; Patton, 2002; Thorne, 2008). Purposive sampling allows for the selection of “information-rich cases” that will produce “insight and in-depth understanding rather than empirical generalizations” (Patton, 2002, p. 230). The following eligibility criteria was developed: The parent

- may be the birth parent, or the parents of an adopted-at birth child or youth under the age of 19 years who has been previously assessed by the CDBC team;
- must have an open file with the Complex Developmental Behavioural Conditions Team; and
- must be a resident of Northern British Columbia.

The following steps were taken to recruit participants once I received institutional approval from the appropriate ethics committees:

- The CDBC team in Prince George, British Columbia, was selected to assist with the recruitment of participants because the multi-disciplinary assessment team provides comprehensive diagnostic assessments to children and youth in Northern British Columbia.
- Prior to submitting my proposal to the ethics committee, I met with the CDBC manager who oversees the team to discuss my research and confirm support for my project.

- Once approval was given by the appropriate ethics committees, I arranged another meeting with the CDBC manager to submit and discuss my list of criteria for potential participants, which made it possible to identify prospective participants in an efficient way. At this point, we also identified a “gatekeeper” or contact person, in keeping with a qualitative research method where gatekeepers are often used to assist the researcher in gaining access to participants (Hatch, 2002).
- The appointed contact person from the CDBC team assisted with the recruitment process by contacting families during clinical follow-up calls and informing them about the research. Prospective participants then had to choose whether to contact the researcher directly or provide verbal consent allowing the contact person to email their information to the researcher.
- I telephoned the potential participants to schedule a day, place, and time for the interview at the convenience of the participant.
- Once the interview was completed, the participant received a \$75.00 gift card as an honorarium, upon which they signed a document to acknowledge having received remuneration (see Appendix).

The sample size used in quantitative studies is often larger than that in qualitative research studies because the researcher conducting qualitative research is generally interested in examining a particular phenomenon from a detailed and in-depth perspective which warrants a smaller sample size (Thorne, 2008). According to Patton (2005), qualitative inquiry typically focuses on a relatively small sample, where quantitative inquiry most often emphasizes the importance of larger, random samples in the search for general trends.

Crouch and McKenzie (2006) note that qualitative research is more concerned about the meaning of experiences than about testing hypotheses.

I chose to work with a sample of approximately twenty participants, a number that was contingent on whether or not I reached the point of redundancy before or after I reached my estimated target sample size. Half way through my recruitment process a decision was made to implement a “snowball sampling” recruitment process to identify additional participants given my sample size was below my intended target range. The purpose of snowball sampling is to identify prospective participants by way of their connections to known individuals, such as colleagues, friends, and acquaintances who understand the research goals and can make recommendations based on their knowledge regarding the eligibility of potential subjects (Patton, 2002). In my case, I solicited the assistance of a colleague to help identify three parent participants that likely met the eligibility criteria. Denzin and Lincoln (2011) advise that the cessation of new themes reveals the presence of saturated data. Once I had conducted and analysed the 17 interviews, I felt confident that no new themes or information were emerging from the data, and I concluded that I had reached the point of saturation.

Details of Data Collection

The pioneers behind this method recognize the relationship between interpretive description and the other traditional qualitative approaches. Thorne et al. (2004) explained: “the design strategies in interpretive description borrow strongly from some aspects of grounded theory, naturalistic inquiry, and ethnography drawing on values associated with phenomenological approaches inherent in the methods of data collection” (p. 6). I used a semi-structured interview guide to gather data. Interpretive description depends on

subjective experience from multiple angles of vision (Thorne et al., 2004). Interviewing several participants and hearing various experiential accounts led to a greater understanding of the clinical experience.

I adopted a semi-structured interview format because it enables the participant to freely express their unique views in their own language (Cohen & Crabtree, 2006; Olson, 2011). The interviews were loosely structured around the main research question and study aims, with follow-up questions designed to elaborate on thoughts that were considered important or relevant (Creswell, 2003; Rubin & Rubin, 2011; Warren, 2002). The interview questions also served to keep both the interviewer and the participant on track with respect to the goal of the research (Rubin & Rubin, 2011). Interviews were scheduled to allow at least one hour per session. They were recorded using two digital voice recorders in case one malfunctioned during the interview.

Interview Protocol

I developed an interview protocol and practised my interview techniques with a graduate student before commencing the research interviews—a strategy identified by Chenail (2011) known as interviewing the interviewer. This rehearsal afforded the opportunity for constructive feedback, which led to improvements (i.e., learning the merits of when to be silent in the course of the interview). In addition, my dissertation committee and the manager and clinical coordinator of the CDBC team reviewed and provided feedback on the questions I developed to address the research topic. The feedback resulted in the identification of weakness in particular questions, which prompted me to adjust the questions and include additional questions (see Appendix).

I was comfortable and relaxed during all of the interviews, and I was acutely aware that co-creation involved a dialogue between the participant and the researcher to foster understanding. The intention behind my conversational style was to foster a connection between myself (the researcher) and the participants with the expectation of eliciting data-rich information in keeping with the idea that “both the interviewer and the study participant influence the quality of the information obtained” (Olsen, 2001, p. 23). Throughout the interviews, I engaged in active listening and reflection, and I used prompt phrases when required in order to encourage participants to respond openly without being influenced by my own assumptions. Also, I clarified any information that I thought had not been understood by rephrasing it in clearer terms.

As the interviews proceeded and my understanding evolved, I became better at intuitively guiding the participants to stay on track in relation to the research question and aims. In interpretive research, data analysis begins during data collection in the course of active listening, reflection, clarification, and intuiting (Mayan, 2009).

Interview Procedures

Participants were contacted by telephone by the clinical coordinator of the Prince George CDBC team, and they were informed about the particulars of my research study. On the basis of their verbal approval, participant information was sent to the researcher. Following this, participants were contacted by phone to set up a mutually convenient time for a face-to-face interview. Participants were asked to choose a quiet setting where they felt they would be comfortable. Before beginning the interview, participants were provided with an information sheet that explained the purpose of the research, along with an informed consent form approved by University of Northern British Columbia Review Ethics Board and

Northern Health Research Review Committee (see Appendix). I asked each participant if they would prefer to read the information themselves or have me read it out to them, to ensure that participants with literacy issues understood the information. One participant had me read the information.

A professional transcriptionist was hired to transcribe all the audio recordings of interviews. To verify accuracy of the transcriptions, I reviewed them by listening to the recordings and reading the transcript simultaneously so that I could make any corrections needed to prepare for the data analysis (Creswell, 2003).

Data Analysis

Crabtree and Miller (1999) assert that if certain basic guidelines are examined prior to the execution of the data analysis the likelihood of a successful process increases significantly. The authors speak about the importance of knowing yourself and your biases, the ability to identify and know your research question, ongoing pursuit of alternate interpretations, flexibility, draining the data, celebrating differences, and pursuing critical feedback as the lone analyst may run the risk of missing vital nuances. The adoption of these guidelines coupled with thematic analysis (Braun & Clarke, 2006; Guest, MacQueen, & Namey, 2012) led to meaningful findings. The purpose of an interpretive descriptive analysis is to take the data and deploy your innate analytic and conceptual capacities that turn data into credible and meaningful findings (Thorne, 2008).

I generated findings by using the thematic analysis approach by Braun and Clarke (2006). Given that the primary purpose of interpretive description is to produce clinical knowledge relevant to a health context (Thorne, 2008), thematic analysis was an appropriate method for my research study—as the emphasis is also on the importance of practical

outcomes (Boyatzis, 1998). Thematic analysis is a flexible and accessible method for analyzing qualitative data that uses six phases to identify themes within data (Braun & Clarke, 2006). These six phases are as follows:

Phase 1: Familiarize yourself with your data. During this first phase, I read and re-read the interview transcripts to be familiar with the raw data. Reading and re-reading transcribed data enables the researcher to become more familiarized with raw data (Creswell, 2003; Patton, 2002; Thorne, 2008). Braun and Clarke (2006) strongly encourage researchers to engage fully in this phase and caution against a skimming approach, as this stage forecasts the trajectory of the analysis. The dance of reading and re-reading is a time-consuming endeavour, but it reaps dividends for the researcher. Following the formal collection of my interview data, I built insight by reading and re-reading, examining, and re-examining—by going back and forth between my observations and the interview data. I re-read all interview transcripts at least three times and reviewed my notes for each participant. I also listened to each audio recording a number of times, while simultaneously reading the transcripts. This level of immersion at the early stages of the data analysis provided me a “developing sense of the whole beyond the immediate impression of what it is that they contain” (Thorne, 2008, p.143).

Phase 2: Generating initial codes. The second step of the data analysis required the generation of initial codes. This phase revolves around the “production of initial codes from the data” (Braun & Clarke, 2006, p. 18). During this phase, the researcher searches for patterns by reading the interview transcript thoroughly before coding. There are several ways of coding; “note writing,” “highlighting,” and using “post-it” notes are some of the ways to code parts of the data set (Braun & Clarke, 2006). For the purpose of my study, I

printed each participant's interview transcript, highlighted similarities and differences within the data, and documented initial codes by noting aspects the participants emphasized, the impact of the delivery of the diagnosis, and other relevant statements made by the participants which were placed into labelled paragraphs that contained information relating to each particular point being articulated. In addition, I captured the components that piqued my interest that were linked to my research question and aims. This process allowed me to see new points of entry into the data.

Phase 3: Searching for themes. On completion of the coding of the entire data set, it was time to organize the coded data into themes. Coding all data fragments and combining them according to patterns was a crucial step in this phase. Applying visuals, which entails labelling each code onto cards and placing them into “theme piles,” is recommended during this step (Braun & Clarke, 2006). The process of sorting codes into “theme piles” is intended to lead the researcher to the identification of “overarching themes,” “sub-themes,” and themes that do not align in either category (Braun & Clarke, 2006). I used several Word documents to assist with my theme piles—phrases were selected from the transcripts, copied, and added to the appropriate document where they were coded under summary phrases aimed at identifying categories and linkages in the data, and I explored relationships and patterns between participants. At the conclusion of this phase, the researcher can discover the overarching themes, sub-themes, and themes that are not relevant to the topic under investigation. It is recommended not to abort any data at this stage, as the application of the next phase may highlight the need to syndicate, enhance and isolate, or remove a theme (Braun & Clarke, 2006).

Phase 4: Reviewing themes. During this stage, the researcher may reach conclusions that dictate the manoeuvring of some of the “candidate” themes (Braun & Clarke, 2006, p. 20). This action was completed by selecting phrases that seemed to answer my original research questions and setting them aside on a separate document associated with each participant. I then copied all of the significant phrases into one document, which I continued to analyse for meanings embedded within the text. At this point, I reviewed the set of preliminary themes I had established and ensured that the data contained in the themes were cohesive. If the researcher’s assessment of the theme reflects a consistent pattern, the researcher proceeds to the next level of this particular phase. If the themes are not cohesive, the researcher is required to re-work the theme until achieving the desired outcome (Braun & Clarke, 2006). This phase of the analysis consisted of me reviewing all the themes and confirming that they linked to my overall research question and aims, which consisted of identifying factors that affected the delivery of their child’s diagnosis during the clinical encounter, and the factors that impacted the parental pursuit of the clinical recommendations subsequent to the family meeting. It is not unrealistic to re-code from the data set, as coding is an “ongoing organic process” (p. 21). In fact, this phase of the analytic approach presented me opportunities to refine the themes and reorient the inquiry according to new insights that were developed. At the end of this phase, I felt confident that I had a solid read on the themes and the overall narrative of the data.

Phase 5: Defining and naming themes. At this point, the researcher assigns each theme a title or name that is succinct, forceful, and instantly provides the reader with an idea of the nature of the theme (Braun & Clarke, 2006). I developed a preliminary analytic structure from the provisional themes to form the basis for identification and exploration of

commonalities and differences among and between the experiences of participants. Ongoing analysis was conducted until I refined the specifics of each theme. This was accomplished by a layered reflection on the text, achieved by writing and re-writing where I accessed a higher level of critical reflectivity.

Phase 6: Producing the report. This phase provided the final opportunity for analysis. My method for engaging in an ongoing reflexive process was to write my experiences and observations into a journal, which assisted with “the continuous and interactive” nature of process throughout my research. Here, I documented areas of understanding, misunderstanding, and possible interpretations, which at times prompted me to consult again with my participants. In this way, I was able to highlight the experiences and identify themes that participants articulated. The responses of the participants to the interview questions yielded three overarching themes and several sub-themes related to each overarching theme, for a total of twelve subthemes. The three overarching themes—clinical encounters, the manner of the delivery, and where we go from here—are discussed in further detail in the following chapters, as per Braun and Clarke’s (2006) recommendation that “extracts need to be embedded within an analytic narrative that compellingly illustrates the story that you are telling about your data, and your analytic narrative needs to go *beyond* description of the data, and make an *argument* in relation to your research question” (p. 93).

Verification Strategies

It is vital that qualitative research is conducted in a rigorous manner. Qualitative researchers have long debated whether rigour can be applied to qualitative interpretive research given that it does not comply with the positivist understanding of rigour. Some scholars even consider applying similar standards of rigour to be potentially damaging to the

data (Mayan, 2009). The search for legitimization and representation in qualitative research has resulted in ongoing discussion and a call for appropriate criteria for the evaluation of qualitative results (Pillow, 2003; Polkinghorne, 2007). There is a proliferation of such criteria in the literature, which can be daunting when trying to work out the best ways to ensure that one's own qualitative research is rigorous. To this end, Cohen and Crabtree (2008) reviewed the healthcare literature and identified seven important dimensions of evaluative criteria for qualitative research:

1. Carrying out ethical research.
2. Importance of the research.
3. Clarity and coherence of the research report.
4. Use of appropriate and rigorous methods.
5. Importance of reflexivity or attending to researcher bias.
6. Importance of establishing validity or credibility.
7. Importance of verification or reliability.

A number of processes were adopted to demonstrate rigour throughout my research. There has to be congruence between the research question and the components of the method in order to establish a unified research framework (Mayan, 2009; Morse, 1999). Throughout my dissertation, I demonstrated clarity and coherence by identifying my chosen research paradigm (relativist/constructionist) and establishing my methodological framework (interpretive description); I clarified the reasons for my chosen paradigm and methodological approach to my research and aligned this approach with my data collection method (interviews) and the analytic approach (thematic analysis).

Several sources identify a number of hallmarks that are used to assess and demonstrate quality research: credibility, relevance, fittingness, triangulation, thick description, auditability, confirmability, prolonged engagement, transparency, member checking, reflexivity, and accountability to name a few (Creswell, Plano Clark, Gutmann, & Hanson, 2003; De Witt & Ploeg, 2006; Doyle, 2007; Finlay, 2002; Morse et al., 2002; Sandelowski, 1986). There is a consensus among scholars that the above actions are intended to strengthen rigour, but there is no set rule on how many of the strategies should be incorporated into one's research to demonstrate rigour (Morse, 2015). Typically, the researcher incorporates one or more of the above approaches and reports the findings in their research demonstrating rigour (Creswell & Miller, 2000).

In my own research, I have used the following methodological strategies to ensure the credibility of my findings: prolonged engagement, peer review, member checking, and reflexivity, all of which are methods appropriate to interpretive description. Guba and Lincoln (1989) point out that prolonged engagement and repeated interactions with study participants will help to bring rigour to the collection of data because it fosters trust, which in turn will lead to a richer data set (Morse, 2015). For my research, data from each participant was collected over a period of two to four months. I had contact with each participant at least twice and in some cases three or four times after the interview. During these encounters, I established connections and gained trust, which provided the level of comfort needed to allow the participants to feel free to engage in several discussions about their experiences around the diagnosis of their children. My ongoing contact with my participants fostered a connection that increased the rigour and the credibility of my doctoral research findings (rich data).

Peer Review

Peer review is a method used to inform and improve the research process by engaging colleagues, to provide a critical assessment of the merits of the research study (Merriam, 2002). Peer review of my research occurred on a number of occasions and at various stages and was undertaken by my academic advisor and various committee members. My initial interview questions were scrutinized, and I had another graduate student engage in a trial interview and provide feedback before I began the formal interview process with my participants. Additionally, one professional clinician read versions of my data analysis and corroborated my analysis, which offered validation. In addition to using a process of peer review to establish the credibility of this study, I also incorporated member checking and reflexivity to enhance credibility.

Member Checking

Member checking in qualitative research can involve any number of feedback and/or validation mechanisms, all of which are designed to improve accuracy and credibility. A qualitative study that attempts to describe and gain insight into a particular human experience gains credibility when both those who have had the experience and those who have not can recognize the interpretation and understand it (Sandelowski, 1986). The purpose of member checking is to confirm whether the researcher's impressions and findings are congruent with the participant's understanding of their experience, to determine whether there are areas of disagreement, and to establish the nature of any discrepancies (Merriam, 2002). Participants were invited to respond to the preliminary research findings and discuss how consistent the findings were with their experience. Each participant was emailed a member checking letter inviting them back to the research project for feedback. The letter also explained what

member checking involved and described the method that would be used. Ten of the 17 participants chose to provide feedback, and each of them confirmed their agreement with my findings. No new insights were provided by participants during the member checking process. (Appendix).

Reflexivity

Critical subjectivity refers to the researcher's ability to reach a high level of awareness (Lincoln, 1995). One way to enhance one's awareness is to engage in a process of reflexivity. Reflexivity is considered to be the defining feature of qualitative research, with the object being to produce less authoritative and more self-critical texts (Finlay, 2002; Hertz, 1997). Dowling (2007) defines the process this way: "Reflexivity refers to the engagement by the qualitative researcher in continuous self-critique and self-appraisal and the provision of an explanation of how his/her experiences did or did not influence the stages of the research process" (p. 136). I used my journal to record my reflections on the research process, including my methodological decisions and rationale for the selection process, my thoughts about the logistics of the project, and my reflections generally about what I saw happening, and how my values, beliefs, and interests came into play.

