TOWARDS CONVERSATIONS BETWEEN FAMILIES AND PROFESSIONALS: WHAT HELPS AND HINDERS FAMILY COPING WHEN CARING FOR A CHILD WITH SPECIAL NEEDS

by

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ABSTRACT

Each member of a family adds to the richness and variability of the family unit. Family members with a disability, specifically, add a unique mixture of joy, fear, hopefulness and despair (Barnbill, 2000). Previous research has shown that different variables account for the diverse experiences of families who have children with disabilities (Appendix A). Furthermore, research has shown that matching the service delivery options to the needs of the family is essential to obtaining positive outcomes from the support. In the present Critical Incident Technique research project, caregivers from 15 families were interviewed to explore what helps and hinder coping (Appendix A) in their journey with their child with special needs. The interview protocols were then analyzed and 17 key themes emerged, nine that were identified and endorsed as helping the families cope and eight that were identified and endorsed as hindering their coping ability. Diversity of family backgrounds was initially oriented around specific “types” of families that were identified by consultation with professionals in the field and were used as a frame for purposive family recruitment. As the research continued, however, the significance of these types faded into the background and the idea of family voice (Appendix A) emerged as a key orienting principle.

Furthermore, this research continued and strengthened the focus of a paradigm shift that is happening in research and service delivery for families with children with special needs. The shift from a focus on pathology to a focus on resilience (Appendix A) within families has been widely acknowledged. More recently, research and practise have taken further steps to recognise the ecology of families and, finally, to hear the voices within families to both identify and define their needs. In this project, a model for reflective practise (Appendix A) and translation among professional and family voices is presented. This model promotes collaborative care built upon recognition of family ecology and voice. Implications of the project for service delivery, case management and family counselling are also discussed.

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CHAPTER I: INTRODUCTION

Life in a family with a child with a disability involves a unique mixture of emotions, thoughts, and behaviours. From the moment that the family suspects that their family member is “different”, their family experience begins to depart from that of the normal family (Cowie, Quinn, Gunning, & Gunning, 1998). Furthermore, within the family, every individual member faces his or her own experience of the challenges and the benefits of living with a person who has a disability. Ideally, families that find themselves operating on a different journey than they had anticipated are able to find help from professionals who understand not only the environment of a family with a family member with a disability but who are also experts who can help the family cope with their own unique and individual issues.

Traditionally, research has looked at the family with a member who has a disability within the context of a pathological model. This indicates that the person with disabilities actually causes the stress and poor family functioning (Appendix A) within the family unit, and furthermore, dictates how the family copes (Byrne & Cunningham, 1985). This outlook is also the one that is taken by many professionals (Urey & Viar, 1990) and has traditionally dictated the kind of support the families receive from the service providers.

More current research indicates that there are many other factors at play within the family that determine the stress level, than just the presence of a person with a disability. Different studies have shown that the coping strategies that the family employs (Bailey & Smith, 2000; McCubbin & McCubbin, 1993; McCubbin, Thompson, & McCubbin, 1996), the background of the family (Boyce & Behl, 1991; Cunningham, 1996; Gottlieb, 1997, Young & Roopnarine, 1994), the functioning style (Falik, 1995; Lazarus & Folkman, 1984; Trivette & Dunst, 1990), the suitability of their support system (Abelson, 1999; Chappell, Reid, & Dow, 2001; Floyd & Gallagher, 1997; Kohler, 1999; Levine & Zuckerman, 2000; Sarbaugh-Thompson, Lobb, & Thompson, 1999; Westling, 1997), as well as the needs of the individual with the disability all play a role in the overall experience of the family. Much of the current research highlights only one of these facets as the primary one that accounts for the different stress levels or experiences between different families of children with disabilities. This could, however, be too simplified as Boyce and Behl (1991) assert that the higher stress that some families experience is a result of a combination of all of the above variables. The move to consider multiple variables was also accompanied by a parallel shift in the research and practise from determining support only by looking at the weaknesses of the families to also identifying their strengths.

The idea that support should be focussed around the strengths in the family, although a positive shift, is still too simple to really address the true needs of a family with a child with special needs. The issue is that the strengths and needs in the family are still defined by the professionals. In the more recent literature as well in practise a movement has taken shape around a focus on the ecological model (Appendix A). In this model it is important that there is a fit between the environment and the person. The ecological model represents a connection or bridge from the professional perspective to the family perspective and, finally, to family voice (Appendix A).

In the present research the idea that the family experience is a result of a combination of various factors is taken to the next step. Minuchin (1974) challenges the idea that increased family stress is identified solely with having a child with a disability and offers the idea that the impact of stress associated with the presence of a child with a disability in the family must be investigated in relation to the families’ coping resources and the environmental contexts if the stress is to be fully understood. Therefore, it can be asserted further that families will show strengths in different areas and need assistance in other areas. It is important for professionals to understand the context of the family to help guide choices of appropriate services (e.g., Dyson, 1996). The present research examines different family contexts as they shape the journey of living with children with special needs. Cunningham’s (2002) strategies for obtaining background information served as springboard for recruiting families and professionals who serve families with these needs. This project identified families with different experiences and background to provide a broad perspective and diverse situations that are faced by families.

The Research Problem

Clearly, the subtleties of any particular family are unique. This research took a step towards clarifying the perceived needs of different families to help to understand their journey through life with a child with a disability. Families vary in background, coping styles, family functioning, needs and suitability of their support systems. This research emphasizes many different features of family life that can play a role in the experience of living family members with disabilities. Moreover, families engage their situations with different stances and employ diverse voices in pursuit of their own well being.

Consultation with professionals active in the field as well as responses to Cunningham (2002) survey (Appendix B) provided perspectives on families, and their situations, and made up the process of recruitment of families to participate in this project.

Within the scope of this research, special attention was paid to fostering family voice in relation to researcher and professional voices. The intentional use of families' own words and reserving first person phrasing for family comments highlighted family voice. Rapport building and establishing a safe environment for conversation during the process of data collection was possible partly due to the researcher's extensive experience in the field (Appendix C). Interpretation by this researcher was based on experience both in the field and in consultation with other professionals. In the process of exploration and reporting, this researcher chose language that fit the context of what was being reported, using professional discourse for the review of the literature and lay person language (Appendix A) to report the voice of the families as it was heard by this researcher. Furthermore, the terminology that was used both in relaying the family voice as well as this researcher's voice was chosen purposefully to maintain respect for the participants (e.g., "special needs" and "disability", and "experience", "journey" and "expertise" were used interchangeably as they were respectful and understandable to participants). This intentional choice of language and terms also spoke to the sensitive nature of the idea of labelling to many of the participant families.

This research identified what helps and hinders coping within the framework of individual families. The results will help professionals to identify unique service delivery plans, and expedite, personalize and simplify service delivery. With a focus on a number of critical incidents within the life of the child with special needs, this research identified the differences in the strengths and challenges of different families in context of their individual life situations.

CHAPTER II: LITERATURE REVIEW

In the current research, typologies of families were created based on different variables that were identified as important both in the literature and in consultation with professionals in the field. As the research proceeded, these family types faded into the background but remained important in the organization of recruitment of families. Based on these predetermined typologies, the researcher was able to recruit families from differing backgrounds with respect to the variables that make up the typologies. As much of the research has focused on the different factors that are identified in these typologies (e.g., family functioning, coping style, availability of resources, and needs of the family), these factors will be explored here as they are identified by researchers in the field. This chapter will go further however, to identify the shift that has happened in the field both in the research and in practise to a focus on the ecology of the family and the idea of listening to family voice to appreciate their experience.

Theoretical Framework

Many researchers have attempted to profile the experience of the family who has a child with a disability. Originally, the research all pointed to the idea that good portions of the identifying features (especially the stress level) of the family were directly attributable to the member who had the disability (Byrne & Cunningham, 1988). In more recent times, most researchers have abandoned this simplistic portrayal in favour of looking to variables that are inherent to the family as a whole. Their research covers many different areas that could define the experience of the family including the needs of the individual with a disability (including type of disability), the family functioning style, the coping strategies, the appropriateness of social supports, the resources and background of the family, and many more. While most of the research has focused on only one of the variables as the most important defining variable, some researchers have proposed the idea that all of these variables play a role in defining the journey of the family. Dyson (1996) and Boyce and Behl (1991) presented the idea that different variables are at play in the overall experience or journey of the family with a child with a disability. The present research not only identifies the themes that define the experience of the family but also discovers if there is a common experience of certain families and if this common experience is related to the relative influence of different variables in their life.

Moreover, as the research progressed it became apparent that the original typologies that were used to organise the families were not as important as listening to the individual voices of the family members. Based on this development, the current research takes a step further into looking at the needs of the family from their own voice as opposed to identifying issues from only the professional voice. This furthers the work of Mazur (2006) who looked at the impact of disability on the family from the perspective of the family.

Needs of the entire family. Traditionally research has asserted that families with a member who has a disability report more stress than families that do not have a member with a disability (Baxter, Cummins & Yiolotis, 2000; Fisman, Wolf, Ellison, & Freeman, 2000; Innocenti & Kwisun, 1992; Knussen & Sloper, 1992). Beyond seeing that the stress of the families is higher, the current research is also looking at why. One of the traditional and still most researched variables used to define the experience of the family is based on the needs of the individual who has a disability. These needs have been identified by

VanRiper (2000) as more childcare, increased time demands, and increased educational demands, to name but a few. Overall, the needs of the child with disabilities seem to take precedence over others. The goal is, therefore, to balance meeting the needs of the child with a disability, the needs of the family and the needs of the family members (VanRiper, 2000).

Dyson (1991, 1996) identifies that although the parents in the group with a family member with a disability did experience more stress than the group who had no disability in their family, the member with a disability did not cause the family dysfunction. Furthermore, in the families who had a child with disabilities, the families were found to be more positive and cohesive, strive for more personal growth and to be more active in cultural and recreational activities than the “normal” families. Innocenti and Kwisun (1992) show that although the stress of the family has traditionally been attributed to the presence of the individual with a disability, in the families that they studied unmet needs were a constant source of stress for the families. Boyce and Behl (1991) went further to explain the family experience in terms of parent related stress and child related stress. Each form of stress had its own exacerbating variables that centred on unmet needs in the family unit.

The present research includes dialogue around the degree of unmet needs of the family with a member with a disability as one of the variables that defines the experience of the family. This view is, however, limited in its scope and this research goes on to identify the other main defining variables as it is the interplay of all of the following variables that define the family.

Professional and Family Perspectives

One of the major shifts that is occurring in some of the literature and practise is to an awareness of the difference between the professional perspective of the needs of the family and the family's perspective. Traditionally, all of the terms that were used when describing the experience of families with special needs were defined by professionals, including coping, resilience, and family functioning. Research is starting to recognize, however, that we need more culturally sensitive views of disability that take into consideration family voice with respect to coping, support, and the competing needs of family members (Banks, 2003). In becoming aware of and embracing this shift, professionals and families are better able to understand one another and when speaking the same language can more efficiently identify the true needs of the family.

The current research project takes this idea one step further by proposing a framework for translation from professional voice to family voice and vice verse. This framework was identified and highlighted through the process of the research. The researcher was able to build rapport with the families and provide space (see Appendix A) for their voice. Furthermore, because of the researcher's professional experience she was able to provide a bridge from the family voice to professional speak (Appendix A). From this, a framework was developed to support the process of families and professionals communicating and hearing each other.

Coping strategies. While it has been shown that the unmet needs and background are important in determining the experience of a family with a child with a disability, it is also important to look to more internal variables. In early work by Folkman and Lazarus (1980), the researchers proposed that coping is influenced by both the person's appraisal of the actual demands of the situation and by the resources he or she has available. VanRiper (2000) examined the relationships among family demands, family resources, family problem solving, communication, family coping, and sibling wellbeing. He noted that if families are strong in these areas they have lower stress. In McCubbin and McCubbin's (1993) research on the Resiliency Model they attempt to explain why some families adapt and become stronger in the face of stressful circumstances and others remain vulnerable and some deteriorate. The central concept of their research was defined as the outcome of the family efforts to bring a new level of balance, harmony, coherence, and functioning to a stressful or crisis family situation. They go further to assert that those families who use numerous coping and problem solving strategies adapt and are more successful while those who use fewer strategies, especially passive strategies, adapt less. Furthermore, in Grant and Whittell's (2000) research, the researchers look further at how coping is different in the family depending on gender, family composition and life span.

In the current research the coping behaviours of families are investigated with a view towards identifying, from the families' point of view, what the different needs are for families who are coping well and not so well. The resources of the families are described in an attempt to provide a clear view of this area of each of the families' experience.

Family functioning. Another area that families seem to vary with regards to their experience of living with a child with a disability is in their family functioning style. In Trivette and Dunst's (1990) work on family functioning styles, they highlight twelve areas of strength for a healthy family. This is born out of a short history of other researchers who attempted to turn the focus from the pathological view to the viewpoint of what makes up a healthy family.

Hornby and Seligman’s (1991) research also shows how important it is to note that the family unit functions as interdependent and that a disability in one member will affect all members. In this way, no one is exempt from the effects of the disability in the family. From this standpoint, the research bears out the importance of the family functioning variable on the experience of the family with a member with a disability.

In as much as all families have strengths and weaknesses, one should never expect that any given family would display all of the 12 characteristics that Deal, Trivette, and Dunst (1988) offer as qualities of strong family functioning style. The combinations and clusters illuminate the differences in experiences that are represented by different family functioning styles.

The following 12 characteristics define what Deal, Trivette, and Dunst (1988) call the family functioning style:

1. A belief in and sense of commitment toward promoting the well-being and growth of individual family members as well as that of the family unit.
2. Appreciation for the small and large things that individual family members do well, and encouragement to do better.
3. Concentrated effort to spend time and do things together, no matter how formal or informal the activity or event.
4. A sense of purpose that permeated the reasons and basis for “going on” in both bad and good times.

5. A sense of congruence among family members regarding the value and importance of assigning time and energy to what the family considers its goals, needs, projects and functions.
6. The ability to communicate with one another in a way that emphasizes positive interactions among family members.
7. A clear set of family rules, values, and beliefs that establish expectations about acceptable and desired behaviour.
8. A varied repertoire of coping strategies that encourages positive functioning in dealing with both normative and non-normative life events.
9. The ability to engage in problem-solving activities designed to evaluate options for meeting needs and procuring resources.
10. The ability to be positive and see the positive in almost all aspects of their lives, including the ability to see crises and problems as an opportunity to learn and grow.
11. Flexibility and adaptability in the roles necessary to procure resources to meet needs.
12. A balance between the use of internal and external family resources for coping and adapting to life events and planning for the future.

These 12 qualities of a healthy family are assessed in the Family Functioning Style Scale (Deal et al., 1988). The Family Context Survey (Cunningham, 2002) includes all 26 items of the Family Functioning Style Scale as it gives a good indication of the context of the family with regards to how the family members work and relate together. The intent of this scale is to highlight the strengths and weaknesses of a family with a child with a disability. From the Family Context Survey, this researcher should be able to isolate with regards to the family functioning variable a difference between families who function “well” and “not so well”.

The present research will take family functioning as yet another variable used to define the experience of the family with a disability. As one of the interdependent variables, it will be used as a piece in the picture of the family experience.

Resources. Another one of the stumbling blocks that is faced by families who have a child with a disability is the inappropriateness or overall lack of services to support them. Olsen (1999) speaks to the idea of family hardiness. He defines family hardiness as a constellation of factors of personal control, challenges and commitment. From this he also highlights perceived family support as a predictor of family hardiness. It is this hardiness that could be yet another factor that accounts for the difference between whether a family copes well or struggles

Unfortunately, service delivery has traditionally been a problem for families with special needs. Kohler (1999) highlights three notable problems with existing service delivery systems for young children with disabilities:

1. Parents lack information about how to identify and access the services that they need.
2. Parents and professionals often fail to collaborate in planning, implementing, and evaluating services.
3. Services received from different providers are often disorganized or lack continuity.

Levine and Zuckerman (2000) also highlight the problem between the professionals in the service delivery field and the families in that they tend to have problems in communication, establishing a working relationship and partnership. This follows what Westling's (1997) research found that parents with children with disabilities identified that what they really need is information and more parental involvement in the services for their children.

The bulk of the research shows that in order for service delivery to be effective and helpful to the parents and the children with disabilities, it needs to be geared to their specific needs. It is this reality that the present research aims to discover. With the use of the Family Context Scale and nomination from professionals in the field, this researcher fit families into different types as described from professional consultation and literature review. Once in groups, a qualitative (Appendix A) assessment was carried out to identify the experience of the families in each type. From this point, themes were identified to describe the strengths and limitations of each individual family specifically around the diagnosis and one other event in the child's life. Once the themes of each group are discovered this can then be used to fit the family with a service delivery plan that will work for them.

The current research not only identifies the needs of some families but also took a step towards bridging the communication gap between families and the professionals that support them. By matching the needs of the family, in their own words, with appropriate supports, the system can work more efficiently in supporting families.

Family Ecology and Family Voice

The background of the family has also been shown to have a large impact on the experience of the family with a child with disabilities. Roth (2001) and Gottlieb (1997) identified the magnified stress the family experiences in a single-parent household. This increased stress is accounted for by the idea that the single parent must provide for the needs of the family plus meeting the extra challenge of caring for a child with a disability. This stress is also more prevalent in the non-employed, non-partnered women who experience elevated levels of depression and parenting stress, and decreased psychological well-being. This stress also increases if the child displays more than average behavioural problems. The research goes further to reveal that a single mother with multiple roles can also experience increased maternal well-being (Marks, 1977) and that the quality of her roles is as important as the quantity. These contrasting ideas illuminate the need for a measurement tool to identify the relative strengths of each family unit.

In looking at the background of the family as it relates to the experience of the family, Young and Roopnarine (1994) studied the father’s childcare involvement as it was related to the overall functioning of the family. They found that there was no significant difference in paternal involvement, marital stress, or functioning styles within families of fathers of children with and without disabilities. Furthermore, they found that there was no significant difference in paternal involvement based on the severity of the disability. The difference that the researchers did find was in the family well-being, empathic skills, internal locus of control and cognitive competence in families that had increased father involvement (Lamb, 1987).

Boyce and Behl (1991) examined other sources of stress that are linked to the background of the family. They identified the mother's age as well as the socio-economic status of the family as being important variables in defining the experience of the family with a child with special needs. Wintre, Sugar, Yaffe, and Costin (2000) have shown that immigration demographics, or length of time the family has been in Canada, and cultural origins of the family play an important role in the context of the family.

With regards to the background of the family, the present research investigates this variable in the context of all of the variables that define the family. Furthermore, contrary to much of the current research that focuses only on the mother's view of the family, this research examined the family experience from different member's point of view.

The idea of listening to the families' point of view, or voice, has received some attention in the literature but has not found its way into common practice. As Ditrano (2006) found, the parents who had the space to share their stories of trying to navigate the special education system, developed critical consciousness about their experiences of stress, powerlessness, and alienation. Furthermore, they became mobilized and obtained information that helped them to advocate for appropriate support. By giving families space to have their voices heard, the current research takes the first step to creating a bridge between the needs of the family and the professionals that support them.