My journal became more reflexive and less reflective once I began my data collection. Reflexivity differs from reflection in that reflection does not require a relational interaction. According to Pillow (2003), reflexivity involves self-awareness and self-scrutiny and the recognition of others in the research process. Pillow (2003) is specifically interested in the power imbalance between the researcher and participant subjectivities and supports this view of reflexivity, as this practice is a way of broadening our understanding of how our self-awareness, social locus and life passions as researchers influence the entire research

process from initiation to completion. Similarly, qualitative analysis is an iterative and reflexive process that begins as data are being collected rather than after data collection has terminated (Stake, 1995). Before conducting each interview, I recorded my thoughts, intentions, awareness, and my overall well-being. On completion of the interview, I re-read my reflections and documented my reflexive thoughts, assumptions, challenges, and perspectives regarding the interview. This type of integration strengthened my awareness of my potential influence throughout the interview and provided an opportunity to examine the participant's meaning.

Guba and Lincoln (1989) note that it is important to make sure the participant's meaning was captured and understood on a deeper level. My personal and professional history working with children and families undoubtedly influenced my perspective and perceptions. Patton (2002) suggests that reflexivity "reminds the qualitative inquirer to be attentive to and conscious of the cultural, political, social, linguistic and ideological origins of one's own perspective and voice" (p. 65). I used reflexivity to question my assumptions and biases and to look at other challenges that surfaced. Morse et al. (2002) argue that validity and reliability are achieved when the researcher rigorously follows a number of verification strategies in the course of the research process:

Together, all these verification strategies incrementally and interactively contribute to and build reliability and validity, thus ensuring rigor. Thus, the rigor of qualitative inquiry should be beyond question, beyond challenge, and provide pragmatic scientific evidence that must be integrated into our developing knowledge base. (p. 13)

I concur with Morse et al. (2002) and therefore incorporated several quality measures throughout my research to demonstrate methodological coherence and rigour.

Summary

My research was conducted using the methodological framework of interpretive description, as set out in the work of Sally Thorne (2008). I used semi-structured interviews (repeat contact) and a process of recording my reflections in a journal as my method for collecting data. Data analysis was informed by Braun and Clarke's (2006) six-step framework. Ethical measures were taken to ensure the protection of human participants by way of informed consent and maintenance of confidentiality. Verification strategies were implemented to ensure rigorous, credible, and quality research. Quality was established through prolonged engagement, member checking, peer review, and reflexivity. The interpretive description approach was considered the most appropriate method to explore the parental experience of receiving a diagnosis of a child's developmental disability. The analysis of these experiences is described in the findings presented in Chapter 4.

Chapter 4 Findings

Introduction

In this chapter, I set out the themes that emerged from my interviews and I have organized the findings in terms of the research question and the aims of this study. The main purpose of this research was to explore and describe the experience of parents who have a child with a developmental disability and who received a diagnostic assessment by one of the CDBC multidisciplinary teams located in northern British Columbia. I identified factors that facilitated or impeded the way in which the parents comprehended the information that was delivered by the healthcare professionals during the final family meeting. I also explored how parents managed the recommendations that the CDBC team set forth in the final report following their child's developmental diagnosis.

I provided an overview of my data analysis method and a discussion of the way in which I developed the overarching themes and sub-themes. Transcript excerpts from study participants have been selectively included (identified by pseudonym) in order to capture the nuances of individual experiences, to illustrate the themes that emerged from these experiences, and to show the way in which their experiences led to the reported findings. The process of drawing out individual subjective experiences, discovering commonalities and framing them was one of the most difficult and rewarding tasks undertaken in this research. I was honoured that the parents involved in this research had chosen to share their personal stories with me, and I felt privileged to have had the opportunity to identify the themes that I thought best represented their experiences. The findings presented here were particular to my research and I make no attempt to generalize these findings or propose their utility for other clinical settings.

Snapshot of Data Analysis

The methodology used to frame this study was that of interpretive description. The purpose of interpretative description is to provide an intellectual narrative that influences our understanding of a specific experience (Thorne, Kirkham, & O'Flynn-Magee, 2004). Thorne (2008) described interpretive description as a useful method to be used in applied healthcare settings as it seeks to understand mutual experiences as well as individual differences (Thorne et al., 2004). The analytic process involved the transformation of raw data into findings coupled with the construction of an interpretive account of what the themes within the data signified (Thorne et al., 2004). Interpretive description uses inductively derived thematic analysis to identify patterns among and between individual cases within a phenomenon of interest (Hunt, 2009).

The audio-recorded interviews were professionally transcribed. Once this was completed, I checked the accuracy of these recordings by reading the transcripts (three times) while I listened to the recordings. Following this, I attended to the text as a whole in order to identify the patterns that I thought captured the primary significance of the text. In subsequent readings of each transcript, I looked for specific answers to my original research question.

I then created a second document (MS Word) for each participant that served as a record of the key phrases (patterns) I copied from the main transcript of the individual interviews; this allowed me to identify and group the relevant data. I used the margins of the hard copy to make notes where I identified possible themes and subthemes. The data from each of these documents were also copied and merged to form an additional document where I grouped all participant interview responses according to the research question. Once the

overarching themes became clear, subthemes were developed to account for nuances and variations from the theme. Overarching themes and subthemes were then clustered on the basis of commonalities, patterns, and connections. The identification and development of the themes and subthemes were enhanced by my continuous reading, reflexivity, and consultation with my committee supervisors and participants, and by writing.

The Participants

The participants in this research were parents of children who had been diagnosed with a developmental disability by one of the CDBC multidisciplinary teams across northern British Columbia. All of the participants met the research criteria for participation. Seventeen parents volunteered to participate in my research. Thirteen of the participants were female, seven of the thirteen were the biological mothers of the children, and six of the 13 were adoptive mothers. Four of my participants were male; two of the four were the biological fathers of the children, and two of the four were adoptive fathers. All of the participants were residents of northern British Columbia at the time of this research. Twelve of the 17 participants resided in Prince George and received their child's diagnosis from the CDBC team located in Prince George. The remaining five participants resided in various locations in northern British Columbia. Two of the five participants were from Quesnel, two resided in Burns Lake, and one lived in Vanderhoof. Each of the five families received their child's diagnosis from the CDBC teams situated in their own communities.

All 17 interviews were conducted during a two-month period (April–May, 2015). Follow-up occurred between the months of May and August of 2015 in order to clarify some of the information and for the purpose of member checking. Nine of the 17 interviews occurred in an office setting at the request of the participants, and the remaining eight of the

17 interviews occurred in the participants' homes. The participants were diverse with respect to income, education, employment, gender, status, and race. Much of the demographic information was garnered by speaking directly to the participants, i.e., not obtained by way of a questionnaire. As a result, education level and employment information are not reported in Table 1 (which summarizes participant attributes).

Table 1 *Demographics of Participants in Terms of Regional Location, Gender, Ethnicity, and Biological or Adoptive Parent*

Location	Numbers
Prince George, British Columbia	12
Quesnel, British Columbia	2
Vanderhoof, British Columbia	1
Burns Lake, British Columbia	2
Gender	
Females	13
Males	4
Biological Parent	
Biological Mother	7
Adoptive Mothers	6
Biological Fathers	2
Adoptive Fathers	2
Racial/Ethnic Background	
Latino	1
Aboriginal	1
Caucasian	15

The research findings set out below were organized according to the research question and the aims of the study. This next section identified and described the overarching themes and subthemes that emerged from the analysis of the interview data.

Overall Parental Experiences of their Child's Developmental Diagnosis

What factors played a role in facilitating or impeding the way in which parents comprehended their child's developmental diagnosis?

Overarching Theme 1: Clinical Encounters

Parents that received their child's developmental diagnosis by one of the CDBC teams in northern British Columbia were involved in a series of individual clinical assessment interviews with each member of the multidisciplinary team. For the purpose of this dissertation the clinical encounter was referred to as the "family meeting"—the setting in which the parents received the final diagnostic assessment for their child. Clinical encounters between an individual and a healthcare professional can be complex and the individual's experience can be characterized along a spectrum ranging from positive to negative, given that a number of variables may influence individual perceptions with respect to the quality and/or nature of the clinical interaction. For example, culture, social economic status, and education are only a few of the social determinants of health that may contribute to an individual's appraisal of his or her clinical interaction.

For healthcare professionals, the delivery of a diagnosis can be viewed as a routine part of their work, but for parents it was likely to be a crucial and stressful time where the words and demeanour of the professional were scrutinized for meaning in hopes of shedding light on their child's situation. Each professional on the team was responsible for contributing a clinical assessment based on his or her expertise in order to formulate an

overall diagnosis. An imbalance of power is inherent to the clinical encounter and this may well interfere with the individual experience of such encounters if they are not managed respectfully. The specialized education required of healthcare professionals in order to conduct clinical assessments can be viewed as a power imbalance. For example, on one hand you have the educated professionals who had chosen to work in the healthcare system, and on the other, there were families in need of a diagnostic assessment in order to better understand and manage the developmental challenges faced by their child—a dynamic which inadvertently placed the healthcare professionals in a position of power. There were, however, professional practices that helped decrease the asymmetries in power and helped restore balance in the clinical encounter. For example, open, respectful, and collaborative communication with the family (or the recipient of the service) was one strategy for mitigating the potential for power imbalance. If healthcare professionals failed to incorporate such practical strategies, then the clinical encounter may in itself compromise the desired clinical outcome.

The participants identified various factors that influenced their perception of their clinical encounter with one of the CDBC teams. The parental experiences of the clinical encounter (family meeting) were analyzed and the following subthemes emerged from the overarching theme “clinical encounter”: structural considerations (attire, seating arrangement, number of professionals in attendance, attributes of the meeting space); professional diversity and new insights; questions about the assessment process; validation; and expectations. In addition, there were a number of questions posed by the data—generated by the individual experiences of the participants with respect to the family meeting: Who should be present at the final meeting between the family and the

multidisciplinary team? Should families receive the summary report prior to the final family meeting? Should the families be informed that they needed to be prepared for the possibility of bad news? These questions were woven through the subthemes set out below.

Subtheme 1: Structural Considerations

A number of structural considerations were addressed by the participants: where the meeting was held (at home or in a clinical setting); how the clinicians dressed; whether the child in question should be present, absent, or supervised nearby; the presence or absence of a partner and/or supportive “other”; advance warning of the final meeting date and time so specific arrangements can be made; how the clinicians were seated relative to the family; and the use of visual aids to enhance the information transfer.

In Lisa’s case, the CDBC multidisciplinary team went to Lisa’s home to conduct the family meeting and delivered her child’s diagnosis. According to Lisa, having the family meeting at her residence was imperative because her prior clinical encounters had been negative. Lisa explained it this way:

I feel more comfortable here, and sometimes when I get into groups where it was focused on the school, every time I went in for a meeting there I felt like I was being bombarded by a bunch of people. So I thought, by them coming to my home, it would be a little easier for me to listen to them and take it all in, and take a break if I needed. . . . So yes, they all came out here. It’s more personal that way too, right? And I felt more comfortable that way too.

Lisa found that having the final family meeting held in her own home environment put her at ease and gave her a sense of comfort which enabled her to fully hear both the

content and the implications of the diagnosis. By supporting parents to have their child's diagnosis presented at home, the healthcare professionals ensured a safe and familiar setting while providing parents with difficult information. A person's home is generally associated with trust and security, both of which were protective factors that influenced the parent's experience as they attempted to take in the diagnosis. Enabling this process to take place in the home was also a way to bring balance and empowerment to the parents granting them a greater sense of control over both their emotions and the situation with which they were faced. When bad news needed to be conveyed, it seemed important to favour a physical setting that would help counteract the inherent imbalance of power. Similarly, a physical setting that facilitated the establishment of trust between all parties was more likely to ease the process of delivering bad news and influence the degree to which the news was understood.

Lisa also raised the question of professional attire of the healthcare professionals when they came to her home:

Not looking so professional. Come in here looking comfortable, just a person. I know you're a professional. . . . I know you're a doctor but come in like comfortable. But coming here with a suit and stuff like that, I just, it changes the atmosphere somehow. Come in here in jeans and a t-shirt and I feel like you're part of a team. I know doctors dress professionally but just for that once, I want to feel like we're family. You know everything about my life; you know everything about my daughter. Now I want to feel like a family.

Partnerships in a healthcare relationship were essential for positive outcomes for the individual and/or the family. Lisa's perspective highlighted the need for a personal

connection with the professionals in attendance, given her sense of exposure around having shared profound feelings, thoughts, and experiences about her life. She found that the professional attire, such as a suit, tended to reinforce the power hierarchy and, in her case, hindered her sense of connection. Healthcare professionals need to be cognizant of their clients and provide an open, comfortable, and productive space for the children and families they serve.

Some participants observed that the physical layout of the family meeting room lacked a sense of cohesion. For example, Tina noted that the physical arrangement of the professionals on one side of the room prompted a sense of uneasiness, which interfered with her ability to focus on the content of what they were saying. She found that this arrangement suggested an “us” versus “them” dynamic, which she felt heightened her sense of vulnerability and reinforced the paternalistic barrier between the physician behind the desk and the patient on the other side.

The dynamics of the room. . . . I had an issue with that. Everybody was on one side of the table and I was with my mom on the other side. That’s more of an authority type of . . . there was a total power imbalance. (Tina)

From her perspective, the absence of a cohesive environment stifled the opportunity for what would have been a valuable inquiry process on her part. Tina recommended that the family meeting be held in a circular formation rather than the hierarchical seating arrangement that she encountered. Along the same lines, another participant (Alley) emphasized the negative effect of the size of the space on her experience, saying “don’t get squished in one little office, have a bigger space.” The small space increased her anxiety and she felt claustrophobic. She also noted the importance of having food present, especially in the case

of Aboriginal families where sharing food was an important element of the culture and aided in processing difficult information.

If you're going to deal with Aboriginal families I think doing it over a luncheon would be helpful because that's our cultural way to eat and process information. I think they should try that once, at least. Cater it or have something brought in, something more personalized not so stuck in an office. Or offer the parent Ativan or something, I'm not joking. That would've helped. (Alley)

Providing refreshments in the course of a family meeting may foster a welcoming environment. Given that many people struggled to relax in a formal, institutional setting (even more so in a small space), the importance of sharing food—a central feature of many cultures—may be worth emphasizing for future family meetings. Alley indicated this approach would promote ease when working with Aboriginal peoples.

Clinical assessments conducted by practitioners in a rural setting (as with Lisa's case) may have greater flexibility and more opportunity to implement innovative practice approaches as compared to the situation in larger urban centres. For example, not only was Lisa able to receive her child's diagnosis at home, but the CDBC team also provided childcare—her child was not exposed to the information conveyed, and Lisa was fully engaged in the process. She said, “they even brought somebody to kind of watch my daughter as they were doing everything so that was nice too.”

Unfortunately, two other parent-participants had no choice but to take their child to the family meeting; they later regretted this decision given the implications this exposure had for their child. In one case, the mother found that the presence of her son inhibited her ability to ask questions because she wanted to shield him from the content. She was worried that he

would internalize the information while he lacked the emotional maturity to fully understand the content.

My son was present for the family meeting. He shouldn't have been present but due to circumstances out of our control we had to bring him. I wish he wasn't there, because he knows and we didn't filter the information from him, so in retrospect, had we been alone, he wouldn't have heard all of it we would've given him the information that we thought he needed to hear. He heard the negatives and the positives and we are still trying to deal with the fallout of the bad that he heard. I guess I don't know if he's playing up to what they say, like he knows what they said about him, so sometimes I don't know if he's playing to that. They said his memory is deficient and he knows that, so now he kind of uses that as an excuse. (Kate)

Similarly, the father (Kate's husband) found that their son did not take the news well, and the son was unable to hear the positive content, but focused on the negative information. Dave shared his perspective regarding the presence of a child at the family meeting. Dave explained:

I wouldn't, I guess it really probably depends on the child, right. I think that's a parent decision probably, a recommendation from the practitioners as to whether or not they recommend it because in our situation, our son didn't handle the bad [news] well and he doesn't take into context all the good things that were said.

A detailed discussion between the parent and the healthcare professional was warranted in cases where children were likely to be present so that the risks and benefits were properly assessed and agreed upon. In the family situation described above, it turned out that

the physical setting was not appropriate but, in the event, no other options were offered or provided. In a similar situation, Cathy's daughter played in a nearby room and heard what went on in the family meeting.

My daughter was in a room that was very close to where we were and I found out afterwards that she had heard part of the conversation. And I'd wished that she was more isolated and had not heard any of the adults talking. I had to explain, before that she did not know that she was any different than anyone else and then after she had heard pieces from the meeting—I had to explain more of what FAS was and that was something I was hoping I could do when she was a little older. Because she does not have the understanding. I didn't realize that she could hear because she was down, I would say two rooms away. But the door was open. She doesn't like to be alone and she could hear what we were talking about. Bits and pieces, not all of it. But I'd wished that she was more isolated. All my children have developmental delays, I shield them from that until I think they're at a stage where they can hear it and have an understanding of it. I would've liked to have had a place where my daughter could've not heard, but in a place where we felt she was safe too. You know, if there would've been someone there to kind of take her, it would've been a lot better. Put her on a computer game, just something so that she was not hearing what was going on. (Cathy)

In this situation, Cathy was not aware that her daughter had overheard the diagnosis until later that day. Her preference—to inform her daughter of the diagnosis at a later stage in her development—was no longer an option. This was an important consideration for Cathy, who anticipated that hearing the diagnosis could have an impact on her daughter's

confidence or, more important, that her daughter would use her developmental challenges as an excuse when met with life's challenges. Cathy disclosed that she witnessed this behaviour from her older daughter who had been through the CDBC process and attended the final family meeting. Cathy stated, "my oldest one that was adopted, she was a part of everything because she was older, and she uses it as an excuse."

With respect to the question of who should be present at the final family meeting, a number of parents were thankful that they had a support person or a significant other present— as they reviewed, reflected, and shared their perspectives on what they heard or what they missed in the course of the family meeting. In some cases the parents were provided professionally trained support workers known as key workers.