Summary

The purpose of this study was to better understand the unique context of families to develop an understanding of the different experiences of families with a child with special needs. The literature traditionally looks at one or two aspects of the experience of the family as defined by professionals and, in order to capture the richness of a family who is living with a child with a disability, this research looked at experience from the family's point of view. The present research also differed from much of the existing literature in the idea that this research looks at the family in a qualitative way rather than in a quantitative way to obtain a true feeling for the richness and experience of the family. In looking at the research in a qualitative way, this researcher was able to identify the aspects of the family experience that help and hinder life of the family with a child with special needs. To add to the richness of the data and to start to bridge the gap between professional speak and family voice, as part of the experience, the family members were asked to identify how they perceive themselves in relation to the types of families as identified by professionals in the field. The differences in the experiences helped in the concretization of the different contexts of families and furthermore lead to a better understanding of the specific needs of a family with a child with special needs.

A brief review of the literature on the family experience of living with a child with a disability demonstrates the richness of the experience of this population and exhibits the need for a more comprehensive exploration of the needs of this diverse group. Within the scope of this research, the researcher creates a space to "hear" the nuances in family voices by exploring the stories of what these families perceived as useful and not so useful within the realm of their coping with their everyday experience. Within this exploration, the ideas of professional consultation with a focus on a translation process between family voice and professional speak, bridging the gap between families and professionals and access to system supports, and implementation of services that are unique to the families' needs and strengths are examined and furthered.

In no way is this examination meant to be seen as exhaustive but only a start of the journey into the experience of these families. By hearing and reporting the voice of the family, this research aims to highlight the need for an individualized approach to working with this population that focuses on their strengths as well as their needs. To this end, this research looks within the unique context of the family to identify what helps and hinders coping with the challenges of raising a child with disabilities. By utilizing the evidence from these families' experience implications for practice, research and community resources will be discovered.

CHAPTER III: METHOD

Critical Incident Methodology

This research had the objective of mapping, in a broad prospective, what helps and what hinders different types of families coping with day-to-day issues of living with a child with special needs and, in doing so, focused on specific events or factors that were conducive or limiting to life within their family. In order to discover the richness of the family experience, this researcher met these objectives by talking to families that live with the joys and challenges of a child with special needs on a daily basis. Critical Incident Technique (e.g., Flanagan, 1954; Woolsey, 1986) is a method in which these objectives can be achieved. A description of this technique is presented in this chapter, followed by definitions of the terms, a description of the participants, the interview process, and procedures for analysis of the information that was gathered.

Critical Incident Technique asks participants to provide descriptive accounts of events that facilitated or hindered a particular process. Participants who are selected for the study have been or are in a position to experience the particular process and are able to comment on the factors that helped or hindered the experience. This technique can draw on interviews of the participants, from which critical incidents are extracted, and then grouped by similarity to form a set of categories that surround the events. This category system provides a guide of what facilitates or what hinders a given process. Formulation of these categories is primarily done inductively and subjectively, by means of determining which incidents seem to group together (Flanagan, 1954). The categorical map that emerges from the current study is intended to have direct application in the counselling setting, particularly to guide professionals in their work with families around service delivery. The number of incidents determines the size of the sample for the Critical incident technique. The researcher collects data until redundancy of categories occurs (Woolsey, 1986). Critical incident technique is very compatible with the values, skills, and experience of people in the counselling profession (Woolsey, 1986). Connection with the participants was essential and was facilitated by reflective listening, empathy, clarification, and summarization.

Conceptual developments and voice. As the current research progressed, the main framework by which the participants were organized, the typologies, gradually became less important to the outcome. These typologies and the development of them were important to the initial organization as the family context survey and nominations from professionals identified the participants by which type they fit into. It soon became evident, however, that the typologies did not tell the whole story and therefore did not lead to the most efficient way to look at families and their needs. During this research it became obvious that in order to truly understand the needs of families with special needs, another framework needed to be discovered and highlighted.

One of the issues that became apparent is that, as professionals developed the typologies, the categories did not speak to the nature of the families' experiences as described by the families themselves. This idea begins the conceptual development that led to the focus of the current research. With respect to organizing families and identifying needs, this research moved from a focus on typologies that were professionally identified and strength based, to a focus that embraces the idea of ecological approach and relies on family voice. The professional categories used to recruit families became less important than focusing on the fit of families' needs with available resources for support. This shift mirrors the current shift in the literature and practice.

Terminology. In this research what helped and hindered coping in families as they live with children with special needs was identified based on key events in the lives of children with special needs that mark milestones along the way (e.g., diagnosis and other turning point events; Appendix A). Each family story describes a specific combination of background factors, ecological contexts, and family dynamics. Other important key terms became essential as the study progressed:

1. Disability: A measure of the severity and scope of difficulties the child with special needs has in his or her life as a result of his or her disabilities.
2. Family Voice: The truest representation of the needs, and experience of the family that is heard only when the family is given a safe and respectful space to talk about their journey. This is often but not always facilitated by someone who is with them in that space to hear and carry their words forward.
3. Family Experience: This term is used interchangeably with family journey, expertise and other terms that relate to the thoughts, feelings, activities, etc. in the life of the family as it is described by the individual and collective family members.

4. Translation: This term is used to describe the process by which family voice as it is related to the families needs, hopes and dreams is connected to and understood by professionals and vice versa. This process is facilitated by an understanding of the ecological model and often functions best with the presence of another party who speaks both professional speak and family or layperson speak and can help facilitate the conversation.
5. Ecological Model: This term is defined as the fit of the individual (or family) to their environment and vice verse.
6. System: This term is defined as the network of professional service providers.

Participants

Seventy-five parents from districts throughout greater Vancouver were recruited for participation in Cunningham's (2002) research and constituted a pool of families for the present study. Families in Cunningham's study (i.e., sample 1) were recruited from agencies that serve people with disabilities (from client lists) and included only the parents who have a child with a disability currently living at home, whose child has a diagnosed disability (mild to severe, mental or physical) and whose child is between the ages of 4 and 20 years old. Demographic information was accessed with background questions provided at the start of the Family Context Survey (Cunningham, 2002). Parents who filled out the survey were initially contacted by phone and invited to participate. They were also asked if they would be amenable to a follow-up interview by this researcher after the survey was completed and analyzed. The survey was mailed to all families who agreed to participate and who met the inclusion criteria, along with instructions and a return envelope.

A preliminary typology of families of children with special needs was developed in consultation with key informants. Families were recruited to reflect a wide range of experience and background to maximize the range of experience reflected in this study. Sample one participants (*n* = 7 participant families) were recruited from the pool of participants in Cunningham's (2002) research (Appendix B). Sample two (*n* = 8 participant families) were recruited from a number of communities in the Fraser Valley Region (i.e., east of Vancouver) in British Columbia, Canada. The multi-community sample was recruited with the help of a descriptive poster (Appendix E) that was given to key informants. The differences between the two groups were studied and no confounding issues were identified. Sufficient numbers of family participants were interviewed until general themes were saturating.

While recruiting families, preference was given to families where more than one family caregiver was willing to participate in the interview. The families were contacted by phone to arrange a time to meet at their convenience at a place to be agreed upon.

In the end, 15 families with a total of 20 participants (i.e., some of the families had more than one participant) were selected and agreed to be interviewed. These families were nominated and fell into seven of the eight family types (Appendix D). Although an intensive search was made and many professionals consulted, this researcher could not find a family who could be described as having low levels of need, relatively low family functioning, and high satisfaction with services (see Appendixes A and F). It is not surprising that few families would be readily described as being both low on the needs criterion, high on the satisfaction criterion and still be identifying as low functioning within their family.

Procedure

After the typology development procedure (Appendix F), families whose profiles closely matched specific type descriptions and who were willing to be contacted were identified from the initial sample. Families were excluded from the study whose child with special needs was not a biological child of at least one parent. Furthermore, additional families were recruited based on nominations from key informants. These families were contacted by phone and, based on the initial script (Appendix G), were invited to take part in an interview at a time and place that was convenient to them.

The parents were asked at the time of the interview to fill out a demographic questionnaire (Appendix B). Parents were also asked about their occupations, level of education, family income, marital status, and length of time in Canada (Wintre et al., 2000). Prior to the interview process during the process of gaining informed consent, confidentiality and data maintenance were explained to the participants. The participants were then given time to read and sign the informed consent form (Appendix H). To protect the anonymity of the participants, names are not included in the transcripts and the speakers are coded so that only the research team has access to the participants' identities.

From this point the interview took place in two parts, an orientation and a semi-structured interview. The purpose of the orientation was to begin to establish rapport and to explain the nature of the study. During the orientation phase of each interview the participants were given a copy of the interview questions (Appendix I) and the researcher read the following statement to orient the family:

> Thank you for agreeing to speak with me today about your family. I am interested to hear about the experiences that you have had living with your child with special needs. I would like to hear about what helped and hindered you in coping with different transition events in the life of your child. I would like to hear from all of you and I understand that everyone may experience the same events in different ways. That is o.k. and I would like you to feel safe in talking about your own experiences. I am hoping to use the information that I gain from interviewing families like you to help give a voice to families with children with special needs in talking with professionals about your needs.

Critical incident interview. The interview was a critical incident, semi-structured interview with questions asking about what helps and hinders coping in caring for the family's special needs child. The family were offered a copy of the interview questions to provide a preview of what we would talk about (Appendix I). The questions focused on the strengths and challenges arising in each situation (i.e., in each situation what helped them and what hindered them in coping as a family). In each case, any family member who wanted the opportunity to be involved was invited to participate. Most of the participants were mothers but in some cases other family members (i.e., fathers, step-fathers and grandmothers) were also involved. During and after each of the interviews the researcher kept a journal of observations and thoughts to provide a richer and more in context view of the participant families.