I was coached through a lot of it by the key worker, which is great. She did a lot of explaining. She really could pick up on a lot of different things where I can't as clearly and so she would cut in sometimes and break it down a little further when she felt that it was needed for me. I think not having her there would've been probably a little more nerve-wracking but having her there was great. (Frank)

Cathy explained that her key worker played an important role in understanding her daughter's situation. Cathy explained:

In the family meeting, the key worker asked most of the questions. She asked me before, "What do you want to get out of this, what do you think?" And she had a list, and when I get in there, I couldn't remember hardly anything and she went through all of it. Made sure every single question was answered. So it was a huge positive that way.

Carol was very appreciative to have the extra family support during her family meeting—she was a former child in care and had a learning disability. Carol reported:

Make sure your parent understands. You know, because she's not going to have support that I have. She might, don't get me wrong, but there's a lot of people out there that don't, right? I was a kid in care, I have nobody. That's life. You know what I mean? I have my son's grandma. Thank God for that and the key worker.

In one case, a mother was not informed of the option to have a support person present at the family meeting.

I would invite them to have a family support person, a brother or sister, an uncle, a favourite cousin, somebody, just to be able to hear, because you can't listen and hear at the same time when you're dealing with that because you're stressed out. Just to have someone else to write notes and just to say, "Hey." I didn't have that. You know, if I had a choice, I would've asked my cousin who's an educator to come in and support me, to hear. (Alley)

Similarly, three mothers acknowledged the importance of having their husbands present at the family meeting, indicating that their presence helped construct a mutual understanding of their child's diagnosis. For example, Ashley noted that having her husband present reduced marital tension as he gained a better understanding of his stepson's situation which encouraged greater support and collaboration.

It was really good too for my husband, his stepdad, to hear the information. I think it was eye-opening at that family meeting because . . . a lot of it, I think, my husband

viewed my parenting like I was coddling him, or doing things for him, or you know, let it be, he needs to have these consequences and he needs to learn and he needs to do this. And I felt like I was always having to defend the way I was doing things with my son . . . so having him sit in that meeting and hear, you know, all the adaptations . . . he is more supportive. (Ashley)

Arlene, on the other hand, regretted that her husband was not present, as she yearned for a mutual understanding between them while raising their daughter. In her case, the family meeting was scheduled at the last minute, leaving her with little or no time to make arrangements; her daughter had been on the waitlist for several years and Arlene did not want to risk a further delay with a request for another date.

I had wanted my husband to be involved in it. I actually even thought of bringing my sister in but due to the short notice, it was just me. So I wished there had been more people involved. I really wanted my husband to be there because I felt that he really expected too much from our daughter. I thought this would be more [the case] of an external person saying, because of her parental exposure to alcohol she has limitations and you have to realize that. Often coming from someone else it's taken with more validity than coming from me.

Another participant, Tina, emphasized that families should be warned prior to the family meeting that hearing their child's developmental diagnosis may have an emotional impact on the parent. As a result, Tina proposed that families can "plan accordingly" (for example, to take time away from work). Tina explained, "they never fathomed to say to me

‘you might want to take part of the day off to process this. I was unable to return to work [and] I shouldn’t have been driving my car.’”

This parent indicated that the receipt of the news had taken an emotional toll on her ability to function and she could not recall her drive home and she would have made other driving arrangements if she was informed when the family meeting was scheduled.

One parent questioned whether all of the professionals on the team needed to make individual presentations during the final family meeting. He was confused by all the information that was provided by each different professional on the team and expressed a strong preference for having a single person review a summary.

I would say I would take that exact same team and have even one person finalize everything, rather than everybody kind of giving their bits and two cents about the whole process. Maybe have one person to be the facilitator to say, you know what, one person sums it all up. Having one person sum it all up, so that it’s all directed at one person rather than having a lot of people in front of you and not knowing who to ask what and that kind of stuff. I wouldn’t say it was overwhelming, but there could probably be an easier way to create that process. Make it easier for the parents to understand and have one person to go through. (Fred)

Fred felt his experience was compromised because of his learning style (needs)—he manages and processes information much better coming from one person rather than hearing all the information from a number of professionals—as such the family meeting. He proposed that he would have perceived a better understanding of the content if it was delivered by a single facilitator. In keeping with the topic of learning styles, another participant shared her view on an additional method of deliverance that can maximize

understanding. Tina emphasized that a visual aid would have enhanced her ability to process the clinical content. Tina explained, “another piece is the visual—they should have like a PowerPoint for the parents, for all you know the parent also has a disability. Some people are more visual.”

It was not uncommon to hear people refer to themselves as visual learners—they retained information better when a visual stimulus accompanied the verbal presentation. It appeared that the use of visual media could help reduce misunderstandings as the parents, family members, or other professionals would then be more able to challenge or correct information as it emerged during the family meeting.

With respect to how the meetings were structured, specifically how and to what extent they were organized ahead of time, the question arose of whether the families would benefit from receiving the summary report prior to the family meeting. Alley found that she benefited from having read the summary in advance; that such preparation helped her to understand her child’s diagnosis when the time came and, more important, it gave her the opportunity to formulate questions ahead of time.

I just had the summary prior to the family meeting, but just to be able to ask questions for clarification, it was a lot easier to understand. Explaining in layman’s terms the technological pieces that were done . . . it was very helpful bringing it down to words that I could understand. (Alley)

Similarly, Lisa received the summary prior to the family meeting and also found it helpful when it came to forming an understanding of her child’s diagnosis.

I received a short summary prior to the meeting. So that's where all the questions were coming from. I'm going, "Well how did you come up with this? And how did you come with that?" So when they came here I was able to sit and go, "Okay well you're saying this, how did you get to that conclusion?" So they were able to explain exactly in great detail.

In contrast, Arlene would have preferred to have the summary prior to the family meeting but it was not provided.

They gave me the paperwork. We went over it briefly in the meeting, and they asked if I had any questions. It would've been nice if I'd been supplied the information ahead of time. Then I would've had time to look over it and be prepared with questions.

Several participants in the study indicated that receiving the summary report at least one week prior to the family meeting would have provided parents with the time to process the diagnostic findings, prepare appropriate questions, and seek clarification if required.

Subtheme 2: Professional Diversity and New Insights

Fifteen of the 17 participants in this study acknowledged the value of learning about their child's diagnosis by way of a multidisciplinary team. The combined expertise was seen as instrumental to being able to gain new insights about their child's circumstances.

Participants found that being able to hear a number of professional opinions—each addressed a different aspect of their child's level of functioning according to their area of expertise—gave them a more complete understanding of their child's overall abilities. In Mary's case, hearing difficult news delivered with hope and sincerity made the content easier for her to

process; Cathy found the diversity of views helped her build not only a more complete understanding but another point of view entirely. Similarly, Dave found the diverse assessments helpful, particularly where the professionals engaged with each other in the course of the meeting in order to answer questions regarding the collective assessment; Arlene found the assessment more encouraging than she anticipated, and Tina found that hearing about different aspects of her son's disability was preferable to a "breezy" summary statement from an individual doctor. These parents all acknowledged that the information provided in this way allowed them to make informed decisions about their children's health, future, education, and support resources. Cathy explained:

The most useful [thing] about the family meeting was hearing everybody's different opinions, different sides, different diagnosis, and coming to an agreement. I think that was the best part, was just hearing others. And some of them have a very different opinion of what was going on than the other one did. It's kind of neat to hear them discuss the different parts and try to piece it all together . . . into one diagnosis. You know, you have this one view when you go in of where you think your child is and then you listen to everybody speak and you just have a more complete understanding of that person. Before, you just have your one side, your thoughts, and your focus. When you get the opinions from everybody else, you can then look it up and see a totally different side. It ended on a very positive note with lots of hope, of she has this potential, not this negative. It makes a whole different feeling about it. Like my daughter's verbal and language skills, I thought she was much higher than what they assessed her at. It was just interesting to see where they thought she was and where I thought she was. Because I thought in that part she was

much higher because she comes off very, she's very well-spoken, but her understanding was not there. She's far more fragile than I thought and I have to um . . . think a lot more about what I say to her, and how I talk to her. It impacted my husband too because before little jokes or something he would say, now you realize you shouldn't because she's not taking the humour out of it. Cause she does not fully understand language and I really did not understand that before this. It impacts the whole family. You have to put a lot more thought into it.

Dave echoed a similar experience:

It was good to have everyone in the same room, all the practitioners and both parents in the same room. They gave their findings and they were able to actually exchange if they wanted to add something to what someone else had said. They would elaborate based on that, and then if we had a question we would ask and there was the ability for everyone to kind of have a conversation. Which I thought was helpful. Without that meeting, then it would've been just us reading the document so we wouldn't have had a chance to hear them describe what their findings were, and what their interactions with our son were, and some anecdotal comments they had around their interviews with him, that was helpful in understanding our son's situation. I was quite impressed with the help; the people that were around the table definitely had a very good understanding of who our son was and a lot of care shown towards him, great, great people. (Dave)

Arlene was pleasantly surprised in her daughter's results of her diagnostic assessment. Arlene explained:

I liked hearing what their perspective or what their feelings about my daughter were and what they noticed. I was surprised that she tested as high as she did. I thought that the findings would be a bit more affirming her limitations. As a parent, you don't see your children quite the same as external people. You see them with parental eyes and it's different. It was good to hear that she will probably continue on into adulthood with fairly limited difficulties. I went from as a parent of a young child thinking she's absolutely the most amazing thing in the whole world and then as she was in school I started to realize maybe the prenatal exposure to alcohol affected her more than I had realized. Then in the final meeting, sort of realizing okay well yes it did affect her but not in a really, destructive way. She should be able to function on the whole, for the most part pretty well.

Tina expressed her experience this way:

The most useful [thing] was that various professionals that came to the meeting, bringing different perspectives and different pieces of assessment about my son. I felt that every individual talked about certain pieces instead of having one doctor breeze through everything. Each person spoke of their findings and their experience. It was a huge multidisciplinary meeting of people and expertise that came to the table. So that was nice to have various opinions.

Two parents claimed that they benefitted from the multidisciplinary approach that arrived at their child's diagnosis. Both children had received prior diagnoses from individual practitioners which resulted in an inaccurate assessment for each of the two children. Tina's son had been diagnosed with ADHD and no further assistance or assessment had been

provided despite her son's ongoing struggles. It was not until a comprehensive evaluation was undertaken by the CDBC multidisciplinary team that her son's cognitive disability was diagnosed and proper interventions were recommended. As such, Tina described her experience:

I went to the meeting, with the only understanding from a previous assessment that my son had ADHD and that's not considered a disability. So when we went to the final meeting and I was actually told no, your son is cognitively delayed. It opened up a huge world of understanding and the other pieces of why he was not communicating and not understanding.

Tina was grateful that a comprehensive assessment had been recommended by her family doctor and the school counsellor because she felt that, since her child had already been diagnosed, there was no need for another assessment. In retrospect, she understood that the original diagnosis was not comprehensive, as it was conducted by a single practitioner rather than by a multidisciplinary team—two distinct diagnostic processes each resulted in different outcomes for the child.

Given the intricacies involved with diagnosing childhood developmental issues it was imperative to have a multidisciplinary approach when providing a comprehensive clinical assessment. It is not uncommon for parents of children with developmental delays to start their inquiry with their primary physician. It was crucial that the primary physician referred parents to a pediatrician for a thorough assessment in cases where developmental issues were suspected. If required, a referral for a multidisciplinary assessment would be recommended.

In Mary's case, a pediatrician who practised in another part of the province diagnosed her son with Fetal Alcohol Syndrome (FAS) early in his development, when he was just four

years old. At the time of this study her son was 15 years of age and his assessment by the CDBC team did not result in a diagnosis of Fetal Alcohol Spectrum Disorder (FASD). This new diagnosis (indicating an absence of this disorder) was not only surprising to the adoptive mother but also to the youth who was present during the family meeting. Mary recalled her reaction this way:

I was shocked because I thought the FASD would come out right away. I was really shocked that he didn't get that diagnosis. He doesn't meet the criteria for FASD. My son was happy. He was very happy that he didn't have that title. He's always known, we've always talked to him about being FAS, and what will happen in school and stuff like that, so he was actually quite pleased, and his comment to me after was "see Mom, I knew I didn't have it."

In this case, the youth was Aboriginal and was removed from his biological parent subsequent to his birth. There appears to be a widespread belief that Canadian Aboriginal children were more likely to have a diagnosis of FASD (Public Safety Canada, 2010). Bray and Anderson (1988) proposed that this belief may have been influenced by earlier research which was methodologically flawed and which may have prompted over-diagnosis of Aboriginal children having FASD. Was Mary's son subject to the practitioner's predisposition to diagnose a child in these circumstances or was he simply misdiagnosed? Either way, this error in diagnosis had several implications not only for the youth but for his birth mother. His adoptive mother indicated that she had a close relationship with his biological mother—who denied that she had consumed alcohol during her pregnancy until the day of her death. Unfortunately, the biological mother passed away prior to hearing that her son did not, after all, have FASD. The misdiagnosed label had followed this child to

school at an early age, and he was required to follow a curriculum designed for his perceived needs. Mary acknowledged that the positive reassessment, which removed the stigma of being an FASD child, motivated her son in so many ways.

The way he deals with things has changed for him. I think it's given him a little bit more confidence in doing his work at school and stuff like that. I think he wasn't really applying himself at school before and it's almost like now that he doesn't have this diagnosis of FAS, he's working better at school. Like I know he was capable of doing it but now he's doing it. (Mary)

While most of the participants were appreciative of the number of professional assessments that resulted from the multidisciplinary team, one of the participants, Rita, was concerned that her daughter was assessed by only two healthcare professionals. She pointed to the absence of input from a speech therapist, which left her to conclude that her daughter's assessment was incomplete.

It left me thankful that it wasn't Fetal Alcohol Syndrome but it left a big wide-open door to what's to come because she didn't get a diagnosis. It all falls under the speech part, her different area of speech, so now that's rearing its head, this isn't over. The concern was "Oh she doesn't have Fetal Alcohol Syndrome," which we pretty much suspected but something was there. It was the psychologist. I was also told that wasn't a complete assessment because it was just the pediatrician and that doctor; there should've been a speech language therapist. And this is the area that affects all the different things. But I thought it was the complete assessment and I've just

recently been told that wasn't a complete assessment because there was no speech language therapist there. (Rita)

In Rita's case, the school had already expressed concern about her daughter's language development, but in the absence of a diagnostic recommendation the school was unable to provide appropriate intervention strategies. Rita emphasized that the only reason she wanted a comprehensive evaluation in the first place was to receive a diagnosis which would allow her daughter access to appropriate educational support in the school setting. Unfortunately, Rita was now required to go through the lengthy referral process to request an assessment from a speech pathologist in order to address what she believed to be her daughter's core issue. In the meantime, she was worried that her daughter would continue to fall behind socially and academically while waiting for a further assessment.

In all, the majority of the participants learned something new about their child on hearing the assessments provided by the CDBC practitioners. Kate knew her child experienced a few challenges but not to the degree that his assessment indicated.

As a parent, my perspective is just very different from somebody outside, right, so I didn't really have any idea of the things that they discovered about him in their analysis, like things that he was gifted at and things he was deficient at. It was actually quite surprising, but accurate. My learning was actually huge. I was surprised because I didn't think that his issues went as deep as they apparently do. (Kate)

It was not uncommon for parents to overlook aspects of their child's behaviour, nuances that specialists were alert to, especially when parents have no point of comparison.

Kate recognized differences between her son (undergoing assessment), and her older daughter—anomalies that she attributed to gender differences.

Subtheme 3: Questions Regarding the Assessment Process

Parents described their journey to obtain a definitive diagnosis throughout the interview process. They talked about when they first recognized questionable behaviours in their child, how they sought a referral from their general practitioner, how they proceeded through the process of the clinical assessments, and how they finally met with the CDBC team to learn the details of their child's diagnosis in the course of the family meeting. In some cases, during the various clinical assessment interviews with each practitioner, participants were concerned that their view of their child did not match the assessment of the practitioner. Other parents questioned the period of time that the healthcare professional spent with their child in order to formulate an accurate assessment. Essentially, some parents simply wanted more information about how the medical professionals arrived at their individual clinical assessments.

Eight of the 17 participants questioned particular aspects of the assessment process which led to their child's diagnosis, and wondered how decisions were made. Arlene recalled an early conversation with one of the practitioners on the team during the assessment process where it appeared that her daughter might be diagnosed with an anxiety disorder. This ran counter to Arlene's own experience with her daughter.

I think when you're dealing with doctors, the problem with doctors is they see your child for a very short period of time but they seem to feel that they have this, I don't know [but] I've done this much schooling so I know so much, but as a parent, you're with your children for these long periods of time, you see them in every kind of

situation. One of the first things that happened when we met the doctor, she said my daughter had an anxiety disorder. And I kind of went, “mmm, I don’t think [so]” and she said “Well, it’s obvious,” and I’m thinking, “I don’t think so.” My daughter had the same teacher for four years. I went to her and I said do you think my daughter is an anxious child? And she went, “What? Nope.” The only thing that really helped was when we were in the family meeting. The psychologist said she’s not an anxious child. He said, “I saw no, absolutely no signs of a child that’s anxious.” But I found that really frustrating because who would know a child better than a parent? (Arlene)

Arlene was frustrated that her own knowledge of her child had not been taken into consideration in the clinical assessment phase. As a result, the mother sought professional validation outside of the clinical assessment team which clearly validated the mother’s observation of her daughter. Given the absence of her contribution, she questioned the physician’s quality of the assessment. Arlene’s experience indicated that the parental perspective must be viewed as a credible source of information during the assessment process unless noted otherwise. Considering the amount of time parents spend with their child from the moment they were born, and the many settings in which they observed their child, parental information must form at least a part of the overall picture. It turned out in the final assessment there were no basis for a diagnosis of an anxiety disorder, but Arlene nonetheless felt sidelined in the process. Healthcare professionals that failed to take the perspectives of the parents into consideration influenced the parental experience which led to parental dissatisfaction.