This researcher moderated the discussion. At the beginning of each interview the moderator provided the family with a copy of the questions, explained the purpose of the study, and explained informed consent. The interview began with introductory questions and then followed up with a series of open-ended questions relating to their experience as a family with a child with a disability. The questions covered different aspects of the experience of the family with a child with a disability. These questions served only as a guide and were not meant to be rigid in their use. The moderator facilitated the discussion by encouraging the subjects to speak and by redirecting in the case that they get stuck or off topic. At the end, the participants were asked if they had any advice for families who were new to the world of caring for their child with special needs (Appendix J). The interview was audio taped and then transcribed.

Care was taken to establish rapport with the participants in order to elicit accurate descriptions of events in the voice of family members. The researcher’s background and professional experience, as well as familiarity with the system and experience with hundreds of families in the field of special needs, lent credibility for families and aided in the rapport building and ability of the families to feel safe to share their lived experience (Appendix C). An indication of the success of establishing rapport is in the nature of the material gathered (Herzberg, Mausner, & Snyderman, 1959). While it can never be known what the participants did not share, the insightful, intimate nature of the information and the emotional response of the participants to what was shared in the interview was enough to provide this researcher with strong conviction that rapport was indeed established.

Throughout this process the researcher was mindful that the family types were based upon professional consultation and literature. The match between these descriptions and family descriptions is part of the present study. The identification of differences in what helps and hinders coping between the different types is part of the analysis.

The interview was intended to focus on the critical incident, defined as the diagnosis as well as a uniquely defined event in the lives of each family. Furthermore, the families were asked to complete a questionnaire based on descriptions of the types of families (Appendix K). Finally, after the interview, they were asked to fill out the Family Context Survey (Cunningham, 2002).

Analysis Strategy

The interviews were taped and transcribed by the researcher. The transcribed interview was analyzed based on a critical incident method. This method was chosen based on the idea that the qualitative and, especially, the critical incident method gives the researcher a richer view of the family experience than the traditional quantitative research does (Woolsey, 1986). According to the critical incident theory the interviews were analyzed based on meaning units (i.e., units related to what helps and hinders coping in the families) to obtain a profile of what helps and hinders the coping in the participant families. After the researcher read over the interviews a number of times to get a feel for the content of the discussions, she identified meaning units within the conversation. Once the meaning units were identified, the material was organized according to categories or themes that were recognized by the researcher.

In analysing the data this researcher began to identify themes. Flanagan (1954) notes that this is done through a process of classification based on three ideas:

1. Choosing a frame of reference that most meaningfully describes the subject of the study. The transcripts will be read over to identify the critical incidents (i.e. the

incident identified as diagnosis and one other critical incident in the child's life) and the positive and negative outcomes related to the incidents.

2. An inductive approach to the development of categories, which entails ongoing modification and revision.
3. Finding an appropriate balance between specificity and generality in choosing categories.

The organization and identification of themes was based on the comparison of the data within the given interviews, as well as between different interviews.

In order to minimize research bias and address reliability within this process, this researcher involved other informed professionals (i.e., counsellors, community support workers, directors in organizations that work with children with special needs, etc.) in the organization of the data. Once the themes had been established, two other professionals were asked to sort 10% of the incidents according to the set of primary categories as described. Discrepancies in sorting were discussed, and the category and theme descriptions were modified as appropriate.

Extraction of incidents. All 15 interviews were transcribed and each meaning unit was highlighted. After reading through the transcripts a number of times the unique incidents were also highlighted and assigned a numeric code (i.e. Incident 1, participant 1 was identified as 1-1). An incident was identified as any discrete event, feeling, or situation that either helped or hindered the process of caring for a child with special needs. Once the identification was complete the incidents were identified based on the most salient feature of the incident, and these identifiers were then categorized according to the events themselves as well as the source and context information to further distinguish the different categories. A total of 1052 incidents emerged and were recorded under the categories.

Category formation. The process began by identifying the unique incidents in all of the interviews and identifying them based on the meaning unit that was most salient. These descriptions were then sorted into a number of categories with brief descriptions. Categories were then subjected to the research supervisor's review as well as review by a number of both participant and non participant families and, as a result, were revised and refined. Any incident that did not fit naturally into one of the categories was challenged and refined until all of the incidents were collapsed into 61 categories.

After these categories were refined, they were grouped based on whether they helped or hindered the families coping and then similar categories were put together based on similar events, situations or behaviours. In the end, 15 themes, 8 themes that helped and 7 themes that hindered emerged from the data. The themes were written in a way to capture the voice of the family participants. The descriptions were written in three parts, the title, the theme statement, and the description. The theme statement was written in the first person to emphasize the voice of the family participants within each theme. The description of the theme was then written in the third person to identify each description as a summary of the families voices put together by the researcher. The verb tense and vocabulary that this researcher used also changes consistently within the themes. This was done to utilize the continuous present (i.e., a suspension of time between the participants) to highlight the different aspects within the descriptions.

Agreement, Applicability, and Relevance Procedures

The establishment of categories requires professional judgement. In light of this, a number of steps were taken in this research to ensure agreement, applicability and relevance of the data, analysis, and results (Butterfield, Borgen, Amundson & Maglio, 2005).

Coding agreement refers to consistency of judgement by informing raters. In the current study relevance related to the consistency that occurred when an independent judge categorized the same incidents into the same categories as the researcher. In the case of this study, two counsellors, one in the field of special needs and the other in another related field were asked to be independent judges. They were provided with the category descriptions and 10% of the highlighted incidents and were asked to code the incidents based on the categories. The purpose of this procedure was to determine how many agreements and disagreements the judges had, both between themselves and with the researcher. An accuracy of 75% was deemed acceptable (McCormick, 1994). The agreement in this study was 85% and upon discussion with the judges around the mismatched incidents it was revealed that the discrepancy was due to the fact that instead of focussing on the entire incident in the context of the interview, as the researcher was privy to, the judges were distracted by one trigger word or section that lead to the misplacement.

After identifying the accuracy and consistency of the categories, the researcher then focussed on applicability, or whether or not the themes accurately capture the essence of the incidents relayed by the participants. To study this, the researcher asked several families, both participant and non participant and two professionals to rate the themes based on three considerations. These considerations were: did the theme fit their experience (or the experience of the families that they worked with for the professionals), what was missing, and would they add any thing to the themes, or create a new theme to make the themes more reflective of their experience?

Another applicability check was based on whether the themes were reflective of what was found in previous literature. As noted in the discussion chapter most of the themes were supported by research.

Another applicability check was based on the number of participants reporting incidents that fit into a particular category. The higher the number of “hits” per category, the higher the probability is that any particular category is indicative of the experience of the participants as a whole. In this study, the participation rates varied from 60% to 100%. The categories that had lower rates were included, as they were needed to accurately reflect the experience of certain participants.

At the end, the participants were asked to reflect upon advice that they would offer to families who were going through the experience of raising a child with special needs. Although not a formal applicability check, this data was interesting in that it was not only consistent throughout most of the interviews, but it also related to the categories as the advice fell naturally into the different categories and themes based on the criterion of what helps and hinder coping.

Another informal applicability check related to the experience of the researcher when the idea that creating space for and listening to family voice was applied to practise. In one instance, after a presentation based on both research and the experience and conversations that this researcher has had with clients in the field, this researcher was approached by a client who shared with the researcher that she felt that the researcher really knew how she felt and that she felt understood. In another circumstance, also in the field, this researcher focussed an intake interview on the ideas that came out of this research, including the power of family voice. The client remarked to the researcher that they felt very comfortable that they had been heard and understood. Although not formal applicability checks, these experiences in the practise of working with families and clients highlight the power of family voice and the ecological model when working with families.

One further informal applicability check relates to the experience of the researcher and her ability to establish rapport with the participants. As the researcher has extensive experience both as a professional in the field and as a caregiver, she was able to bring that experience into building the relationship with the participants. This relationship was established quickly within the realm of the interview and because of the quality of the relationship, many of the participants stated that they felt at ease and often relieved to be able to tell their story to the researcher. The quality of the relationship and the connection between the researcher and the participants leads to more confidence in the applicability of the information that the parents are sharing.

Further to the interview, the participants were also given a website address that lead them to a survey that mirrored the questions in the interview and allowed the participants to either add to their own answers or invite other family members to have a voice and add their thoughts to the research. In the process of this research, few participants accepted the offer so little data was collected by way of this survey (Appendix L).

Typology Formation

The typologies that organized the current research were developed based on professional literature, research, professional consultation and the experience of the researcher (Appendix D). Although, as this research progressed the typologies did fade into the background, they were integral for organizing participants for the research as well as providing a starting point. The typologies as defined here are identified as coming from a professional perspective and are a beginning for the shift through the ecological model to a focus on family voice.

CHAPTER IV: RESULTS

The results are presented in the present chapter by describing the background of parents who participated in the study, then by summarizing facilitating themes followed by hindering themes. It is important to keep in mind that while the families who participated in this study were recruited based on the predetermined types, these types became less important to the research as a lens with which to see the journey of the families. They were, however, essential in the organization for the recruitment of families from varying backgrounds.

The themes became organized around a new focus for understanding families and family voice and based on this new focus, the themes are described not only from the professional perspective but also from that of the family. These perspectives are identified within the theme by using first person for the family’s voice and third person for the professional voice.