Sally had a similar experience where one of the professionals on the CDBC team during the individual clinical assessment phase indicated that her son had Oppositional Defiant Disorder. Sally explained:

One area of confusion that sort of stood out was how one of the professionals came up with the assessment. We filled out forms about our son but the professional didn't really meet with him alone, she talked with us and then she did more of a physical with him, and I thought she would've spent a few hours with him to come up with some of her assessments of him. At one point she had said that he had Oppositional Defiant Disorder. I would've felt a little bit more secure about what her findings were if she would've actually spent time with the child. 'Cause she wasn't there with him very long, like 20 minutes. It just didn't seem long enough to me for her to really get an understanding of him. Maybe spending more time with the child to feel like you got a more accurate assessment and recommendations, but I don't know, just from a questionnaire, I think physically you need to be there with the kid.

Sally told the physician that she did not believe her son had Oppositional Defiant Disorder (ODD) and felt that her own estimation of her son was dismissed. Sally was familiar with ODD, having watched her friend's son in close proximity over a number of years. When she discussed this diagnosis at some length with her friend, they believed that there were no indicative characteristics of ODD present in the behaviour of Sally's son. Sally acknowledged that, while she was not a doctor, it seemed that a longer assessment time with her child was required for a more accurate diagnosis—on the basis of a questionnaire and in the absence of Sally's contribution—she felt confused. Fortunately, this physician's assessment was combined with the other clinical assessments as part of the multidisciplinary

diagnosis, which meant that, when a final diagnosis was formulated, Sally's son's symptoms did not meet the criteria for a diagnosis of ODD.

Sally was not the only parent that questioned the duration of the assessment time spent with their children. In fact, several parents thought that the assessment time spent with their child was insufficient. Carol explained:

I don't agree, maybe I'm wrong, but I feel like these people came into my son's life, they met him for a day, some of them met him for a couple hours, they go away and they do whatever they do and they come back and they say your son is "boom" but how the hell do you know? You took two hours with my kid. You took a day with my kid. Who the hell do you think you are to come to me to tell me for the rest of my son's life, that he's going to have ADHD? He's never going to outgrow it and this is that and here's medication and go around labeling children like they're a paint jar. But you know what, I'm glad you took this time with my son and I'm glad these are the things that you said that he has. Now I'm watching. I'm watching now and I have him all life, so I'm watching.

Individual children vary in temperament, cognitive development, and behaviour. These differences play a role in how a child responds to a healthcare professional and to new situations. Effective communication was a fundamental skill when building rapport between a healthcare professional and a child, especially when ensuring that assessments were appropriate and accurate—children required a unique relationship with the professional so the interaction can elicit quality and accurate information. Study participants indicated that children must feel comfortable and safe before they were likely to reveal themselves; they emphasized that the clinical encounters were more likely to result in accurate assessments if

children were engaged with this in mind. Children who felt safe and comfortable in the clinical encounters disclosed their true thoughts. Fred not only felt that the time devoted to his child's assessment was limited and superficial, but combined with the lack of familiarity the clinician had with his son, Fred felt his son's diagnosis was suspect.

Our regular pediatrician, he has seen him multiple times and he's quite friendly and cordial with our son. He speaks with him on his level and I think my son's a little more himself, open and relaxed with the doctor, and my son shows his true colours 'cause he's seen him several times, so I was expecting a longer appointment or several to get a better sense of my child.

When engaging a child during a clinical assessment the study participants confirmed that sessions would be more productive—if more time was actually spent with their child—ensure the healthcare professionals were welcoming and the child was addressed in a language that he or she understood. For example, Arlene found that her daughter shut down when she met with one particular physician.

You put a child in certain situations and they will be anxious, and my daughter always struggled a little bit with authority figures. She doesn't know how to respond to them and her doctor was a very sort of intimidating figure. So my daughter shut down when we would meet. (Arlene)

Matthew queried the relevance of certain information that was provided during the family meeting.

Some of the pediatrician assessment was accurate but there was some of the pediatrician assessment that was very off-base, not around developmental stuff but she had diagnosed him with some allergies and stuff, potentially life-threatening allergies, which actually didn't turn out to exist, so some of the pediatrician stuff I found not really an applicable or relevant or even appropriate. (Matthew)

Similarly, Sally questioned the relevance of having her son's diagnosis compared to ADHD in dogs; she was given a resource (book) which was intended to help her gain a better understanding of her son's situation. Sally explained her surprise:

I found it odd that I was given a dog book. So it was a book about dogs with ADHD, and so I think it was just a way of understanding if these traits fit your child . . . each page showed a dog and then asked, "Does your dog do this?" So it was about dogs with ADHD. I thought that was a little strange because I don't have a dog. I have a child. It was kind of a cute book about [dogs], and you kind of go, "Awe," but then I'm like, "Okay we're supposed to be here talking about my son."

Given that parents of a child with a developmental disability worry about the social stigma that their children may encounter, Sally felt that professionals needed to be sensitive to this and that resource material does not exacerbate the vulnerability of both parent and child.

Subtheme 4: Validation

Throughout the interviews, parents acknowledged that the professional clinical information shared during the family meeting provided them with a sense of relief and that it validated the issues associated with parenting a child with developmental challenges. As a

parent, the moment that you were informed that your child had a developmental disability was the moment that your life changes in crucial and irrevocable ways. Some parents felt a sense of validation because the diagnosis had been a long time coming. At the same time, a few parents expressed mixed feelings about their child's developmental diagnosis—wondering if they were somehow responsible for their children's developmental challenges. Eight out of seventeen participants addressed the issue of professional validation. One participant did not receive the validation she hoped for, while the other seven felt relieved at having their own assessments validated by professionals. In particular, one parent was very relieved as her son's behaviour prompted an investigation by child welfare which in turn made her question her parenting: Alley explained her experience:

Relieved. I struggled for eight years, and to actually have medical professionals tell me that we can't believe you've gotten this far with him, I was relieved and acknowledgement that I wasn't going crazy. It was just really great, to know that, you know, at least someone understood the struggles and the challenges.

Alley was in the process of a child welfare investigation because of her son's behaviour in the school environment which called her parenting practice into question. She felt increasingly responsible for her son's behaviour as scrutiny from outside agencies came to bear on her situation. Alley was very relieved that her son received a formal clinical diagnosis because it legitimized her son's condition, affirmed that her experience was real, and helped to deflect outside attention when it came to questioning her competence as a parent. At this point, she was also relieved that she was given several constructive strategies to help her son and she revelled in the fact that she forwarded her son's report to the organizations that caused her such unnecessary grief.

It was not uncommon for parents to question whether their actions during pregnancy or following delivery contributed to their child's developmental disability. Kate recollected:

As a parent maybe a sense of failure because now he needs to be on meds which isn't rational thinking but it's kind of what immediately comes to mind, so personally it was kind of like, "Hmm." Well I internalized it, it wasn't about my son, but it was . . . what could I have done? Did I have enough folic acid when I was pregnant? I look at him and I think there's absolutely nothing wrong with this kid but he seems to be having trouble, and to be able to get that outside perspective was really great. It was a relief.

Similarly, Tina experienced thoughts that were indicative of self-blame, but felt disappointed that she did not receive validation.

You're given this news and you're sitting across all these professionals and as soon as they see that pain in your eyes, they all look down at their paper and then there's no more discussion or validation for your feelings. They follow through with do you have any questions? Of course you have zillions of questions like was it me? Is this biological? Is this genetic? Was this because I didn't do this or I didn't eat my vitamins? What did I do wrong? Didn't I look after my body right? Did his father not look after himself? And then you question after his birth, was it because of this, was it because of that? And you started there and then I ended with how didn't know, I am his mother. So you go through a whole process. (Tina)

Given that parents were flooded with many different feelings, it was important for practitioners to assess the extent to which a parent had internalized the reasons for a child's

behaviour, and the extent to which this impacted their understanding of their child's developmental diagnosis. If the professional deliverance of the information was managed appropriately and parents were satisfied it can have a profound and sustained effect on parents' attitudes, not only toward healthcare professionals but most importantly, to their child. The parent participants in this study acknowledged that, following the formal clinical diagnosis, they restored their sense of confidence around their parenting practices. On the whole, they felt better equipped to parent in light of their new understanding of their child. For example, Frank felt that he had a clearer sense of direction.

You're happy to actually understand what is going on. You don't feel like you're playing a guessing game. You know what direction to focus on. When things are not going well, you can always look at them and say, "Okay, this is this and that." I think you feel relieved in that sense that, "Okay, now I know where my direction has to be." It's a relief because now you know what it is and you know the expectations, you know what needs to be done in order to help him along. (Frank)

Ashley explained her experience:

We'd been living with this for 11 years. We knew something was wrong but we didn't know what. I've known something was up from birth and then as he grew, there was red flags his entire life and so to finally leave with that information was like, "Oh thank God!" I felt relieved as there was acknowledgement and that I wasn't just an overbearing mom. Feeling validated I think is a big piece.

Ashley was particularly relieved that she received this form of validation. She disclosed to one of the physicians during the assessment interview phase that she had

consumed some alcohol during the early stages of her pregnancy, before she was aware that she was expecting. She regretted making this disclosure because she wondered whether her son's diagnosis would have been different had she not said anything during the assessment interview. Ashley had been a foster parent and had cared for several children with FASD. Her experience told her that her son's issues were unlike the children who had been diagnosed with FASD. In the final analysis, while he was diagnosed as being on the spectrum, there was no conclusive evidence for FASD. In the end, Ashley was relieved that her son received a complete diagnosis that made sense to her.

The majority of the parents felt that the professionals on the CDBC teams understood their point of view and had some sense of the distress involved in having a child with developmental issues. Validation was one way to receive constructive feedback. Parent participants in this study found the validation process beneficial, which allowed them to comprehend their child's diagnosis and thereby to move forward.

Subtheme 5: Expectations

Families sought developmental assessments for their child for a host of reasons. The participants in my study identified several reasons for pursuing a comprehensive assessment. A significant motivation was the hope that a definitive diagnosis of a developmental disorder would result in services, support, and possibly financial assistance for both the child and family. This was the outcome for some families, while others were disappointed. On the whole, parents who had waited for some time in hopes of a definitive assessment felt relieved when the assessment was finalized.

Eleven out of the 17 participants indicated that they hoped for some form of social or financial support in order to increase the chance for a better outcome for their child. In this

respect, the experiences of the participants varied. For example, Cathy secured support at school for her daughter and her family, and saw this as one of the distinct advantages of her child's diagnosis.

The major advantage is now that it's on paper and you can take that to the school, they can't just brush you under the rug. Before it was written on paper, she got no support at school because there was nothing there. And putting it down on paper opens up a whole new world. And she now has an aide, she now has help that she never had before, and the school no longer overwhelms her with endless homework knowing that she can't complete it. They have to agree with it, they can't get out of it. (Cathy)

Cathy had waited a long time for her daughter's diagnosis and could not access appropriate services at school prior to the diagnosis. Her daughter's problems were not apparent to the school staff, and as a result, they tended to be dismissive of the parental concerns, which were not viewed to be legitimate. A number of parents had a similar experience where they took the final report to the school in order to get appropriate support for their child. Frank explained:

A big piece is now you can get help. As soon as you have that little piece of paper and you walk into somewhere or you are dealing with the school, government, you don't even have to say anything, you just lay it down. That piece of paper says it all, right? Now you have a piece of paper that gets you the help you need.

Carol discussed her son's support this way:

He gets more support at school. The diagnosis has given us a little of funding or something, the school, I don't know about the school money nonsense thing, but this has helped my son. So it's been good that way too, right. But I mean, I don't understand it so I'm like ya sure you got some extra stuff to help my son, awesome

As a rule, in order for certain services and funding to be made available to children and families in need, a formal assessment with a certain diagnosis is required. The formal assessment process was a time-consuming process for many parents, which was inopportune given that early intervention services promotes positive outcomes for a child with developmental delays. The premise that a child required a formal diagnosis in order to access appropriate services appeared problematic. As a result, some parents were put in a position of wanting their child to be formally "labelled" even at that cost of the stigma associated with a developmental disability. For example, Kate reported that she was "kind of upset about the ADHD determination but it got him support at school." Although Ellen's child did not receive the diagnosis needed to initiate the support at school she had hoped for, she had much the same response as Kate. Ellen explained:

Our son didn't get an FASD diagnosis he got an ARND or something. He didn't qualify for supports at school so we were, it might be kind of weird to say, but we were hoping for a diagnosis to get the support at school. It didn't happen but I understand why it didn't happen. It wasn't enough to guarantee him support in school.

In Matthew's case (Ellen's spouse), given his professional standing in the community and his ability to work with the system, the CDBC team was able to have his son recognized

as having a learning disability and thereby receive better support at school. Matthew explained:

In looking at his psychological profile, they were able to give a learning disability designation and a medical one. Even though they knew based on the constraints around the program that he has this impact they gave a name to it, so they're able to work around it a little bit . . . so he can get support.

Arlene had a similar experience where the CDBC team provided additional documentation that supported her daughter's learning disability so that she could mobilize support at school.

They assured me that we could have something to take to her school and say, "Look, can you just give her a bit of leeway?" They weren't able to give the full diagnosis of FAS but they were able to work other things so that she could still get support from the school. (Arlene)

Fred's primary reason for wanting a formal diagnosis for his son was to secure additional support at school. He was disappointed by the diagnosis, or lack of it, and also felt misled by those who had encouraged him to proceed with a formal assessment. From his perspective, he was set up for the disappointment that followed the family meeting.

Not to be negative but I didn't find we had the outcome we thought we'd have. We found the meeting kind of disappointing because we were assuming our son would be getting much more support from everything we'd been told. We walked away feeling, "Wow, we went through all this for what?" Disappointed and frustrated

because we learned at that point there wasn't going to be the help that we wanted available to our son. Basically, I think it's probably a bit of a setup in what we were told prior to what can happen and to what did happen are two different things. Other professionals in the industry were telling us, that when you go through this process you'll get the assistance that you'll get the help that you want and need. (Fred)

The absence of a formal diagnosis should not stop a child from having access to resources that would better help them achieve their full potential. Unfortunately, agencies that once provided services have been impacted by local and provincial budget cuts. Fred was convinced that his son required one-on-one support at school in order to achieve his full potential.

Overarching Theme 2: The Manner of the Delivery of the Diagnosis

What factors played a role in facilitating or impeding the way in which parents comprehended their child's developmental diagnosis?

Parents reported a range of responses to the way in which the formal diagnosis was delivered in the course of the family meeting. Parents characterized certain features of the delivery that aided their understanding, and other features that challenged their ability to understand what they heard. It was important to note that the emotional impact of hearing a child's developmental diagnosis triggered a wide range of experiences which influenced the way in which the parents' understood the diagnosis. They also talked about how their parenting changed in response to the diagnosis.

Four subthemes were identified in relation to the overarching theme "The Manner of the Delivery." These included the following subthemes: impact (emotional impact and impact on parenting practices), the level of professionalism displayed during the delivery of

the diagnosis, the language used to convey the diagnosis, and the quantity of information provided at the final family meeting.

Subtheme 1: Impact (Emotional Impact)

Eleven of the 17 participants talked about the emotional impact of hearing their child's diagnosis. They reported having a complex range of emotional reactions, feeling overwhelmed and challenged by the onset of the emotional cascade, and it felt like their emotions prevented them from processing the information on first hearing the diagnosis. Six of the 11 parents acknowledged that their emotional response presented them with an obstacle to their processing of their child's diagnosis. Three of the parents found that they were very emotional when they thought about the implications of the diagnosis in relation to their child's future. Additionally, two parents felt that their emotional needs were not taken into consideration. Parents' experiences with emotional impact were grouped into three categories: emotions related to hearing the diagnosis, emotions regarding their child's future, and emotions associated with the parent's own well-being.

On first hearing the diagnosis, Alley felt overwhelmed by the disparity between her desires for her son and the severity of his developmental disability—a response that was compounded by her own emotions.

It's still difficult [crying], sorry, this is hard. It's still pretty hard for me to talk about it because it's hard to think your son is broken, right. You struggle for years and you put your whole life on hold to be able to support your child to be normal or to be seen as normal by his peers and other people. (Alley)

At the time of her interview, Alley was in the early stages of coping with her son's diagnosis, and it was a challenge for her to speak about her son's situation without crying. Tina compared her response to the same feeling as hearing unexpected news of a loved one's sudden death; the diagnosis took this parent by complete surprise. The sudden shock blocked her ability to absorb what she heard. Tina remembered her experience this way:

It was similar to being told someone had died, you know. I was not prepared for bad news. The first thing was the shock of the news, as a parent not knowing your son has a disability, right, your first initial piece is how did I not notice? All of a sudden I started crying and somebody slides me a box of tissue, your whole body shuts down, your mouth gets really dry, your heart is pounding.

Ellen was also visibly upset during the interview as she reflected on the final meeting. She was shocked that the family meeting had such an emotional impact as she was already well informed about her son's history prior to his adoption. Hearing the various professional narratives of her son's early and traumatic experiences triggered an unexpected flow of emotions—perhaps in part due to the attachment that formed between Ellen and her son since the adoption.

Yeah, it was a hard meeting. The pediatrician was talking about all of his losses and trauma that our son has been through, so to hear it all in a list, it was very emotional to hear. It was hard to hear so I kind of hurt for him. That probably affected how I processed the whole rest of the meeting. It was information that I knew about his background but to hear it in that way, just like “bang, bang, bang,” it was hard to hear. (Ellen)

Ashley recalled that she felt emotionally depleted, saying that “a piece [of my reaction] was definitely overwhelming. I was exhausted emotionally, absolutely drained. Sitting through that is like, it’s just exhausting and it is so much to take in.” Similarly, Carol felt “helpless. That’s my child and they’re telling me he’s being diagnosed with all these things. I didn’t win the lottery. I felt pretty helpless.”

Three parents talked about their concern for their child’s future. Fear for their child’s future was a common emotional response that parents recounted in the course of the interviews. The parents’ noted that their subjective emotional experience during the family meeting limited their ability to fully comprehend the information—as the nature of the content disrupted their ability to be in the present as their thoughts fast forwarded to what this meant for their child’s future. Kate explained:

Then you start thinking about how it’s going to impact his future and so some fears and worries. You think of what that means for him, right? It means he’s going to have to take medication every day and then you worry about whether he’s going, how that’s going to affect him, you know. I’m also worried, when kids are put into a category, I’m a little concerned when it comes to school and whether that limits them, so that’s concerning.

Tina recollected her experience in this way:

I’m still numb, all of a sudden my perfect little baby boy is not perfect. You see here I am in my bubble thinking about what’s going on, what’s going to happen? What does this mean? It’s like a big humming feeling in my brain. Now graduation is not the same, weddings are not the same, riding the bike is not the same, um, dating’s not

the same. I don't know what's going to happen to this little boy. Here I'm thinking do I have him until I die? Who will look after him?

Both Tina and Lisa felt that there was a lack of concern or support regarding the parent's well-being while the team conveyed the diagnosis at the family meeting. Lisa recalled:

I felt like somebody should've stayed behind and ask how does this make you feel? They are doing my daughter's part but not the parent. It was a challenge to tell them exactly how it all made me feel, about me. I didn't want to make it feel it was all about me because it wasn't, right, but we've done the process that we needed to do to get the help for my daughter, now the challenge is help the parents get through it too, you know. They could've said, you know, we're leaving and here you go, here's some information to help you move on and help yourself. I wanted to go beyond the diagnosis and I felt like I wasn't able to tell them that because I felt they've done their job. They do what they need to do and then they're out of here. So I went into a deep depression.

Tina explained her situation:

Acknowledge the impact, this is a lot of information today, would you like to have some time so we can discuss this further? [For example:] "Would you like to meet later today? Would you like me to come to your house? I can bring some resources and we can continue this? How do you feel right now?"

Lisa recommended the addition of an extra professional to the team—a counsellor that solely addresses the emotional needs of the parent. Lisa explained:

Add that one extra person on the team for the support for the family. So after they leave, they stay. It's a lot of information to "get." Like I'm sitting here and they're all telling me what's wrong with my daughter. It would've been nice if they would've, took this information, and say we're going to tell you this, tell me how you feel about that? And then stop and talk about it. And we kind of did, but I felt like I had to make them quick questions. I felt like I had to be rushed. Where a counsellor would've been nice, where he or she could've stepped in and said how does that make you feel?

Impact on Parenting Practices

A number of parents talked about changes in their parenting practices after they better understood their child's diagnosis; they found that they had gained a greater understanding of the ways in which their child was different—that was pivotal in shifting their parenting strategies. It was not uncommon for a child with a developmental disability to require specific parenting strategies. A parenting approach that worked for a child with typical developmental patterns may not be the right match for a child with a developmental disability.

Following the clinical assessments and the diagnosis, parents asserted that they were better equipped to read their child's cues—which in turn fostered appropriate parenting techniques and reduced their level of frustration. Ten of the 17 parents identified a shift in the way they parented their child following the family meeting. Being reminded that their child had a certain skill set gave the parents a realistic grounding with respect to the capacity

of their child. For example, Sally gained a better perspective on her son's needs and abilities, and both Sally and Mary examined and revised their expectations of their children. Sally reported:

I think we had been pushing our son a bit too hard academically beyond his level, and making him do all this extra work and they said it's starting to be too much and that was one thing I never even thought about, was his anxiety. That was good because that diagnosis has made us a little bit more aware of his capacity and a little more compassionate. We don't push him. I think one of our biggest things is getting a proper diagnosis so that we can maybe be taught properly how to deal with his type of personality. So knowing these things, it had a big impact because I think we're trying to parent a little bit softer with him, because I think we were heightening his anxiety without even realizing it.

Dave described how he modified his interactions with his son once he understood that his son had difficulty processing information.

It's helpful to know that he has processing issues, so we know that he is very quick on certain things and certain knowledge sinks in, as he's a smart kid. It's hard when you know that he knows so much and his level is here, that's the level you tend to speak to, but now that we understand there's some processing difficulties, then we make sure that we deliver it to him, not in a condescending or young manner, but we give him time to process it and if he's kind of distracted, maybe he's still thinking about it, maybe he's kind of repeating it to himself in his head, we give him a moment to do

that. It's helpful to us so that we know he needs a bit of time to think about directions or questions. (Dave)

In the process of coming to terms with the diagnosis, parents acquired a greater sense of knowledge associated with the range of developmental milestones experienced by typical childhood development, and the behaviours and physical skills that were particular to their child's unique developmental journey. The following reflections made by the parents highlighted the way in which parents came to better understand their child's behaviour patterns and changed their parenting approach accordingly.

Just understanding that diagnosis means you need to follow certain directions with certain behaviours and how to prevent certain behaviours. I find now I'll look at my son and I'll be like, "Hmm, this is this, right?" It changes your whole parenting skills by just understanding what he has control over. (Frank)

Arlene explained:

I need to constantly tell myself that the prenatal exposure to alcohol did do damage, that's a fact. I have to constantly tell myself that although there are things that may drive me crazy, she doesn't always have complete control of that.

Kate described her experience in this manner:

It really helped to understand where he was coming from and what his issues had been and it offered us a little more understanding of how he was behaving, and how he works as an individual. I am more patient with him.

Alley explained that her child's developmental diagnosis created a space for more comfort: "My son and I do more talking and cuddling and less frustration on my part, as a parent." Similarly, Carol said, "He's still the same kid. I just have more tools to learn how to deal with his behaviours. I've put my pride away for a little bit and started looking at stuff." Ashley talked about how the diagnosis changed her husband's perspective (her son's step-father): "He heard [my son's] diagnosis in the family meeting [and] he changed his approach—he is gentler."

Subtheme 2: Professionalism

On the whole, participants indicated that the delivery of their child's developmental diagnosis was communicated in a positive and professional manner. According to the participants, the practitioners on the team provided positive feedback, showed respect, displayed empathy, commitment, openness, and honesty. The majority of the parents talked about the kind words that the team members used to characterize their child. They enjoyed hearing positive comments and consequently, felt that the professionals recognized their positive parenting practices.

There were no judgments. They started the meeting saying first and foremost we need to say he is so polite and he was a dream to work with, and I was just like, "Okay, they said you've worked hard, as a parent, you've been proactive." They gave positive feedback and it was appreciated, it was comforting. (Ashley)

Arlene explained it in this manner:

You honestly got the feeling that they cared, that this wasn't just a job and that they cared. So that was a real positive. I thought they did a fairly good job of explaining

it, for the most part. The positive responses of everybody and the great things they said. They were very impressed with how she presented herself. Maybe I did a lot of things right. So in that way I felt very happy because as a parent you constantly doubt yourself. I felt maybe like yay, I did more right than I thought.

Mary shared her experience in this way:

To me it was a very open and honest conversation. I didn't feel like I was being singled out in the room. You know how sometimes you feel like, they are doctors, they're this and you feel a little bit insecure. I didn't feel that in that meeting. I was relaxed. It was professional.

Dave explained his experience in this manner:

I was quite impressed with their professionalism. The people that were around the table definitely had a very good understanding of who our son was and a lot of care shown towards him, great, great people.

Frank recollected:

Finding a positive and putting it out there to make you feel comfortable before delivering the negatives that do impact you emotionally, right. They were quite good with that.

The level of professionalism that was displayed towards the families during the family meeting was well received. The parents deemed the recognition of their child's strengths as an important reminder, as these strengths had a tendency to be overshadowed by

some of the challenges encountered during the activities of daily living. All of the participants felt positive about the team as a whole, which enhanced their ability to hear and understand their child's developmental diagnosis.

Subtheme 3: Professional Language

Effective communication has many core aspects, and it is a necessary skill required of healthcare professionals. First and foremost, effective communication requires the use of language that was most appropriate to the situation to ensure that the intended message was understood by all the individuals involved in the clinical interaction. The use of professional jargon resulted in miscommunication and thereby impeded understanding.

The participants shared their experiences about the way in which the members of the multidisciplinary team used language to communicate the results of the clinical assessment during the family meeting. It appeared that a lack of communication was not the issue. Instead, some participants reported that it was the choice of words the professionals used in the process of conveying the developmental diagnosis. Eight of the 17 participants felt that the use of specialized language, particularly medical jargon, was not ideal, especially in cases where the parents felt they did not have sufficient education to make sense of the information at hand. For example, Carol, who herself had a learning disability, had difficulty understanding what she heard as "doctor jibber-jabber," which raised the question of adjusting the delivery of information according to the particular capacity of the listener.

Use English, or try. That's just normality to them but it is way over our heads. It's not that they're doing wrong, they're not doing anything wrong, they're just being themselves and they just know medical terminology. They talk medical we don't know that, we never went to school. I don't understand a lot of doctor jibber-jabber

nonsense. What if I did not have my son's grandma with me? I would not even know what happened over there. I would know nothing. I'm lucky I have that because I don't know what the person does when they don't have that. (Carol)

Matthew, a well-educated professional who worked in a related field in the community, confirmed that the importance of using "every day terms" when conveying information.

If I was someone who wasn't working in this area and didn't have an education, I would not understand. The best thing that helps around understanding the assessments is really putting it in, like, every day terms. A lot of times it just goes over the family's heads. I would say at the family meetings, bringing it down to the level of what does this mean for this child in everyday life, and what does it look like for this child in everyday life. I think that's really what's going to be important for the parents to walk away with. They don't care in the end what his visual processing score was and stuff like that. (Matthew)

Both Arlene and Sally recommended that the team should use examples or elaborate further on the meaning of the content being conveyed:

I think sometimes when you're trying to understand something, examples help you grasp it because when you're being told something it's not making sense because some of the words used, and it really helps to use examples during the meeting. (Arlene)

A bit more thorough descriptions of stuff, not assuming that someone knows what that is, like I thought I did. (Sally)

It also turned out that Sally and her husband understood their son's diagnosis quite differently from each other; they compared their understanding at length after the family meeting in order to decipher the facts.

At the same time, when Mary found that she was unable to fully understand the implications of the diagnosis, the team explained the information in terms she understood.

I found they were really good at explaining anything I didn't understand or anything my son didn't understand. We were able to say, "Hang on, what you mean by this?" I think that's really important that they were able to come to my level of understanding, like some of the terms they used I was just, like, "What are you talking about?" And they were very good at sitting down and explaining everything. I didn't feel rushed. I didn't feel stupid with any question that I had. (Mary)

Subtheme 4: Quantity of Information

The fourth subtheme that emerged from my consideration of the theme "The Manner of the Delivery" was that of the volume of information provided in the course of the family meeting. While the parents acknowledged that receiving information about their child's diagnosis was of utmost importance, the amount of information was seen to be excessive given other factors that were in play during the final meeting.

Six of the 17 participants talked about the quantity of information that was conveyed in a relatively short period of time (an hour), which made it difficult to absorb given the emotionally charged context. For example, Kate explained:

I probably should've used a tape recorder but I'm pretty sure both my husband and I were taking notes at the time it's just a lot, a lot at once, you know. You start thinking and then you miss the next piece or whatever and actually they encourage you to bring other people in, like maybe somebody who isn't so emotionally involved. Everybody hears different things, hearing the same words but different interpretations, so a tape recorder would be a really good idea because you could go back and ask what did they really say and in what context do they say it?

Ashley shared her experience this way:

So much information and you get one hour to talk with the team. It's not even one hour to talk with them, that one hour is listening to the findings. Kind of a snapshot of what each one came up with, so I have a lot of questions and I inquire a lot. I probably could have had four hours with them and that would have been great. So having the hour with them was tough.

Ellen explained her story:

Instead of just hit you with all the information and ask do you have questions? [I'm thinking that] I don't know. I probably do [have questions], but [they say] "Okay, well, check back in with us, we have an hour, thank you, the next person is coming."

For optimal understanding—preferred clinical practice was to have healthcare professionals relay medical information by way of clear and concise language and to limit the amount of information provided to the client. Healthcare professionals should be alert to this practice because often parents felt uncomfortable admitting that they experienced difficulty

comprehending everything that was being said. In other words, the responsibility of whether or not the knowledge transmission in a clinical encounter was understood should not rest with the parent. For example, Sally noticed that one team member referred to funding details with respect to school support for her son saying, “they reviewed certain scale information related to school funding. That was very confusing and I guess that part confused the hell out of me.” As a result of not wanting to ask further questions Sally and her husband walked away from the family meeting with two different interpretations of what supports their son would receive based on the funding information conveyed during the family meeting. Fred described:

My wife was a little confused about what an Independent Education Plan was, because she thought we were getting someone helping us. I was like no, no we’re not. We’re not getting that. We’re getting an education plan. She’s like what’s a plan? I’m like well, they work with people at the school and try to help our son with the facilities they have available to them. No one person at any point in time is going to be present with our son. Yes, they’ll be getting funding but not for our son but for the school. Basically we were told that because of our son’s assessment, he will be getting funding for the school. They will be putting somebody in place, not necessarily for our son. Nobody will be dedicated to our son per se. If someone else needs it in a different classroom, they’ll be with that child, but the school will be getting funding for it, because of his assessment from what we understood.

In this situation, both parents were grateful that they attended the family meeting, as they defaulted to each other to clarify what they understood from the meeting.

Overarching Theme 3: Where Do We Go From Here?

Which factors influenced parent follow-through with the clinical recommendations developed by the team?

Receiving a child's developmental diagnosis was an important turning point for a number of participants in what they described as a "long journey." For some parents it was important to have a name for what they observed in their child's behaviour. Many participants reported mixed feelings at this juncture of their journey—how to proceed into the future with their child was on their mind? Following the final meeting, the participants reported feeling ambivalent about the next stage. Much of the uncertainty articulated by the participants had to do with concerns about addressing the recommendations, and how they would decipher some of the content in the final report. The diverse views of the parents were grouped into three subthemes related to the theme of "Where do we go from here?" which were identified as post disclosure, recommendations, and the final report.

Subtheme 1: Post Disclosure

A number of the participants were concerned by the lack of opportunity to meet with the healthcare professionals following the disclosure of the final diagnosis. Essentially, participants saw the necessity for the opportunity to ask follow-up questions in order to fill the gaps in their understanding of both the diagnosis and the recommendations. They described their experience of being left to digest the outcome of the diagnosis in the absence of professional contact post-disclosure from the multidisciplinary team. Six out of the 17 participants specifically addressed this issue. For example, Ellen had no further contact with the CDBC team subsequent to the family meeting and felt that her understanding of the diagnosis and recommendations diminished over time.

The opportunity for follow-up down the road would be really good. After the meeting we came away, we had the recommendation, we had this understanding and then that definitely had decreased over time. If someone would have checked in with us three months later, to see if we are doing anything, if we read the report, if we had any questions, that probably would have been good. (Ellen)

Ashley was excited that she received a call from the clinical coordinator informing her about this research opportunity but she questioned the timing of the call. Ashley recollected:

I think having someone reach out, even just getting this call from CDBC, when she called, and I was, like, that's wonderful to feel like somebody was checking in. That's what she said, "I'm just calling to check in and follow up." I said, "Wow, I'm so happy you called because, some questions have come up," and so she was able to say, "Yes, there is this key worker who can kind of go through this with you and fill in those blanks." Get somebody to call and check in sooner, right? So the family meeting was in November. It's now March, so they could've even got her to call earlier.

Lisa shared that she was very distraught when she did not receive a call in a timely fashion following the family meeting, and Kate remembered feeling overwhelmed as there was no opportunity to ask further questions after the family meeting.

I felt I can do this, I know what I'm doing, I've done all the research that I possibly can and it was about a week or so later when somebody finally called and said how are you doing? And I went, "Are you kidding me? How am I doing?" Like, I hate

you, you know. And that's what I said to her. And I'm sorry I feel that way and I don't want to hate anybody but I hate you for not asking me how I felt. You just gave me all this information [crying], there you go, deal with it. That's how I felt. So that was the hard part. (Lisa)

Kate shared her thoughts:

It is a little overwhelming to have it all and then to have no opportunity for questions after. Another meeting maybe after you get the full report because it was nice for them to go over the summary with us.

It was clear that many parents required time to digest what they heard, but as time passed additional questions surfaced. Sally said that she "wasn't very prepared as to having questions ready for them during the meeting and it wasn't until I got home, you start thinking about things and saying, "Hmm, I wish I would have asked that." This was a common reaction, where parents felt the need for another opportunity to ask questions about the diagnostic findings. Allowing time for parents to develop their comprehension post disclosure and return at a later date to discuss outstanding questions was crucial for parents to move forward. This outcome can be achieved by providing an opportunity for the parents to ask for clarification either by way of the team or a key worker.

One parent suggested a strategy that the multidisciplinary team could implement immediately, in the context of the family meeting, if follow-up was not made available due to external factors. Rita suggested that "there should be breaks between every piece of information allowing the parent to ask everybody questions rather than at the end asking, 'Do you have any questions?'" The parents that expressed a need for further contact were the

same parents who felt a strong emotional impact when they were given their child's diagnosis at the final family meeting. These parents indicated that a follow-up meeting after the family meeting could again convey the information that was lost in the wake of their emotional response.

Subtheme 2: The Final Evaluation Report

As part of the child's diagnostic assessment and evaluation process, the multidisciplinary team completed a comprehensive final report that was provided to the families. Many of the families were given a summary report at the conclusion of the meeting and were told they would receive the final copy in the mail. Recommendations were included in the report to maximize the child's full potential for development, which included information on support services and other various interventions. Six out of the 17 parents talked about the quality of the report—whether and to what extent they thought that the report was understandable, accurate, and informative.

While four of these six parents felt satisfied with the report they were given, two had qualms. Rita was concerned about demographic inaccuracies in the information recorded for her family, errors which in turn made her wonder about the credibility of the report. Rita explained, “the report that was received from the team has errors regarding my daughter's ethnicity and the gender of her sibling.” Arlene felt that aspects of the report were inappropriate and unnecessary and was more about personal opinion—an emphasis on her daughter's weight, which Arlene thought could have impacted her daughter in a negative manner—if she had chosen to read the report (she did not).