In the next chapter, the themes themselves are also organized to highlight the family experience. Helping themes are presented with their hindering counterpart if appropriate to further strengthen the idea that not only does the presence of a particular theme in the life of the family support them but also the lack of that theme puts significant stress on their experience. Furthermore, in the next chapter, the overall thematic structure is integrated and interpreted.

Participants

The families that participated in this research each brought with them unique stories of their experience living with and caring for a child with disabilities. The following descriptions provide a brief “snapshot” of each of the families using their participant numbers as identifiers. The typologies (Appendix D) that were used in the recruitment process are also identified here in the descriptions of the families in order to highlight the variability in the families in the study.

Participant Family 1. This family lives in the Fraser Valley and consists of a mother and another family member who recently purchased a house together to help move the family to a nicer place to live. There are two children in this family, a daughter who is 11 years old, and a son who is 10 years old. The son has been diagnosed with Autism. Mom and the other family member both work. The children's father lives in another province and is not in the children's lives consistently. They describe themselves as a family who communicates well and name their faith as one of their strongest coping strategies. This family has been identified as low needs (i.e., pertaining to the child with disabilities), high functioning family, and low satisfaction with services (i.e., LHL).

Participant 2. This family lives in the Fraser Valley and consists of a mom and a dad, and two children, a 14 year old daughter, and an 11 year old son. Their son has been diagnosed with Asperger's syndrome. Mom and dad both work (mom works part time in the field of special needs). They describe themselves as a very close family including their extended family and name communication as one of their strengths. This family has been identified as low needs, high functioning, and high satisfaction with services (LHH).

Participant 3. This family lives south of Vancouver and consists of a mom and a dad, and three children: a 3 month old daughter, a 4 ½ year old son and a 13 year old stepdaughter (daughter of husband) who lives with them part time. Their son has been diagnosed with Townes Brock Syndrome (i.e. an autosomal dominant condition that's characteristics include lack of an opening for the anus, abnormal bones of the hands or feet, kidney problems (usually small, poorly formed kidneys), "lop" shaped ears, and mild sensorineural hearing loss and a developmental delay). Dad works outside of the home and mom works as a graphic designer from the home. Mom is also very involved in support groups and advocacy groups for families with children with special needs. Mom describes their family as close but that she takes on the bulk of the care-giving role with little support. This family has been identified as HHL.

Participant 4. This family lives south of Vancouver and consists of a mom and a dad and three children, an 8 year old daughter, a 4 year old son, and a 2 ½ year old daughter. They also have a stepdaughter (the husband's daughter) who lives in another country and two home stay students who live with them. Their son has not been given a specific diagnosis but has been given the label of global developmental delay, midline defect, partial cleft and pituitary, kidney, and thyroid issues. Dad works in the field of special needs and mom works part time in the same field. Mom is also very involved in advocacy and support groups for families with children with special needs. The family immigrated to Canada 3 years ago. Mom describes the family as close with few supports outside of the immediate family. She names education and awareness as their strongest coping strategies. This family has been identified as LHL

Participant 5. This family lives south of Vancouver and consists of a mom, a dad and two children, a 7 year old son and a 12 year old son. The 7 year old has a provisional diagnosis of bipolar disorder, pervasive development disorder, oppositional defiant disorder, attention deficit hyperactivity disorder (ADHD), anxiety disorder, and panic disorder. He is at present attending British Columbia Children's Hospital to obtain an official diagnosis. His brother has been diagnosed with multiple severe learning disorders. Both mom and dad work full time outside the home and have been taking alternating stress leaves to cope with the stress in the family. They describe their family as chaotic and unpredictable. They name humour as their strongest coping strategy. They have been identified as HLL.

Participant 6. This family lives north of the Fraser River and consists of a mom and her 18 year old son who has been diagnosed with developmental delay and severe seizure disorder. Dad also lives in the area and sees their son every other weekend. They also have a daughter who lives outside of the home and is 25 years old. Mom works full time in the field of special needs and dad works as a therapist. They have developed a micro board around their son to create an individualized program to meet his needs. Mom states that the well-being of the family is linked to the well being of her son and that although she has a positive attitude about the future; she still spends time grieving the loss of hopes and dreams for her son. She names her faith, her mission work, and an active support network as her strongest coping strategies. She describes her family as loving and caring. They have been identified as HHH.

Participant 7. This family lives in north of the Fraser River and consists of a mom, a dad, and three children: two daughters aged 23 and 33 years, who live away from home, and one daughter who is 16 years old and who lives at home. The 16 year old daughter has been diagnosed with Aicardi Syndrome. Dad works full time in his own engineering business and mom works for him part time. Mom and Dad are from two different cultures. They fund and hire their own support team for their daughter. They describe their family as “in progress of becoming closer” and say that they have worked through many issues within the family through the years. They name humour and education as their strongest coping strategies. They have been identified as HHH.

Participant 8. This family lives south of Vancouver and consists of a mom, a step dad and two children, an 11 year old son, and a 10 year old son. The 10 year old has been diagnosed with Aspergers' and ADHD. The children's biological father lives in the same community with his wife and two children and is very involved in the lives of his children. Mom and step-dad both work full time. Mom describes her family as very supportive of one another and as a blended family they get along very well. She names humour and the ability to accept things as they are as their strongest coping strategies. This family has been identified as LHH.

Participant 9. This family lives north of the Fraser River and consists of a mother, her partner, and her 18 year old son. She also has an older daughter who lives away from home with her daughter and husband. Her son has been diagnosed with cerebral palsy and seizure disorder for which he has had brain surgery. The children's father is not in communication with the children at this point, although he has been in the past. Their daughter supports the family by providing respite for her mom. Mom works full time in the field of special needs while her partner does not work. They have developed a micro board around her son to create the individualized program to support his varied needs. Mom describes the family as struggling at times but with hopes for the future. She names education and support network as her main coping strategies. This family has been identified as HLH.

Participant 10. This family lives in the Fraser Valley and consists of a mom, a dad, and three children. Two of the children, an 18 year old daughter and a 16 year old daughter, live at home and a 21 year old son is married and lives away from home. Their 18 year old daughter has been diagnosed with cerebral palsy. The family lived in another country (while doing missionary work) when the children were born. They moved to yet another country when their 18 year old daughter was born in order to acquire therapy for her disabilities. They emigrated from there to Canada 2 years ago. Dad works full time and mom is at home. Mom describes her family as quite supportive, including extended family but names herself as the main caregiver in the house. She names their faith as their strongest mechanism of coping. They have been identified as HHL.

Participant 11. This family lives in the Fraser Valley and consists of a mom, a step dad and three children: a 16 year old son, a 13 year old daughter, and an 11 year old son. The 11 year old has been diagnosed with high functioning autism. Their dad lives in the community and has inconsistent contact with the children. Both mom and step-dad work full time. Mom describes the family as chaotic with many issues and very few "normal" times. She names education as their strongest coping strategy. They have been identified as LLL.

Participant 12. This family lives in the Fraser Valley and consists of a mom and her 4 year old son. Her son has been diagnosed with autism. Mom states that her mother and siblings are her support system. Mom does not work and is on social assistance. Mom states that they do not cope well as a family and that she does not have many coping strategies. She does state that she is happy with the services that she receives presently. This family has been identified as HLH

Participant 13. This family lives in the Fraser Valley and consists of a mom, a step dad, and four children: two sons, aged 14 and 15 years old, and two step-sons, aged

13 and 17 years old. The 15 year old son has been diagnosed with autism, ADHD, and obsessive-compulsive disorder. The children's biological father is not in communication with them. Both mom and step dad work outside of the home. Mom names the flexibility of her employer as one of her strengths for coping. She also describes her family as a "work in progress" and states that it has been difficult blending the family but they are working hard at it and she feels that they are being successful. She names faith as one of her strongest strategies for coping. This family has been identified as LHH.

Participant 14. This family lives in the Fraser Valley and consists of a mom and two sons aged 8 and 11 years old. The 8 year old son has been diagnosed with autism and a developmental coordination delay. The children's father is not in communication with them. Grandma is a big support and takes on some of the care-giving role. Mom works full time. Mom describes her family as chaotic and states that she is not coping well and has few coping strategies that work for her. She does name faith as one of her strengths in coping. This family has been identified as LLL.

Participant 15. This family lives north of the Fraser River and consists of a mom, a step dad and two children: an 18 year old son, and an older daughter who lives away from home. The 18 year old has been diagnosed with Prader Willy Syndrome. Dad lives in Langley and is involved in the children's lives on a regular basis. Step-dad works full time while mom does not work outside the home. Mom describes her family as functioning well but tired. She names her support network as her strongest means of coping and is relying on her daughter to help support her son as mom herself gets older. This family has been identified as HHH.

As these descriptions point out, the participant recruitment process was successful at obtaining involvement with families reflecting a wide range of backgrounds and experiences. The results summarized here thus represent insights gleaned from a diversity of important contexts. However, because of the voluntary nature of the selection process, cultural diversity was limited (i.e., only one of the families was from a culture other than a Caucasian culture).

Resources that Facilitate Coping

In the description of the themes it is important to understand that they are represented here in no particular order and that the sequence is not indicative of the importance of the theme. As it is highlighted in Table 1, although there was some variation in the endorsement levels of the themes, overall the families supported the themes consistently.

The theme descriptions are meant to highlight the interplay between family voice and professional perspectives. To do this, the researcher has identified family voice with the first person and professional voice with third person.

Faith gives strength. Belief in something larger than ourselves is often a source of strength and peace. Participants in the study spoke about transcendent concerns or “higher powers” in very different ways. Diversity in spirituality in families can be respected and it can be a source of tensions. Personally, faith can help hold things together or it can be the root of deep personal anguish. Church families can be important sources of support or a great source of disappointment (this disparity will be examined further in the discussion that follows).