I felt a lot of anger when I left the meeting because of one thing that happened, which really, really bothered me. When you get the summary, it's got the main highlights at

the very top. The third one was “overweight” and that really bothered me because my daughter is 5’1.” She’s extremely active and at the most she’s carried ten pounds extra. I really thought that, in this day and age, with our teenage girls, [with] many of them having eating disorders, I thought it was absolutely ridiculous to have that [as] one of the first things you read. I mean, it’s different if you’ve got a child that’s morbidly obese because, yes, that is a health risk, but for a child that’s carrying maybe 10 pounds too much? She was very involved in this process, and I gave her every opportunity to be involved in everything. I offered to show her the report. Now luckily she didn’t ask for it because I didn’t want her seeing that. (Arlene)

The parent discussed the hypocritical nature of the physician as the parent indicated that this individual’s body mass index appeared to be outside of the standard recommendation. The parent further elaborated that the physician’s comment would have carried more influence if this dichotomy was not present. Some of the parents found the final report too complex and required assistance when it came to interpreting much of the information.

When you get the report, some of the information, it’s really not in layman’s terms. So you find you’re Googling, or trying to kind of figure stuff out . . . when you’re reading the information. (Ellen)

Kate explained it in this way:

The summary and the final report . . . it was well done. The final reports were pretty concise and they used big language but with the Internet we kind of tried to piece things together trying to relate the information to how he behaves. Maybe some

interpretation of the report might be beneficial, like, I don't know what "cognitive behaviour" is.

Tina acknowledged that she enjoyed reading the report—she referred to the document in terms of a diary that included a thorough historical picture which gave her an opportunity to reflect on her journey as a mother.

The report was very clear, concise. Every person involved did a historical piece. So from the beginning it flowed completely to the day of the assessment. It was just super thorough. It provided a lot of professionals' perspectives and their knowledge, and it was very clear and concise and very positive. (Rita)

Cathy appreciated the clarity of the report and noted that it included additional information that was not covered at the meeting.

When I got the report too, it even had more information in it than what was at the meeting, and a lot of resources. The key worker assisted me in reviewing the report. (Cathy)

The assistance of key workers played a significant role in helping some parents understand the final report. The observations of the parent participants with respect to the content documented in the final report highlighted the importance of a professional standard when it comes to documentation in a clinical report—accurate records reflect integrity. When healthcare professional's document in a client's record one must avoid personal opinions—if a comment was required be certain to frame your comment based on facts. Needless to say, this can affect the client in a negative manner, as observed in this study.

Good quality reports were necessary for the competent delivery of clinical services and interventions.

Subtheme 3: Recommendations

The experiences of the parent participants varied when it came to dealing with the recommendations that arose out of the diagnostic assessment for their child. In some cases, parents had received their child's diagnosis within two weeks of the time of their interview for this study, while others had received their child's diagnosis within the last six to 12 months. Given the differences in the amount of time that had passed, each parent was at a different stage when it came to interpreting and implementing the recommendations for their child.

During the course of their interviews, the parents talked about the significance of the recommendations that had been developed for their child, as well as the ways in which the recommendations could be incorporated in the home setting. Fourteen of the 17 participants specifically addressed the question of recommendations; of these, eight were relatively satisfied and six wanted further direction. The following examples best captured the divergent views, where some participants felt well-advised and satisfied, and others felt as though they needed more guidance and information. For example, Alley felt the recommendations were helpful and well-outlined and that being able to bring them forward into the school setting made a "significant difference" to her son's behaviour.

It was very helpful, and it was outlined such as "step one, do this." They gave me online resources, and I'm pretty computer savvy and . . . able to self-help and be an advocate for yourself to seek out further steps and stuff that was super helpful.

There's a challenge with being out of the main centres in the province, right, to be

able to access more support, but we've implemented almost all when it comes to the school system. Since the implementation of the recommendations there has been significant difference with my son, like night and day. (Alley)

Cathy indicated that she successfully implemented all of the recommendations because she had the assistance of a key worker.

All of the recommendations were implemented. That had a lot to do, too, with the key worker because she went to the school with me afterwards and met with everybody and explained what needed to happen and what she needed. (Cathy)

On the other hand, Betty wanted more information with respect to her son's diagnosis but appreciated that her education enabled her to do her own research, while she realized that this may not be the case for everyone.

More information on my child's diagnosis. I wasn't given any of that. I've done my own research, and I've read quite a few books prior to having the suspicion. But let's just say if I wasn't as high functioning, I would think that might be a difficult thing if you were given a diagnosis without any sort of resource material. That's the first thing you say, "Okay, what do I do, where do I go, what's next? How do I treat this person now that I know this?" More tangible, physical resources available then and there to say here's some information. Nobody said this child should take this medication or that medication, or you should be going to find your family doctor to see him about medication. The school, in so many words said, your child needs medication. So I took the initiative, made the family doctor appointment and said, after much research on my part, you know, "I'm willing to go forward on this, here's

his diagnosis, it's ADHD, what do you recommend?" There was no medication recommendation at all. (Betty)

Betty appeared to be quite open to the possibility of administering medication to her child, despite the fact that this intervention was not included in the recommendations for her child. Interestingly, Betty was one of only two parents in this study where medication was not recommended for their child. In contrast, Carol was opposed to her son being medicated and was upset that medication had been recommended.

They did describe medication. Did I get medication? No, I do not believe in medication. The school told me to get medication, the doctors told me to get medication. I told them all to go have their own babies and medicate them and leave mine alone [laughs]. He does not need medication. I've got a fear of my own self about medication. I've had a hard life, right. So it's tough. I'll play it out another year, maybe two and we'll go from there. He's not a guinea pig, he's a boy. (Carol)

A number of parents admitted that they were reluctant to give their child medication but nonetheless proceeded with the recommendation. By the end of the family meeting, Sally was open to the idea of medication, as one of the doctors articulated the use of medication in such a knowledgeable manner that Sally was reassured:

I did like the doctor's knowledge of the medication to make me feel a little bit more comfortable about going forward with that. Because I think if she wouldn't have said those things to me, I probably would've just been, like, "You're just pushing pills." Because that's how I felt, but she had a different interpretation of it and it made me feel a lot more comfortable.

Both Arlene and Matthew changed their views about the administration of medication to children—once they observed the improvement in the emotional and behavioural health of their children their beliefs shifted. Arlene explained the positive effect that it had on her daughter.

I've never been a big fan of medication and I worried about it but when we put her on medication. I have to be honest that I saw a huge difference. It really, really, really helped her. It helped her to stay on task, it's helped her to stay focused and that in return helped her feel way better about herself. So knowing that the medication may be a part of her life for a while, not necessarily forever, but, you know, as long as she feels she needs it, it's a positive thing and has been just a huge good thing in her life.

Matthew explained:

With the assessment also came the recommendation for medication to help him keep focused and stuff and anxiety because he's got a lot of anxiety. It helped.

Fred was prepared to give his son medication, but indicated that he wanted additional strategies for dealing with his son's learning disabilities, that medication alone was insufficient.

But in my mind, it's not clear . . . what would help our son besides medication, like how do we treat his learning disabilities? So, in my opinion, it got us part way. We were trying to line up someone to help us with our son and we don't have any help for his learning disabilities.

Rita felt that the recommendations prompted more questions than answers when her daughter did not receive the definitive diagnosis Rita had hoped for.

She didn't have any of the effects of the alcohol, but it wasn't over. She has speech issues. I was left with probably more questions than answers. They were knowledgeable answers that they gave, you know, based on what they did, but there was no diagnosis. Just, you know, "Okay, continue to watch her," and [I'm] like, "Okay, please tell me what I'm supposed to be watching." I don't want to interpret everything, like you've got to pick it all apart. Being clearer to the parent, this is what you should do, or here are the next steps. (Rita)

Many children do not fit neatly into diagnostic categories, which can be difficult for professionals looking for ways to help children and even more difficult for parents who are desperate for assistance and for answers. Families with children who have behavioural issues can have a particularly difficult time finding help—in the way of appropriate services. For example, Lisa's daughter had severe behavioural issues and missed many school days due to suspensions. She felt that the report fell short when it came to making practical and helpful recommendations, that it essentially told her what she already knew: that her child needed external support services.

There weren't really any recommendations. It was just that one sentence stating that mother needs extensive support services and that was it. I ended up having to go to my counsellor saying, "What do I do? Like, where do I go?" They're saying I need extensive support services. I know I do. In order to help my child's behaviours I need some support, but there was no follow-up on that or "do you have any questions

about what we can do for you,” any services and stuff like that. They just basically said you need that full report. Medication was not prescribed for her ADHD. I am dead set against medication so perhaps that is why they didn’t prescribe it.

Furthermore, Lisa had an interesting experience where she felt that the CDBC team breached confidentiality as the final report was sent to the school. Lisa described an incident where her family history was unprofessionally and inappropriately shared with personnel at her child’s school. Lisa explained:

The school and everybody else but me had a copy of the full report. After I talked to the school and said I don’t even have the full report, she comes back and she says “Oh, here’s your copy.” I was told it was going to be mailed to me. There’s information in there that I would’ve blacked out for the school to read it. Now they know things that I didn’t want them to know. Even though I signed that piece of paper that says these people are allowed to see it, I made it a point, I want that report first. The summary, I was okay with everybody having that, because it was just basically a summary. The full report tells them things about my life that I don’t want them to know. It’s none of their business, I want some privacy in my life, you know. Even my husband got quite upset about that.

Clearly, the parents had varied experiences when it came to considering the recommendations they were given. A number of parents felt that medication provided an effective strategy, but others found the recommendation to administer medication raised concerns and questions. Given the controversy that surrounds this topic, all risks, benefits,

and alternative methods associated with the medication should be fully explained to the parents so an informed decision can be made.

The themes and sub-themes that arose from my interviews are summarized in Table 2.

Table 2 *Themes and Sub-themes Arising from the Interviews*

Themes	Sub-Themes
Clinical Encounter	<ul style="list-style-type: none"> • <i>Structural considerations</i> • <i>Professional diversity and new insights</i> • <i>Questions regarding the assessment</i> • <i>Validation</i> • <i>Expectations</i>
Manner of the Delivery of the Diagnosis	<ul style="list-style-type: none"> • <i>Impact</i> • <i>Professionalism</i> • <i>Professional language (medical jargon)</i> • <i>Quantity of information</i>
Where do we go from here?	<ul style="list-style-type: none"> • <i>Post-disclosure</i> • <i>Final Report</i> • <i>Recommendations</i>

Summary

I would like to emphasize how open and candid parents were as they shared their experiences with me. Their words were borne from their experiences and they were happy to share their knowledge in hopes that it would help other parents in a similar situation, and that their information would lead to the continuous improvement of the northern clinical CDBC teams that serve children and families.

The findings described here shed light on the factors that played a role in helping parents understand their child's developmental diagnosis. These findings also identified other elements in the process that parents found impeded their understanding. In addition, the parental experiences identified factors that played a role in their ability to respond to and implement the recommendations that emerged from the diagnosis and were set forth in the final report. The array of responses of the parent participants to the interview questions yielded three overarching themes and twelve subthemes: Clinical Encounters (structural considerations, professional diversity and new insights, expectations, questions regarding the assessment process, validation, and expectations). The Manner of the Delivery of the Diagnosis (impact— emotional and impact on parenting practices, professionalism, professional language, and quantity of information). Where do we go from here? (post disclosure, the final evaluation report, and recommendations). The themes and subthemes served to outline and group the parental experiences in the process of receiving their child's developmental diagnosis by way of a multidisciplinary team of professional specialists. Chapter 5 examines my pathway through to the results, the implications for the process of delivering a child's diagnosis to the parent(s), and recommendations for future research.

Chapter 5 Discussion

The purpose of this study is to describe and explore the experience of parents who have received a diagnostic assessment and recommendations by way of the CDBC clinical multidisciplinary teams located throughout northern British Columbia. This study is particularly concerned with the factors that facilitate or impede parents' understanding of their child's developmental diagnosis at the final family meeting—the final stage of the diagnostic process. Significant findings are discussed in relation to the relevant body of literature, with an emphasis on how the results from this study either confirm or contribute to clinical practice knowledge. The findings have a unique relevance that pertains to the clinical practice of the CDBC multidisciplinary teams in northern British Columbia. This chapter is structured in a manner that highlights protective factors that were identified as effective in facilitating parental understanding of their child's developmental diagnosis and aspects of the delivery that impeded their understanding, as per the findings highlighted in Chapter 4. Specifically, the three overarching themes—clinical encounters, the manner of the delivery, and where we go from here—are discussed. In my study, the term “protective factor” is used to demonstrate an action that was conveyed by the clinical team that strengthened parental understanding, whereas a “risk factor” reflects a limitation that compromised parental understanding. A discussion on how the parents managed the recommendations that the CDBC clinical teams set forth in the final report is also included. Finally, the limitations of my study and the need for future research are considered.

Clinical Encounters

The first overarching theme, “Clinical Encounters,” encompass five subthemes that the participants talk about in a way that either supported or obstructed their ability to understand their child’s developmental diagnosis. The clinical encounter is a key component in the delivery of healthcare services, and understanding what factors positively influence that exchange is essential to providing the highest quality care to children with developmental disabilities and their families. In most healthcare organizations, clinical healthcare encounters are generally held in either the physician’s office or a clinical environment located in a larger organization. As a result of this structure, one of the problems healthcare clinicians encounter is ways to implement innovative practice in the delivery of clinical services—as creative, innovative practice can be restricted by the confines of a bureaucratic system. However, it is evident in my study that one particular CDBC team was able to shift the location of the final family meeting from the traditional organizational setting to a more relaxed environment, which engaged the parent much differently and changed her overall experience in a positive manner. All of the participants with the exception of one parent received their child’s diagnosis in a clinical setting (organization). Research studies cited in the medical literature underscore the importance of building a therapeutic environment when bad news is being delivered—which includes a safe and private space and an atmosphere that feels warm and welcoming (Buckman, 2010; Rabow & McPhee, 1999). This clinical practice was confirmed as a protective factor in my study, which is consistent with the medical literature that identifies the advantages of a comfortable, safe environment that strengthens the process and aids in the parent’s ability to

hear difficult news that is being delivered by way of a team of clinicians (Fallowfield & Jenkins, 2004).

There appears to be support from Northern Health (organization) for clinicians on the CDBC clinical teams to implement creative practices to ensure quality services are being provided to the child and the family, honouring the needs and preferences of the family. One of the many objectives outlined in Northern Health's implementation strategy—to provide outstanding health services to northerners—directs healthcare professionals to establish a culture of patient and family-centred care (Northern Health c, n.d.). Northern Health claims that in order to deliver effective healthcare quality services, clinical practice needs to honour the family's preference, a requirement that is stated in Northern Health's 2015/16–2017/18 service plan (Northern Health c, n.d.). This approach aligns with the plethora of research that recognizes the positive health outcomes for children and families when healthcare professionals adhere to the framework of patient and family-centred care (Greene, Tuzzio, & Cherkin, 2012; Sevin, Moore, Shepherd, Jacobs, & Hupke, 2009). My study finding suggests that one of the CDBC clinical teams is implementing strategies that honour patient and family-centred care.

In contrast, a few parents identified additional structural considerations in the clinical encounter that impeded their understanding of their child's diagnosis. One factor identified draws attention to the concept of cultural competence. This concept covers a variety of practical strategies that can be deployed during a clinical healthcare encounter that positively shapes the individual's experience (Campinha-Bacote, 2011). Research studies document that the quality of care can diminish when cultural barriers exist in the context of a healthcare setting (Singleton & Krause, 2009). One of the participants felt that her culture (Aboriginal)

was not taken into consideration during the family meeting, which had a negative impact on her ability to focus on the content being delivered. My study finding reinforces the importance of the CDBC clinical teams acknowledging and addressing cultural diversity in order to mitigate this risk factor to quality care.

To foster and promote culturally informed practice, a clinical team within a larger organization requires the commitment of the system, which will support and motivate cultural clinical practice. Sevin et al. (2009) states that for true success to evolve, the organization's mission statement and vision must be committed to the development of culturally competent healthcare professionals by way of providing mandatory cultural evidence-based intervention training for all healthcare professionals who provide direct services to diverse children and families. Northern Health has recently gone through a systems change that has shifted the organization's priorities, making the health outcomes for First Nations people front and centre (Northern Health b, n.d.). The Northern First Nations Health Partnership Committee, which is part of the new First Nations Health Governance structure in the province of British Columbia, works in partnership with all aspects of Northern Health. The overall purpose of this committee "is to collaborate and partner on planning, implementation, and evaluation of culturally appropriate, safe and effective services for First Nations residing in the North" (Northern Health b, n.d.). Fortunately, my research findings come at a perfect time—the northern CDBC teams can incorporate ideas into their clinical practice that actively and visibly encourage an inclusive framework—as Northern Health identified this service gap to provide quality services to diverse populations, in particular to First Nations people.

In keeping with the subtheme of structural considerations, the notion of power was conceptualized in my study. The parents' perception of power is related to the physical constructs observed at the family meeting—the seating arrangement coupled with the professional attire created a feeling of division between the clinical team and the families. This finding serves as a reminder for healthcare clinicians on the clinical teams to examine the role non-verbal communication plays in the delivery process, which may unintentionally highlight the power differential and act as a barrier hindering the parental experience. Research from various professional disciplines, in particular social work, identifies effective practice methods that clinicians can employ during a clinical encounter that strategically dismantle power imbalances when communicating with individuals and families (Jupp, 2005). My research finding sheds light on certain physical features of non-verbal communication that compromised the parent's ability to focus on the clinical healthcare message that the clinical team intended to convey.

In my study, all of the parents valued the comprehensive assessment that was conducted by way of the multidisciplinary clinical team. The plethora of diverse developmental knowledge shared by the clinical team provided the parents with new insights into the mystery of their child's unique developmental trajectory. The parents viewed the professional diversity as a positive determinant in the process of understanding their child's developmental diagnosis. My findings coincide with research that was conducted in a clinical cancer setting, where patients expressed their positive experience of receiving a comprehensive assessment and treatment plan by a multidisciplinary assessment team (Lamb et al., 2014).