> Back when I first became a single parent I didn’t have the faith that I have now, so I

> kind of hit depression, all that fun stuff but when I found it, when I found the faith, there was more of a strength there (Participant 1).

Sense of community. We gain strength and a sense of belonging from caring members of our community. Who that community is varies from family to family. Parents spoke of different ways that family and friends “give what they can.” Encouragement, whether it is practical or emotional, fits well with what parents need at the moment. Parents give and receive support, educate and inspire others, and cultivate a “place” to belong and a process for “giving back”.

> What things help me? Well to have understanding from friend really helps me and my husband and support from the gov’t , the system that I am in. I am sort of getting, I don’t know (Participant 3).

Diagnosis as a relief. The diagnosis gave us a sense of relief in that we now know what we are fighting and have the language to talk about it with others. Parents spoke of the time of diagnosis as a time of relief. The diagnosis often signals the beginning of the healing for the family. They spoke of it as a time of understanding and the beginning of the “work phase” as they now have something to educate themselves about and work towards. These families also spoke positively about the wait time as they saw it as a time to organize themselves and begin the education process. The diagnosis for many also signalled financial help as some diagnoses come with resources.

Appreciation theme. Appreciation is an approach to life that permeates our attitudes, toward our family, our supports, and the unfolding events of our lives. The families spoke of an appreciation of the inherent and extrinsic gifts of each of the family members with each individual taking on roles based on their strengths and limitations.

This appreciation went beyond acceptance into an appreciation for life and was spoken of as a mindfulness of what happens in the moment as they experience their life with their child (as different from others). Even when not together, the adults work together in the best interest of the child. Many spoke of learning and appreciating as they struggled and grew with their child

*Skills and gifts of family***.** Our family is a cohesive, caring unit that is built and grows on the strengths and gifts of each of the individual members. Many families spoke of the gifts and skills that they use such as caring, advocacy, organization, persistence, creativity, etc. that help them to cope with and move through the world of disabilities. The parents spoke most loudly about the gifts of the children in the family. They spoke of their sibling children being strong, caring and educated individuals who with the support of the parents often become drawn to supporting others. The parents also saw their child with special needs as a teacher who showed them resilience, honesty and an appreciation for the beauty in the world. The other side of appreciation of skills is the families' appreciation of their limitations (importance of self care).

> The two younger ones are very, a better term, beautiful inside, and we enjoy having them around, and as I said our relationship is very strong, I wouldn't have made it without it (Participant 11).

Fit of services theme. The service providers that appreciate our children and validate our struggles help us cope with the uncertainty and chaos of navigating the world of disabilities. The parents spoke of feeling heard and endorsed by professionals in the field who were knowledgeable and educated themselves. Some spoke of a professional as being the first to notice that "something was wrong", and it was these individuals who encouraged the parents to pursue a diagnosis and helped them to navigate the system. Parents commented that without these caring individuals, they would not have had the strength and knowledge to plot the correct course to diagnosis and support for their child. The families also spoke of an appreciation for the funding that they received to hire appropriate services for their child.

Education theme. We are empowered as a family to take charge of the care and growth of our child with the understanding that comes from educating others and ourselves about our child's disability. Families asserted that it is through education of themselves and others that they gain strength and resilience to support their child. With this education comes the creativity and knowledge that parents utilize to fight for proactive, appropriate services that are individualized for their child and family. Furthermore, according to the families, as the family learns how their child communicates, learns, and copes they are better able to appreciate the positive experiences and this knowledge helps them to cope as a family through transitions and other stressful times. Parents who work in the field enjoy not only a network of support, but also the advantage of education on what to expect as their child grows.

> Me being informed a lot has helped a lot, being involved with groups cause now I feel that I am in control more. That's the only way that I am going to feel better is that to be informed (Participant 3).

Successful grieving. We, as parents, understand and acknowledge the stages of grief that we must go through with our child with special needs as we move to acceptance of our loss of hopes and dreams. We move to acceptance while building resilience through our loss. Family spoke about acceptance in many ways and saw this acceptance as the positive side of not having a choice in their life. The family learns to accept all emotions as they came to them. They accept the uncertainty of their life with their child with the only certainty being that they will care for their child for the rest of their lives. This acceptance leads to a sense of peace and hope for the future.

Normalization theme. We strive to create a positive, inclusive, normalized environment within our home and community and share the belief that we will get through the hard times as a family. Parents see their family as similar to other families only differing in the things that they have to cope with. The families spoke of an appreciation and celebration of the small steps forward that they take as a family. The parents spoke of happy times with the family being together, away from the situations of stress. They experienced life in their family with a relaxed attitude, taking life one day at a time.

> Again, good times for us are…we go camping as well, just by our selves and that is really good fun. Every week we like to walk or we usually walk or do something together. It's usually fun. We went shopping this week it was not so much fun. We're always doing something as a big family (Participant 4).

Factors that Hinder Coping

In the descriptions of the hindering themes, the researcher used the same manipulation of tenses to represent family voice and professional perspective as was highlighted in the helping themes. Furthermore, in the next chapter, the hindering themes will be organized with their corresponding helping themes to strengthen the idea that these themes are powerful in the experience of families with children with special needs.

Isolation. As caregivers, we feel that we are not supported, and we often feel isolated, like we do not belong anywhere in community or family and cannot ask anyone for help. Parents, especially when on their own, reported that it was hard to maintain the consistency of support, and education of those around them. Parents spoke about losing friends because of the intensity that goes along with supporting the unique needs of their family. Furthermore, rather that being put in a position of support to each other, families report that parents of children with special needs are set against each other due to the difference in funding between different diagnoses.

> When you feel that you are the only one there that can handle these situations and there is really nobody else there that can help and later my mom was there and D was there as well as he could be at that particular point cause that was and so he was still kind of distant on how to handle this (Participant 13).

Diagnostic trajectory. We find that the diagnostic process is frustrating and is undermined by the lack of coordination within the system, and without a diagnosis or the wrong diagnosis, we feel that we cannot properly support our child. The parents spoke about feeling let down by the way that the system is practiced and that they are afraid that they will miss out on their child's potential through key times. Parents talk about struggling with issues at different points in the diagnostic trajectory. Before their child has a diagnosis they state that receive little support as they do not have the education or the language to talk to professionals about what is wrong. After the diagnosis, the parents find that the labels that their child is given can sometimes have an "unintended" negative effect on how their child is treated.

Lack of fit of resources. We experience a lack of fit between our child and family's needs and the support and resources that are offered to us. Parents spoke about a mismatch between professionals' expectations and the parents' own expertise. They suggested that services, such as respite, behavioural management, school support etc., are inconsistent, unsupportive, and offer ineffectual support based on ignorance of their child's disorder. In speaking about their own desire for education about their child's disability, parents also referred to a lack of fit. Each child's experience of a disorder is individual and it is difficult to find research and educational material that fits the issues specific to their child. They spoke also of the lack of appropriate services or even recognition of the unique issues that the sibling children face. Furthermore, parents spoke about feeling as if they had no choice but to accept what was offered even if it did not fit.

> If you have a child that is a square peg in a round hole, the school system doesn't support them (Participant 11).

Ignorance of others. We are constantly challenged to work through the hurt that comes from the ignorance of others while taking on the role of educator and taking care of ourselves as the caregiver to our child with special needs. Families spoke of the struggles that they have in dealing with the ignorance of those around them. They articulated experiences of feeling as if they were given the "job" that they were not fully trained to do, yet were criticized for their attempts (i.e. they were bad parents). This experience of lack of support made them feel as they were constantly fighting to have people accept them and their children. Furthermore, parents report having to deal with stigmatization of certain resources such as medication that could help their child.

> I have to say sometimes, other people, other people and their ideas, I guess, their

> judgments. Uh, what other things hinder? (Participant 8).

*Challenges with the grieving process***.** We have challenges with and get stuck in the grieving process and are not able to move through to acceptance of the loss of hopes and dreams for our child. Parents spoke of getting stuck at the blame stage where they reported feeling guilt, and blaming themselves for their child's disability. Loss of hope is a common theme in parents who do not see their child progressing. This lack of acceptance of the reality of living with and supporting a child with special needs leads to added stress and negative feelings towards the families' situation.

Child's characteristics and behaviour. The inconsistent nature of our child's behaviour consumes our family, hinders our ability to cope, and leads to a loss of hope that things will stabilize in our family. Parents speak about the erratic or aggressive behaviour of their child with special needs as being a roadblock to or "getting in the way of" coping for the family and the child. The characteristic of the child or his or her disorder also makes it difficult for him or her to fit in with peers and this causes anxiety within the child.

> I cannot send him out on his own, because he will get into, I don't want to say trouble, I don't like using that, but he has confrontations that he is not capable of handling or understanding, why he is having these confrontations (Participant 8)

Constant change. The constantly changing experience of taking care of our child with special needs wears us as caregivers down, compromises our ability to cope and makes us feel as if we are in a constant cycle of crisis with no rest. The parents spoke of transition in the lives of their child with special needs as being frequent and difficult to go through for the whole family as the changes involved inconsistency and new learning.

They spoke of feeling as if they were on a treadmill as they were constantly going through changes which required adapting to new circumstances, environments, and people.

Stress of providing support. Meeting the needs of our child with special needs causes stress and exaggerates other life challenges in a vicious cycle both because there is a lack of financial support but also because our time is split between caring for our children and working to pay for costly services. Appropriate and research-based services are costly, hard to get and are not funded by the Ministry. Parents spoke quite emotionally of the dilemma of having to work long hours to earn money for expensive services to support their child and then having to search for more support because they are away at work. The stress that ensues from providing appropriate support for their child also puts extraordinary strain on the marriage and families often struggle to stay together.

Summary

All of the themes are formulated to help professionals fully engage the expertise of families living with children with special needs. The identification and understanding of each distinctive theme gives professionals and others an idea of how life in a family with a child with disabilities can be supported and hindered. Together the themes paint a picture of current existence and future aspirations for families. The families who shared their insights in this project have helped shape a space for families to be heard. These participants appreciated a collaborator to help translate these themes and to help begin a conversation that can bridge the gap between families’ needs and professionals’ support.

Table 1

Endorsement of Themes by Participant Families

	Family														
Theme	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
Faith gives strength	☑	☑	☑		☑		☑		☑	☑		☑	☑	☑	☑
Sense of community	☑	☑	☑	☑	☑	☑	☑	☑	☑		☑	☑		☑	☑
Diagnosis as relief	☑	☑			☑	☑		☑			☑		☑	☑	☑
Appreciation	☑	☑	☑	☑		☑	☑	☑	☑	☑	☑	☑	☑	☑	☑
Skills and gifts of family	☑	☑	☑	☑	☑	☑	☑	☑	☑	☑	☑	☑	☑	☑	☑
Fit of services	☑	☑	☑	☑		☑	☑	☑	☑	☑	☑	☑	☑	☑	☑
Education	☑	☑	☑	☑	☑	☑	☑	☑	☑	☑	☑	☑	☑	☑	☑
Successful grieving	☑		☑	☑	☑	☑	☑	☑		☑	☑	☑		☑	
Normalization	☑	☑	☑	☑	☑	☑	☑	☑	☑	☑		☑	☑		☑
Isolation	☑		☑	☑	☑	☑	☑		☑	☑		☑	☑	☑	☑
Diagnostic trajectory	☑	☑	☑	☑	☑	☑	☑	☑	☑	☑	☑	☑	☑	☑	
Lack of fit of resources	☑	☑	☑	☑	☑	☑	☑	☑	☑	☑	☑	☑	☑	☑	☑
Ignorance of others	☑		☑	☑	☑	☑	☑	☑	☑	☑	☑	☑	☑	☑	☑
Challenges with the grieving process	☑	☑	☑	☑	☑	☑		☑	☑	☑	☑	☑	☑	☑	
Child’s characteristics and behaviour	☑	☑	☑	☑	☑	☑	☑	☑	☑		☑	☑	☑	☑	☑
Constant change	☑				☑	☑	☑	☑	☑	☑		☑		☑	☑
Stress of providing Support	☑			☑	☑	☑	☑	☑	☑	☑	☑		☑	☑	☑

CHAPTER V: DISCUSSION

One of the greatest strengths of qualitative research is the richness of insight that is produced through the depth of interviews with participants and the organization of their thoughts and experiences into distinctive themes (Woolsey, 1986). The themes that emerged through this process created space for the voices of the participants and provided professionals with previously neglected insight into the experience of families. Stroul and Friedman (1996) suggest that parents are the single most important resource for their child and must be an integral part of the service delivery and planning process. Furthermore, Hunter (2003) speaks about her experience as a parent with a child with a disability as “an uphill struggle in unfamiliar territory”. In the current study, parents’ voices are highlighted to help bridge the gap between professional knowledge and family experience in order to help tailor services for families with children with disabilities.

This chapter explores ways that the results fit with and extends professional literature. For sake of clarity, facilitating themes are discussed along with the counterpart hindering themes when applicable. This structure further highlights the power of the themes as not only is the presence of the helpful themes strongly endorsed by the participant families, but the absence of the theme, or the hindering counterpart is also strongly endorsed (this is highlighted in the percentages of endorsement in each theme discussion). The pattern of results is then integrated within an ecological model of family functioning reflecting new paradigms emerging in current literature. Translating among the voices of families and professionals by a person skilled in hearing both the family’s and the professional’s voices, facilitates collaborative forms of effective service delivery.

This will be followed by a look into the family type analysis, implications for practise and policy, limitations of the current research as well as ideas for future exploration.

Synthesis of Family and Professional Themes

In this section all of the themes from the results will be explored and integrated with the literature. The themes that emerged in this study are reflective not only of the current literature or professional ideas of family needs but also and, more importantly, they speak to the families' ideas of their experience. This idea is highlighted in the recognition that while some of the themes are endorsed both by the families and in the literature, there are a number of themes that were found only by listening to family voice. These unique themes are endorsed by most of the families which show that they, although not spoken about in the literature, are important to the experience of families with children with special needs.

Faith. One of the most pervasive themes that came out of the research was the theme of faith. The families who endorsed this theme as a strength in their coping toolkit suggested that it was a faith in something that is larger than the family members themselves that helps them cope. Some suggested that it was a relief to be able to give their struggle over to a higher power while others spoke about their faith giving meaning to their challenges or experience. Tarakeshwar and Pargament (2001) found that families who saw religion as a positive resource could be encouraged to use religious coping as a source of support and strength including experiencing a feeling of being closer to God, of being able to give up some of the control of the situation to God and even having the church as a community of support. Furthermore, in this study, it was found that those who did not use positive religious coping had greater outcomes of depression and anxiety than those who used positive religious coping. With respect to a focus on service delivery, Hathaway, Scott and Garver (2004) found that psychologists believe that client religiousness or spirituality is an important area of functioning although it is often neglected in their treatment planning. This can serve as a reminder to professionals that faith can be an important focus for some individuals and may give them relief from their challenges.

Further to this idea of seeing faith as strength in coping, Hill and Pargament (2003) speak about a growing body of evidence that links spirituality to mental and physical health, while Dollahite (1997) suggests that, for fathers in his study, faith in a divine plan helps them create meaning despite their child’s disability.

While most of the participant families endorsed faith and a faith community as a strength, it is important to also listen to those who did not list this as a support to coping in their journey. The families that stated that faith was not a help to their coping went on to talk about feeling let down by their faith community and feeling isolated or judged when they reached out for help. This highlights again that it is important to really listen and give space to the family’s voice as just because they may be a part of a community you cannot assume that it is helpful to their coping.

Community and isolation. Another idea that was strongly endorsed by most of the family participants (Table 1) was the idea that having some sort of community of genuinely caring individuals surrounding them in support was a strong component of their coping strategy. This community varied from family members, to church community, to caring professionals, to support groups of other family members with children with disabilities but regardless of the type of community, the idea that the family had a group of other individuals who cared and were interested in providing appropriate support was important. This theme is supported by Armstrong, Birnie-Lefcovitch and Ungar (2005), Fox, Vaughn, Wyatte, and Dunlap (2002), and Hodapp, Fidler and Smith (1998), who indicated that it is important for families to have support from people who genuinely care.

The idea of support groups as a strength was strongly endorsed in this study. This is backed up by Kerr and Macintosh (2000), who found that although families in the early stages of diagnosis often had support from family and friends, they continued to have feelings of isolation and concern for their family's future. Parent-to-parent support provided a sense of normality, and the idea that there were other families out there experiencing similar things lessened feelings of isolation as well as giving these families a more positive vision of what their child's future could be. Contact with others also provided emotional support, helping the parents resolve some of their feelings of guilt, anxiety, and depression. Finally, other parents were able to give them practical advice from those who had been there. As time goes on, the parents' role shifts and evolves from one who receives assistance to one who gives as well as receiving support.

Conversely, all of the families endorsed isolation as an idea of what significantly limits the family's ability to cope. Feeling as if one is a stranger in a strange land, who does not know the language or the customs was an idea that was pervasive to the experience that the participants expressed. Kerr and MacIntosh (1999) and Taanila, Syrjala, Kokkonen, and Jarvelins (2001) state that families assert that parents with kids with disabilities are uniquely qualified to help each other and engagement in some sort of community is a necessary part of coping as it lessens isolation.

Diagnosis as a relief and diagnostic trajectory. As the experience of diagnosis was one of the focus events in this study there was much discussion around the effect that this experience had on the family. Every family endorsed this event as having an effect on the experience of living with a child with a disability but the judgement of that effect was split. All but one of the families endorsed the diagnosis as a time of struggle. This related to the idea that the path from the first moment that the family recognized that their child was special to the time that they were in a place of support and appropriate guidance (if this place was reached at all) was loaded with challenges from a lack of diagnosis and the judgement that came from others in their life, to misdiagnoses, to ignorance of professionals of not only the families' needs but also of the true nature of the disability, to a lack of or inaccessibility of appropriate services and support, to the negative impact that a label may have on their child. All of these experiences add to making the road through the diagnostic trajectory confusing and fraught with, at the least, frustration and, at the most, despair and hopelessness. This lack of trust in the process of diagnosis and the diagnostic process itself is strongly endorsed by most participants as a factor that severely hinders their coping. This idea bears further investigation and the implementation of a "user friendly" acquisition of services and support is one of the main focuses of this research.

The other side of this idea of diagnosis (i.e., the process by which the child acquires a diagnosis of their disability) is, if not surprising, at least enlightening for professionals and others who support these families. More than half, (i.e., 9 of the 15 families), also endorsed the time of diagnosis as a time of relief. The interesting caveat to this is that it was the correct diagnosis that was the theme that was identified as helping them cope. Although most of the families saw the diagnosis time as a time of struggle, some of those same families found this same time as a time of relief when they did get the correct diagnosis and then could focus their strengths and attention on finding appropriate assistance. These same families also fell into the category of families that were high functioning. This idea of diagnosis as a relief also seemed to come from families whose trajectory to diagnosis was not as long as those who did not endorse it.