In keeping with the overarching theme “Clinical Encounters,” some parents questioned the significance their knowledge held in the formulation of the assessment. Parents in my study expressed a strong desire to have their contribution viewed as a valuable source of information and not dismissed, as they wanted the assessment to reflect an accurate portrayal of their child’s overall functioning. Research conducted by Crais, Roy, and Free (2006) highlights the importance of the parent’s contribution in a multidisciplinary team assessment. The absence of parental contribution in the assessment process has a profound impact that goes beyond the clinical encounter. One consequence identified in the related literature mentions the propensity for the parents to discredit the diagnosis, which may hinder the parents’ motivation to implement the clinical team’s recommendations (Graungaard & Skov, 2007). In my finding, parents were included in the assessment process, but the lack of inclusion stemmed from a feeling that the information they provided was not deemed credible. Nonetheless, my study finding emphasizes the need for clinicians on the CDBC clinical teams to be aware of how they communicate—to ensure that the parents feel they are an active participant in their child’s assessment and that their voice matters in the overall assessment.

The Manner of the Delivery of the Diagnosis

The second overarching theme, “The Manner of the Delivery of the Diagnosis,” encompasses four subthemes that the participants talk about in a way that either facilitated or impeded their ability to understand their child’s developmental diagnosis. Professionalism played a protective role in the way the parents understood the diagnosis. Van Mook et al. (2009) claim there is “no universal understanding of what the term professionalism means and it is unlikely that any one definition is applicable across all relevant contexts” (p. 89). In

my study, professionalism was conceptualized in relation to the clinicians' ability to extrapolate sources of strength within the child's abilities. This clinical insight provided a shift in parental understanding of their child's developmental diagnosis. All of the parents appreciated the level of professionalism the clinicians conveyed, in particular, the special set of skills and expertise the clinicians used to shed light on the best traits present in their child's repertoire. The parents were most delighted by the way the clinicians were able to frame their child's strong developmental attributes in the context of delivering a developmental diagnosis. As such, this clinical technique uncovered positive opportunities the parents may have overlooked if the delivery was not communicated in such a professional manner. The parents felt optimistic to explore and reinforce their child's identified strengths to promote their child's development. My finding is in line with the results of a study completed by Choi, Lee, and Yoo (2011) where healthcare professionals provided positive information to the parents in the context of delivering a developmental diagnosis and, as a result, the parents reported that they developed an optimistic outlook towards their child's future.

Furthermore, my findings reflect a 100% satisfaction rate related to professionalism. My study finding is higher in comparison to relevant research that has explored the concept of professionalism in the process of delivering a developmental diagnosis. One large quantitative study where parents (1047) completed an online survey related to professional conduct revealed a satisfaction rate of 71.1% (Crane, Chester, Goddard, Henry, & Hill, 2015). Another similar study identified a 66% rate of satisfaction (Jones, Goddard, Hill, Henry, & Crane, 2014). In essence, professionalism is a factor that positively affects the outcome of the understanding of a child's diagnosis. Professionalism amplifies parental

understanding when clinicians include positive information about the child in the context of delivering the diagnosis.

Additional factors associated with the manner of the delivery are related to the use of professional language and the quantity of information that was shared during the final family meeting. The parents in my study reported mixed experiences when it came to the use of language and the amount of information that was delivered during the family meeting. Several parents found that the clinicians used terms that were easily understood, and they were encouraged to ask questions if they did not understand the information. Nine of my participants did not encounter any communication issues associated with the language the clinicians used during the final meeting. These participants felt that the clinical team communicated in a clear, effective manner, which aided them in their ability to comprehend their child's diagnostic information.

In contrast, my study finding reveals that eight of the participants found it challenging to decipher the content as the choice of words used by the clinicians left them feeling confused. They reported that the use of medical jargon interfered with their ability to fully understand their child's diagnostic information. Given this disparity in my study finding, there is room for clinical improvement in the way clinicians on the CDBC teams effectively communicate to improve parental understanding. The use of medical jargon during the family meeting ought to be examined at the clinical level—given the poor health outcomes for the child—when the parent does not comprehend the medical information (Katz, Jacobson, Veledar, & Kripalani, 2007). Research conducted in a healthcare environment focusing on the effects of the physician's ability to communicate medical information demonstrated that the use of medical jargon has been linked to poor clinical outcomes, in part

because the specialized language used in consultations is poorly understood and therefore tends to result in a lack of adherence to clinical treatment recommendations (Roter, Hall, & Aoki, 2002).

Given the knowledge about the poor health outcomes combined with my study finding, it is important for all health practitioners to adhere to a best practices guideline in keeping with the notion of universal precaution when communicating medical information with families. For example, healthcare personnel approach disease control by wearing the proper medical gear whether or not a particular individual may be contagious. Likewise, clinicians on the clinical teams should impart diagnostic information in layman terms to all parents regardless of their apparent level of health literacy.

The quantity of information provided to parents during the family meeting is another subtheme of the second overarching theme “The Manner of the Delivery of the Diagnosis.” The parents in my study had different experiences when it came to their ability to understand the amount of information given at the time of the family meeting. Six parents in my study reveal that the amount of information was influenced by three factors that hindered their understanding of their child’s diagnosis. One of the factors was the amount of time the clinicians devoted to the delivery of the diagnostic finding. Some of the parents found the time inadequate to process all the pertinent information that was provided. In addition, some parents found that certain material the clinicians discussed was not relevant, which led to parental confusion. The parents indicated that in the context of the family meeting a professional discussion ensued between the clinicians regarding what sectors of government were responsible for funding as it pertained to accessing services. Tina reports, “all of a sudden people started talking, talking, talking about who’s what, whose pocket of money is

going to pay for what.” From the parent’s perspective, the nature of this dialogue had no relevance as the parent had no control or understanding of the financial component as it relates to the provision of health services.

The final factor parents spoke about relates to the challenge of managing their emotions while trying to understand their child’s diagnosis. In fact, 11 out of the 17 participants talked about the emotional impact of hearing the diagnosis. In some cases, parents claimed the emotion compromised their ability to comprehend the diagnosis. My study finding is in line with several similar studies that showed that more than half of parent participants experience an emotional reaction during the disclosure process, which plays a role in hindering comprehension (Kessel, Roth, Moody, & Levy, 2013; Klein et al., 2011; Morse, 2011).

All the parents in my study expressed the need to know and want all the relevant information associated with their child’s developmental diagnosis. For the clinical teams to strengthen the clinical delivery, it would be helpful if the clinical teams impart information in a slightly different manner, taking into consideration the features identified in my study. Increasing the time associated with the family meeting may appear to be a simple remedy, but it is beyond the control of the clinical CDBC teams. It may be a challenge to implement at the clinical practice level, as there are a number of systemic barriers such as time constraints that face a healthcare organization. It is not uncommon for clinicians in clinical practice environments to have multiple demands on their time, which requires a broader systems change at the macro level (healthcare system). Concerning the other two barriers the parents identified—relevance and emotion—perhaps clinical practice changes can be implemented at the clinical level to ameliorate the negative effects on parental understanding.

Clinicians can be cognizant of the nature of the information being discussed at the family meeting, ensuring the content has a relevant application for the parents. In addition, clinicians need to incorporate best evidence approaches when delivering emotionally charged information to ensure that the message is not lost in emotion.

In keeping with the subtheme “The Manner of the Delivery of the Diagnosis,” my research findings showed that there was a positive impact on the parents’ parenting approaches pre- and post-delivery of the diagnostic findings. In fact, 10 of the parents claimed that they altered their approach to parenting after forming a better understanding of their child’s capabilities. Research on parenting a child with a developmental disability has addressed various aspects of the parenting experience but has not explored the shift in parenting practices before and after the delivery of the diagnostic finding (Ritzema & Sladeczek, 2011). My research finding highlights the positive shift in parenting practices subsequent to the family meeting. This finding is both interesting and important, given that the child-parent relationship is profoundly important for all aspects of a child’s development.

To summarize the discussion regarding the first aim of the study, Table 3 below lists the protective factors that facilitate and the risk factors that impede parental understanding of their child’s developmental diagnosis during the family meeting. It is important to note that the parents had mixed experiences when it came to the various protective and risk factors.

Table 3 *Protective Factors that Facilitate and Risk Factors that Impede Parental Understanding*

<i>Protective Factors—enhance parental understanding</i>	<i>Risk Factors—diminish parental understanding</i>
<ul style="list-style-type: none"> • Clinical Setting (Client’s Residence) • Validation 	<ul style="list-style-type: none"> • Structural Considerations: Space, power imbalance (seating arrangement), and cultural clinical practice delivery.

• New Insights	
• Professionalism	• Medical Jargon/the quantity of information.
• Clear communication	• Length of the family meeting.
• Improved parenting practices	• Emotional Impact

Where Do We Go From Here?

My study findings related to the third overarching theme “Where do we go from here?” are relevant to my second study aim—a focus on the parents’ journey regarding the implementation of the clinical recommendations outlined in the final diagnostic report. The parents describe their experience in relation to their child’s clinical recommendations by way of three subthemes: post-disclosure, the final report, and the recommendations. Many of the parents in my study express a strong desire for follow-up subsequent the family meeting so they can ask questions regarding their child’s diagnosis and clarify information about the team’s clinical recommendations. A few parents were contacted after the family meeting as they were informed about my research study. In the context of this contact (a telephone call), the clinical coordinator asked if the parent had any outstanding questions related to their child’s diagnosis or the recommendations. Several parents embraced this opportunity and had some of their lingering questions answered which improved their knowledge about the process of implementing their child’s clinical recommendations. The parents suggest reducing the length of time between the final family meeting and the contact from the clinical coordinator—have the clinical coordinator check in sooner as it was very helpful. Amanda stated, “Get somebody to call and check in sooner, right, so the family meeting was in November. It’s now March and they’re asking about the research . . . great . . . so could they get her to call earlier?”

According to my research finding, follow-up between the family and a healthcare professional shortly after the disclosure is required to improve health outcomes for the child and the family. A truly integrated team would include the clinical diagnostic assessment process, the final family meeting, and a healthcare professional that aids in bridging the family to the community resources. Perhaps the role of the clinical coordinator can include follow-up with the parents shortly after the family meeting to verify that the family is linked to the appropriate community resources.

Several parents in my study were assigned a key worker, which was revealed to be a protective factor for the child and the family. The key worker was instrumental in creating the shift from the clinical diagnostic team to the various wraparound services in the community where the clinical recommendations were applied. The key worker informed the parents about information on local community services, and in some cases improved the communication between various systems—the child's school personnel, allied healthcare professionals, community agencies, and the parents. A collaborative team was developed and intervened to alter the child's developmental trajectory for the well-being of the child.

Unfortunately, some parents were not assigned a key worker nor had any knowledge of such a professional. The inconsistency of key workers attached to parents is a result of budget cutbacks and funding issues faced by the larger healthcare system—which in turn, affects vulnerable children and families, as was shown in my study. Hence, there exists a need for the clinical teams to engage in dialogue regarding the possibility of having the clinical coordinator follow up with the parents, enabling a more cost-effective approach and supporting favourable outcomes for the child's developmental growth.

It is not surprising that post-diagnostic support was an area of concern as other comparable studies indicate a similar experience following the disclosure of a developmental diagnosis (Crane et al., 2015; Jones et al., 2014; Mansell & Morris, 2004). In the study conducted by Crane et al. (2015) in the United Kingdom, 40% of parents revealed that they received no post-diagnostic support, and less than 25% of parents were provided support subsequent their child's diagnosis.

The parents had mixed experiences in relation to the final report regarding the accuracy, clarity, and complexity of the report. The parents who received a summary report of their child's diagnosis prior to the family meeting reported a positive experience as it gave the parents the opportunity to read the summary report and prepare questions before the meeting, inadvertently making the final report much easier to understand. The clinical practice of mailing out the summary report prior to the final family meeting was deemed as a protective factor as clinical teams in various parts of the northern region are providing this service. The parents who faced difficulty comprehending the final report were not connected to a key worker and did not receive the summary in advance. My study finding shows that sending the summary report to the parents at least a week prior to the final meeting will not only improve the parental understanding of their child's diagnosis but also assist the parent with the implementation of their child's clinical recommendations.

To summarize the discussion of my second study aim, Table 4 lists the protective factors that facilitate and the risk factors that influenced the parents' process of implementing their child's clinical recommendations.

Table 4 *Protective Factors that Facilitate and Risk Factors that Influenced Parents' Implementation of Clinical Recommendations*

<i>Protective Factors—supports the application of the clinical recommendations</i>	<i>Risk Factors—limits the application of the clinical recommendations</i>
<ul style="list-style-type: none"> • The clinical coordinator contacting the parents shortly after the family meeting. 	<ul style="list-style-type: none"> • Lack of follow-up from a healthcare professional.
<ul style="list-style-type: none"> • Connecting the parents to a key worker. 	<ul style="list-style-type: none"> • Lack of key worker
<ul style="list-style-type: none"> • Send the summary report to the parent—at least one week from the scheduled family meeting. 	<ul style="list-style-type: none"> • Not receiving the summary report until the day of the family meeting.

Summary

My research findings provide a meaningful picture of the overall experiences of the parents who received a developmental diagnosis by one of the clinical teams in northern British Columbia. As mentioned above, the clinical teams are situated within a healthcare landscape that is embedded in a complex social, political, financial, and legal environment. As a result, a few of the risk factors identified are beyond the scope of the clinical teams, for example, the under-funding of services and the maldistribution of resources (keyworkers). The mitigation of these risk factors primarily rests with the executive level of the healthcare organization. In addition, my study findings yield risk factors that the CDBC teams can apply at the clinical level to enhance health outcomes for the child and family. In contrast, my study findings reflect several protective factors that the clinical teams currently practice, manifesting positive outcomes that really made a difference to the families they serve.

Practice Considerations

My findings provide practical information that can be applied to the clinical services offered by the CDBC teams in northern British Columbia. These practices can be implemented at the clinical team level, building on the team's strengths and identifying opportunities for improvement and consistency on the various clinical CDBC teams. I highlight several feasible practices that can be adopted to improve the way in which the clinical teams deliver diagnostic information and engage families.

Providing the summary report prior to the family meeting: Providing accurate information to the family one week before the scheduled final family meeting (by way of summary report) has a number of benefits for the child and the parents. A few parents in my study spoke about how the receipt of the summary report prior to their family meeting facilitated understanding, which led to a rich discussion about their child's future developmental trajectory and the necessary paths associated with the recommendation process. This practice obviously occurs, but it is not applied broadly across all the clinical teams. Adopting this action by way of a professional practice standard ensures that all families will receive the summary report prior to the final family meeting. This applied action resulted in several positive outcomes: it increases parental understanding by giving parents the time to develop and ask meaningful questions about their child's diagnosis, and it reduces the emotional impact of the diagnosis as it provides time for the parents to prepare mentally and emotionally, diminishing the emotional impact of hearing unfavourable news.

Implement a short recess during the family meeting: One way to mitigate the risk associated with the parent's inability to understand emotionally charged information is to incorporate a short recess subsequent to the delivery of the final diagnosis and reconvene

once the parent has regained composure (Crane et al., 2015). This is a critical step, as the parents require a presence of mind to form an understanding of their child's diagnosis.

Support the use of a recording device during the family meeting: One of the parents in the study regretted not having recorded the family meeting—over time, pertinent information was difficult to recall. A number of scholars advocate using recording devices for several reasons (Price, McNeilly, & Surgeror, 2006). A recording of the meeting will allow a parent to listen to the information at a later date. It also acts as a safeguard for parents whose emotions had an impact on their comprehension. Additionally, a recording can be shared with significant others who could not be present at the family meeting, further enabling the transmission of accurate information. This proactive intervention works well for clinicians who do not have the time for follow-up sessions with families after they have presented their diagnosis (Levetown, 2008). Given that we are in the age of technology, many individuals have devices that are equipped with a recording mechanism that can be viewed or used as a form of note-taking to enhance understanding.

Use plain and simple language during the family meeting and simple writing in the report: It is important for clinicians to shape the practice of their clinical delivery (content) in a way that is congruent with the parents' level of health literacy. It is imperative to deliver and share healthcare information in a manner that facilitates a parent's ability to retain, read, and understand their child's diagnostic information so the parent can make the best decisions and follow the recommendations that promote optimal child development. Some parents struggled with the language shared during the family meeting and reading the final report. One parent suggested restructuring the family meeting by having one clinician deliver the content, mitigating the risk of confusion. In addition, having a primary clinician

deliver the diagnostic finding may increase the clinician's ability to assess and identify what pertinent information the parent did not understand, prompting the clinician to provide further information.

Creating culturally safe practices during the family meeting: Northern British Columbia is home to people from diverse cultural backgrounds. In 2006, 30% of the residents of Northern British Columbia identified as Aboriginal (Northern Health, b, n.d.). Investing in creative ways to incorporate cultural practices will improve health outcomes for families from multicultural backgrounds, First Nations people in particular. Northern Health and the College of Physicians and Surgeons of British Columbia has committed to mandatory educational training in Indigenous cultural competency (ICC) for all healthcare professionals (College of Physicians and Surgeons of British Columbia, 2015). Ensuring that all of the clinicians on the CDBC clinical teams have completed the ICC training is one way to strengthen clinical practice when serving First Nations people.

Contact families shortly after the family meeting: The level of contact and support that the parents felt they needed post-disclosure requires a higher level of approval because it relates to the budget and financial resources of the organization (key workers). However, this issue can be raised with the local manager of the northern CDBC teams so that the department leader can advocate and support the need for a strategic change at the higher managerial level, emphasizing the improved health outcomes for families and children with developmental disabilities.

Changing the model of the team by way of one additional clinician—in particular, a registered social worker—whose primary role is to mitigate the risk factors would intensify the health outcomes for the child and the family. In fact, most multidisciplinary clinical

teams include a social worker to address the essential services that the family requires (Klein et al., 2011; Min et al., 2016). As noted earlier, one frontline action that can be adopted on a regular basis—at the clinical level—is to have the clinical coordinator contact the families shortly after the final family meeting as this practice was proven to be very beneficial for the families.

My research findings reveal important insights into the professional clinical practices that may guide and inform clinicians on the CDBC teams in northern British Columbia in relation to the delivery of a child's developmental diagnosis. Practice considerations are presented in Table 5 to promote parents' understanding of their child's developmental diagnosis.

Table 5 *Practice Considerations for Delivering a Child's Developmental Diagnosis with Parents*

Provide the summary report prior to the family meeting.	<ul style="list-style-type: none"> • Provide the summary of the final report one week before the scheduled family meeting. • Connect the family to a key worker.
Implement breaks during the family meeting.	<ul style="list-style-type: none"> • Provide a short recess after the disclosure and reconvene when the parents have had some time to regain composure.
Support the use of an audio recording device during the team meeting.	<ul style="list-style-type: none"> • Provide the parents with the option to record the final family meeting.
Use plain language during the family meeting and use simple writing in the report.	<ul style="list-style-type: none"> • Adopt a universal health literacy principle to deter the use of medical jargon. • Write the report in layman's terms.
Increase clinicians' cultural competency by ensuring that all clinicians have completed the mandatory training offered by Northern Health.	<ul style="list-style-type: none"> • Integrate the sharing of food in the context of the family meeting to acknowledge difference in cultural ways of learning and reduce parental anxiety. • Attend ICC training.
Provide post-disclosure support for the family.	<ul style="list-style-type: none"> • The clinical coordinator should conduct a follow-up call with the family within two weeks after the final family meeting. • Ensure that the key worker continues to engage with the family until the clinical recommendations are implemented.
Change the model of delivery by the addition of new clinician.	<ul style="list-style-type: none"> • Secure a registered social worker (MSW) for the team to attend to the emotional health of the parent(s) and the navigation of the child's clinical recommendations.

Limitations of the Study

Despite the relevant findings into the views of parents in relation to a very critical part of the delivery of a child's developmental diagnosis, my study has limitations that should be kept in mind when considering the findings. The sample size in my study is small. However, qualitative research does not require large sample sizes, and in my study, saturation was reached, suggesting that the sample size was sufficient, especially given that the scope of my research was limited to the final family meeting. Another limitation in relation to the sample size is the relatively low number of participants from the various areas across northern BC. The majority of the parents received their child's diagnosis from the CDBC clinical team in Prince George and, consequently, it was difficult to get a sense of the regional variation in clinical practices.

Future Research

My study has begun to lay a foundation for future researchers who are interested in the experiences of parents who received a child's developmental diagnosis and their journey of implementing their child's clinical recommendations. Current gaps in the knowledge associated with the importance of implementing a child's clinical recommendations subsequent the final family meeting warrant further exploration, specifically regarding the support and coordination of services provided to the family post-disclosure. The funding granted to families who have a child with developmental disabilities appears to be non-existent or much less compared to the funding families receive when their child has a diagnosis of autism (Autism Society of Canada, 2004). Thus, there is a vital need for more research on the funding a parent receives when their child has a developmental disability outside of the autism spectrum.

Although my study intended to focus on the perceptions of both mothers and fathers, fathers are, for the most part, under-represented in this research, as the majority of the parents in this study are mothers. This study also included two parents from different cultural backgrounds, Latino and First Nations. Future research initiatives in this area could be encouraged to recruit an equal number of fathers and mothers, allowing an exploration of gender differences when it comes to understanding how men and women experience the delivery of their child's diagnosis in a clinical setting. Similarly, a larger sample size could be assembled in order to allow for greater cultural diversity, especially a study that takes into account the relatively large concentration of First Nations families in northern BC. In this way, differences in perceptions could be examined in light of cultural differences, and considerations for culturally competent practices could ensue. A sample that includes an equal number of parents serviced by the various clinical teams across the northern region could highlight exemplary practice techniques and generate best clinical practice guidelines for the north region. The logical next step indicated by this research is to operationalize my study findings and evaluate the level of effectiveness in the near future.

Conclusion

In my study, I explored the factors that facilitated or impeded the parental understanding of a child's developmental diagnosis communicated by one of the CDBC clinical multidisciplinary teams in northern British Columbia. In addition, I explored the factors that influenced the parent's journey with the implementation of their child's clinical recommendations. My study highlights a set of protective factors that maximized parental understanding during the final clinical interaction between the CDBC multidisciplinary team and the family. Also, a set of risk factors limiting parental understanding of the child's

diagnosis were identified. Some of the limiting factors can be managed at the clinical team level while others require the attention of the executives in the healthcare organization, as the issues are connected to the fiscal budget. The protective factors identified are consideration of the location of the clinical setting while delivering undesirable information, validating the parent's concerns, and presenting the child's strengths in a manner that initiates new insights. Professionalism and clear communication were deemed as favourable clinical practices that heightened the parent's understanding of their child's developmental trajectory, prompting a positive shift in parenting practice.

The risk factors call for a deeper level of professional awareness in relation to the inherent power imbalances by tuning into the non-verbal cues that may unintentionally highlight the discrepancy in the final clinical encounter. Delivering a child's clinical diagnosis in the absence of a culturally sensitive approach is described as a barrier that diminishes parental understanding. The additional risk factors request that clinicians use plain language while communicating the child's diagnosis, extension of the time devoted to the final family meeting, and the need for clinicians to be cognizant that the nature of the content can have an emotional impact on one's ability to synthesize the information, and a new clinical approach that addresses the issue should be encouraged. A number of clinical practice considerations flowing from my study findings have been devised and can be adopted, acting as a buffer to mitigate the risk factors and enhancing health outcomes for the child and family.

Overall, my study is a call to healthcare professionals and researchers to develop increased knowledge in the area of how parents understand their child's developmental diagnosis, recognizing the importance of implementing the child's clinical recommendations

and ensuring that the optimal intervention is provided to the child. As a result, strengthened services and supports need to be provided post-disclosure, bridging the parents to the community services to nurture their child's growth and development toward adulthood.

Reflections

In correspondence with interpretive description, the findings have special relevance for the clinical teams in the healthcare setting. Through my research journey, I have learned that the experience of parents receiving a child's developmental diagnosis is larger than the final diagnosis. My professional theoretical orientation influenced by social constructivism made it abundantly clear that the diagnostic disclosure does not occur in a vacuum and needs to be considered in a broader context of social and cultural nuances to explore the unique ways parents' process the diagnostic information. The clinical encounter is a relational process with different parties confronting a diagnosis—bringing forth different explanations, understandings, values and beliefs. As such, it is the role of the clinicians during the delivery process to translate medical information in a way that creates a shared understanding of what this knowledge means for the parent and the child's future.

Yes, the receipt of their child's diagnosis was described as a pivotal turning point in that their exhaustive search for answers had reached a conclusion. I was intrigued by the parents' level of commitment, love, and devotion in the name of their child. It is disheartening to learn that many of the parents waited several years to receive their child's diagnosis, and some of these parents were left to their own devices after the final meeting. This level of disconnect seems absurd given that the healthcare system provides funding for highly skilled clinicians to conduct comprehensive behavioural developmental assessments that include clinical recommendations for the child's well-being. It is obvious that the health

and social services systems need to engage in an in-depth conversation and create a shared vision for children with developmental disabilities, bridging the diagnostic assessment/clinical recommendations to the helping professionals employed in the various community resources. Is there value in a developmental assessment if the recommendations are not implemented due to systemic issues? Directing and guiding parents in the right direction subsequent to the disclosure of the diagnosis is paramount to the child's best interest.

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APPENDIX A: INTERVIEW GUIDE

1. What did you find most useful about the family meeting?
2. Can you describe how the family meeting increased your level of knowledge regarding your child's diagnosis or functional assessment?
3. Can you recall and describe how you felt when you left the family meeting?
4. What are some of the challenges that you experienced during the family meeting?
5. What are some of the successes that you experienced during the family meeting?
6. If you could change one thing about the process what would it be?
7. In what manner has your child's assessment changed your situation?
8. Do you think the delivery of your child's diagnosis or functional assessment helped you understand what is needed for your child's future plan? If so, how? If not, why not?
9. What are the major advantages of your child's recommendations?
10. What are the major disadvantages of your child's recommendations? Were you successful in implementing your child's recommendations? If so, what was your experience? If not, what was your experience?
11. How did the diagnosis or functional assessment impact you?
12. What factors played a role in you understanding your child's diagnosis or functional assessment? What factors played a role in you not understanding your child's diagnosis or functional assessment?
13. What changes would you recommend to the team in order to enhance the understanding of a child's diagnosis or functional assessment?
14. What did you like about the delivery of the diagnosis or the functional assessment?

15. What parts of the delivery of the diagnosis or the functional assessment were clearly communicated?
16. Did you experience any confusion in regards to understanding the diagnosis or functional assessment during the family meeting? If yes, what part was confusing?
17. If you had the opportunity to create your own team and deliver diagnoses or a functional assessment to parents what would this team look like?

APPENDIX B: INFORMATION LETTER AND CONSENT FORM



INFORMATION LETTER AND CONSENT FORM

Tammy Pearson (PhD Student Researcher) Shannon Wagner (Faculty Advisor)
 250 301 6544 250 960 6320
 Tammy.Pearson@unbc.ca shannon.wagner@unbc.ca

Title of Study: “Exploring the Parental Experience of a Child’s Developmental Diagnoses”

Dear Mr/Mrs/Ms:

My name is Tammy Pearson (researcher) and I am a student at the University of Northern British Columbia (UNBC) in Prince George, BC. I am pursuing a doctoral degree in Health Sciences. For my dissertation, I am conducting research regarding the diagnostic process of children who received a developmental diagnosis by the Northern Health Complex Developmental Behavioural Conditions multidisciplinary team in Prince George, British Columbia. The purpose of this study is to explore the experience of parents who have been through the diagnostic process. You have been invited to participate in this research study as you have been through the diagnostic process.

What will I be asked to do and what are my rights?

Your participation in this research study will involve being interviewed in person by the researcher. Your interview will last approximately 90 minutes or less. There is no right or wrong way to answer and what you say is important. To assist the researcher, I will be asking you for permission to audiotape the session. The audio recording is to help ensure I capture detailed information of what is said. Only the researcher will hear the audio recordings, which will be transcribed to help me understand and appropriately document your experience. The interview will be conducted in a neutral, safe location of your choice. Upon completion of the interview an honorarium of \$75.00 will be given to thank you for your time and valuable information.

Your participation in the study is completely voluntary and you are in no way obligated to participate in this research and there is absolutely no penalty if you do not participate in this research study. You have the right to confidentiality and anonymity of any information you provide. As a participant, you also have the right not to answer any question you choose and withdraw your information without consequences at any point during the research.

All personal identifying information about you will be kept confidential.

Please understand that all information, including your and your child's name, will be kept confidential. To protect your privacy, your transcript or any quotes from your interview will be assigned a pseudonym (fictitious name) and no identifying information will accompany your information. Digital and hard copies of any information gathered from you during this research will be stored on the researcher's professional computer at UNBC which is located on a secure server with password and anti-virus protection. Hard copies will be stored in a locked cabinet in a locked office at UNBC. At the end of my dissertation all audio recordings will be erased and any other paper/hard copies will be shredded. The electronic file of analyzed data will be stored on my UNBC computer account for five years, at which point the electronic file will be deleted. If a professional transcriber is used to transcribe interviews, a Transcriber Confidentiality Agreement will be signed beforehand. An exception to confidentiality is disclosure of a child in need of protection that has not been reported to the Ministry of Children and Family Development (MCFD). Under this circumstance, the researcher must report this information to MCFD according to legal and ethical obligations.

What are the benefits and risks of participating in this research study?

There are no guaranteed benefits for your participation in the research study. Possible benefits for telling your story may result in new insights or understanding about your particular experience. However, the interview conducted in this study is not intended to be therapeutic.

I anticipate no risks to you during your participation in this research study. However, as with any form of self-reflection, your participation may result in new awareness and undesirable memories. As a result, possible risks to you during the interview may include anxiety or uncomfortable recall of unpleasant experiences. It is understood that individual participants may experience some negative effects particular to individual situations. However, please understand that you have the right to end your participation in this study or revoke your permission to use your information at any time during the interview or the course of this research study. If you decide to withdraw from the study, any information that you have provided up to that point will also be withdrawn and securely destroyed.

If you experience emotional or psychological distress as the result of reflecting upon your experience with the topic of this study, or participation in this study, you are encouraged to contact a mental health therapist, and the researcher will provide a list of resources with referral information.

If you have any questions or concerns following your participation in the research, please do not hesitate to contact me, Tammy Pearson at 250-301-6544 or via e-mail at (Tammy.Pearson@unbc.ca). I will be happy to discuss your questions or concerns, or make any appropriate referrals necessary to resolve your concerns. If you would like to receive

information indicating the results of this research either with respect to your participation or with respect to the research as a whole, please let me know during the interview process or by contacting me at the above phone number and/or e-mail address.

Please keep this information letter for your own records. For further information on your rights as a research participant or if you have any concerns about this project, please contact my PhD Faculty Advisor Shannon Wagner (shannon.wagner@unbc.ca) at UNBC or the Office of Research at UNBC at 250-960-5650 (reb@unbc.ca). I sincerely thank you for your interest in this study.

Informed Consent

I, [participant's name], voluntarily consent to participate in the research described herein, conducted by Tammy Pearson. I understand that my participation is entirely voluntary and affirm that no pressure has been applied to me to encourage participation. I have received a copy of this information letter and consent form and understand that my confidentiality will be protected. The researcher of the project has explained the study and the participation requirements to me, and answered my questions.

I understand that the purpose of this research project is to gain insight and information regarding the experiences of parents who have been through the diagnostic process with the Complex Developmental Behavioural multidisciplinary team in Prince George, BC. I understand that I was chosen because my child has received a developmental diagnosis by the above team. The researcher, Tammy Pearson, will use an interview guide to explore my experience.

1. This consent is given on the understanding that Tammy Pearson will use her best efforts to protect my identity and maintain my confidentiality.
2. I understand that all citizens are required by law to report situations of a child in need of protection due to suspected neglect/or physical, sexual, or emotional abuse to the Ministry for Children and Family Development (MCFD). Any disclosure or failure to report a child in need of protection overrides any promise of confidentiality, and the information about suspected abuse must be reported by the researcher to MCFD.
3. I give my consent freely and understand that I may end the interview, refuse to answer questions, and/or withdraw from the research process at any time.
4. I understand and agree that the information I have given to Tammy Pearson during our interview will be treated in the following manner: a) I will be assigned a false name to protect my identity, this information will be stored on the UNBC secured drive and deleted at the end of the research project. b) The interview will be audio recorded and transcribed; hand-written notes may be taken during the interview. c) During the study, this non-identifying data will be stored by Tammy Pearson, in a locked filing cabinet, in her locked professional office at UNBC. Electronic files will be stored on her professional computer using a secure log-in, password protected, and anti-virus software. d) The data will be used by Tammy Pearson and her supervisors for her research dissertation, presentations, and publications regarding this research.

e) Following completion of the research project, all paper copies will be burned, audio recordings will be deleted, and electronic files will be deleted from Tammy's professional computer. Five years after the study is completed, the stored electronic copy will also be deleted.

5. I understand that if I have any comments or concerns, I can contact the UNBC Office of Research at 250-960-6735 or reb@unbc.ca.

To request a brief written summary of the research report relating to your participation and/or a brief written summary of the study as a whole, please provide your mailing address or e-mail below. Please be informed that these summaries will be provided upon completion of the study and will only include concise and conclusive reports, not the entire study.

I would like to receive a brief written summary of the research report relating to my participation

_____ (please check or mark X if yes)

I would like to receive a brief written summary of the study as a whole _____ (please check or mark X if yes)

Name and address (e-mail or mail) to which report will be sent

 Participant's Signature Date

 Researcher's Signature Date

APPENDIX C: MEMBER CHECKING LETTER

Member Checking Letter

Hello Valued Participant,

In April 2015, you participated in my dissertation research by agreeing to be interviewed about your experience regarding your child's developmental diagnosis completed by Northern Health CDBC team. I very much appreciate your participation! I am writing to ask if you can once again lend your valuable time by taking a few minutes to review the attached document. This review is referred to as "member checking" and is a valuable contribution to my research.

The document is a list of primary themes that had been developed from your interview. It is my attempt at capturing your overall experience. It was written after analyzing your transcript. I am conducting a check for accuracy. I am asking you to tell me if you can recognize your general experience in my description (in the attached document). The following questions may guide you:

Did I capture the essence of your experience?

Do the list of themes reflect your experience accurately? If not, where is it inaccurate?

Have I missed something in this description that you feel is essential to your experience?

After reading the attached document, you may follow up with me in two ways:

First,

Second, if circumstances permit, I would also like to schedule a brief meeting with you to discuss your reactions to reading this summary description. If a meeting is not possible, I am hoping that a phone consultation can be arranged.

Once again, I greatly appreciate your participation in this research. Without you, this research would not be possible! I look forward to meeting with you soon.

Best regards,

Tammy Pearson

Phenomenological research aims to establish a renewed contact with original experience.

APPENDIX D: ETHICS BOARD APPROVAL**UNIVERSITY OF NORTHERN BRITISH COLUMBIA****RESEARCH ETHICS BOARD**

MEMORANDUM

To: Tammy Stubley
CC: Shannon Wagner and Glen Schmidt

From: Michael Murphy, Chair
Research Ethics Board

Date: January 19, 2015

Re: **E2014.1210.097.00**
The Parental Experience of a Child's Development Diagnosis

Thank you for submitting revisions to the Research Ethics Board (REB) regarding the above-noted proposal. Your proposal has been approved, pending receipt of a letter of approval from the Northern Health Authority for this project. Once that letter has been received, we will be pleased to issue approval for the above named study for a period of 12 months.

If you have any questions on the above, or require further clarification, please feel free to contact Rheanna Robinson in the Office of Research (reb@unbc.ca or 250-960-6735).

Sincerely,



Dr. Michael Murphy
Chair, Research Ethics Board