Skills and gifts. This theme was strongly endorsed by the participants and lends a positive light to the strengths of these families. Most of the families endorsed the idea that the skills and gifts that were inherent to their family members were a source of incredible strength in their coping process. Stainton and Besser (1998) found that families saw their child with a disability as a source of joy and happiness and of family unity, and also saw their role in the family as one that increased tolerance and strength within the family.

Furthermore, it was encouraging to hear so many of the family members voice without hesitation that the strength that they see within their family members and themselves is not only instrumental in their coping but also something that the families take as obvious. This should be a strong message to researchers and professional service providers alike. Families with children with disabilities have an inherent strength that they recognize and it is up to both the professional and non-professional supports to not only recognize it but to help foster it. Families with children with special needs not only need to accept their child where they are at but also believe in themselves as having the strength and courage to push for more for their child’s future (Hartshorne, 2002).

Fit of services and lack of fit. These ideas seem fairly obvious in that the support that families require needs to be individualized and based on their own unique strengths and challenges. This idea further highlights the hypothesis put forward by this author that service delivery needs to be tailored to the needs of the individuals. Brantlinger (1991) suggested that professionals who work with families with children with disabilities should search out the needs of the family with recognition of the parents' expertise and willingness to advocate for their child, a clear appraisal of the goals based on individual needs, a realistic exploration of the professionals most suited to achieve the goals and, finally, an examination of the strategies that are mostly likely to accomplish the objectives with a particular family. In other words, the services need to be individualized for the family. Furthermore, collaboration between family and professionals (family-centred behavioural support) has been shown to lead to positive behavioural support in the home (Marshall & Mirenda, 2002)

The other side of this issue is the devastating effect that inappropriate or inaccessible services have on the family's ability to cope. Research has shown, and this study lends credence to, the idea that to support the child with a disability one must support the entire family and if the family members are struggling, they are not as able to provide the support to the child. Research tells us that grandparents and others are often willing to engage in the promotion of well being within their family; however, there has not traditionally been the education, professional assistance or even direction to sources of information on their family member's disability. It has been shown to be important that professionals see other family members as resources and help meet their needs for support (Scherman, Gardner, Brown, & Shutter, 1995).

Williams et al. (2002) also asserted that if professionals can help and increase the knowledge of the sibling about their brother or sister’s disability, their mood, self esteem and feeling of social support which were related to their behaviour would improve. When these needs are not met then the stress level increases and cohesion in the family decreases.

In a study by Opperman and Alant (2003), the researchers found that adolescents in their study reported limited family interaction and were often reticent in expressing their feelings about their sibling including feelings of guilt. Furthermore, they suggested that these adolescent siblings received limited information and guidance with respect to their sibling. This lack of education could contribute to ambivalent feelings that they have toward their sibling.

These studies all lend credence to the idea that support must be individualized to not only the needs of the family member with the disability but also to the family in its entirety with all of it nuances and differences. This study also suggests that these families have inherent strengths that when supported can be built upon within the family so that the family becomes more able to support themselves.

Successful grieving and challenges with grieving. The grieving process is a natural and difficult process to navigate for anyone who experiences a loss. With families with children with special needs, this often becomes particularly fraught with difficulties as they are not only mourning the loss of hopes and dreams for their child as they navigate the path of disability, but this loss is never stable. With the development of the child and transition through different stages of life this grieving process also develops and changes. This is called chronic grief as it is not only grief for a finite loss it is grief that carries on and is added to by the necessity of a change in expectation of what the family thought would be throughout the child’s life. Early conceptualizations of parent’s grief focussed on guilt, denial, projection, and rejection (Jaffe-Ruiz, 1984) and when the parents spoke of their strengths it was seen as denial or overcompensation (Wikler, Wasow, & Hatfield, 1983) within that framework. Drotar, Baskiewicz, Irwin, Kennel, and Klaus (1975) presented a model that seems to be a more useful backdrop for identifying positive adaptations by parents to the diagnosis of a child with a disability. This model outlines five stages including shock, disbelief with denial, sadness, anger and anxiety, adaptation and attachment with subsequent lessening of intense emotions and, finally, reorganization with possible long term acceptance.

The differences between families that achieve so called “successful grieving” and see this as a support to their coping and those who have challenges in grieving and see it as a hindrance, seem to be in their ability to adapt to a new situation or expectation (Knussen & Sloper, 1992). If parents and family members can adapt, they suggest that they feel and are seen as being successful in their grieving and are treated as people who have strength and ability to change with the needs of the situation. Conversely and unfortunately, those who show that they have challenges in adaptation are often treated as resistant by professionals and the focus of support is on getting them to change their attitude not on helping them cope with or reframe their experience. This, as suggested by the participants, is a common experience in those that state that they are stuck in the grieving process, and the experience often leads to a feeling of hopelessness.

Education and ignorance from others. Each of these themes was endorsed almost unanimously by the families (Table 1). The idea that families who take the time to educate themselves and those around them are better able to cope with their journey with their child with special needs is suggested in many areas of research. This does not appear to be a stand-alone idea in the literature, as it is often suggested as one of the ingredients in family resilience. Once the family gains the strength of knowledge they are more likely to feel confident to advocate for what they need for themselves as well as their child. This knowledge takes them out of the unknown and arms them with tools to begin to forge their own path. At this point it is support and guidance along that path that the families are requesting from professionals over and over again.

On the other side of this issue research has shown that often people with disabilities are treated similarly to those seen as having a minority status, including discrimination, segregation and subordination (Gliedman & Roth, 1980). Gray's (2002) study found that both mothers and fathers experienced stigma from others in the form of avoidance, hostile staring and rude comments from others. Families of children with disabilities state that this display of ignorance adds to the families' feeling of isolation and therefore, hinders their ability to cope.

Stainton and Besser (1998) found that even in their search for the positive impact of children with disabilities in the family, the participants could not refrain from expressing their disappointment in the ignorance of the service providers in how they work and deal with families. Furthermore, it seems that the professional status of the family member often does not have an impact on how they are treated by service providers as they seek support for their family members. Anecdotally, several of the participant families who were also professionals in the field spoke of feeling frustrated as they navigated the system seeking support for their family.

Characteristics of child. This is again a theme that was almost universally endorsed by the participant families. Even the families that struggled to find things that hindered their coping were able to give incident after incident that reflected that their child's behaviour or characteristics not only hindered their coping but also lowered their child's quality of life. Fox, Vaughn, Wyatte and Dunlap (2002) indicated that there was a pervasive impact of the child's behaviour on all aspects of family functioning. In addition, the longer that the behaviour exists in the family, the more deleterious it is.

Implication of familiar themes. The themes discussed in the previous pages are well represented in the literature in the area of families of children with special needs. While consideration of these themes with respect to current research may be confirmatory of existing research rather than ground breaking, this researcher contends that the identification of these themes does contribute to the field in valuable ways. The first involves the use of qualitative techniques to provide space for the voice of the family rather than the more typical quantitative research. Quantitative research, although important to the field of children with special needs, may not capture the richness of experience that is accessible to the researcher who has the time and creates the space for the families to share their experiences in their own words.

A second contribution that was made with respect to the familiar themes has to do with the interaction of the themes. Much of the research focuses on one or possibly a few of the themes but the present research highlighted the importance of many different sources of strength as well as hindrance in the lives of families with children with special needs. In doing so, it gives the reader a richer picture of the experience as the families cope and thrive or struggle with caring for children with special needs. From this picture one can determine different paths of support that would be individualized to the family and fit their needs as well as utilizing their strengths.

Novel Themes

The following themes were not represented strongly in current literature but were endorsed by such a high percentage of the family participants (Table 1), further exploration and emphasis was necessary to truly capture the experience of the family. These themes included the following: appreciation, normalization, stress of providing support, and constant change.

Appreciation. The theme of appreciation suggests an approach to life that the families consistently adopt when speaking about their family, their supports, and the unfolding events of our lives. The families spoke strongly of an appreciation of the individual family members with many making a special note of their appreciation of the gifts of their child with special needs. This appreciation went beyond acceptance into an appreciation for life and was spoken of as a mindfulness of what happens in the moment as they experience their life with their child (as different from others). Many spoke of learning and appreciating as they struggled and grew with their child. This theme is strongly endorsed by almost all of the families and suggests an inherent hope that the families carry with respect to their journey with their child with special needs.

Normalization. The theme of normalization or the ability of the family to either create a normal environment or feel just like everyone else was endorsed by many of the families. It was very important to these families that the idea was expressed and validated by professionals. The idea that they were just like everyone else, only with more exaggerated experiences came up again and again. This idea and the realization of the ideal in their lives gave the families that endorsed this theme strength and they felt like they and their special needs children belonged. This helped them cope.

Stress of providing support. The theme of stress of providing support to their child with special needs as a hindrance to coping plays out repeatedly in the literature, but the way that the family members spoke of it was a little different. They spoke of this particular hindrance, not coming from the child necessarily but from the fact that life happens whether or not you have a family member with special needs. They spoke of the stress of having to care for the siblings and their issues as being a challenge to their coping. Furthermore, the families spoke passionately about the stress that they feel from the vicious cycle of having to be away from the family to work to support them financially and desiring to be with the family to support them emotionally.

Constant change. The theme of constant change rang true for almost all of the participants (Table 1) although it has not been picked up strongly in current literature. The idea that their coping is hindered by the fact that their child's and therefore the families' experience is ever evolving without the existence of stability or consistency in the process, was obvious to the families. They spoke about never being able to plan things as they would never know how their child would be at any given time. This inconsistency leads to frustration and exhaustion in the caregivers and family members.

All of the above themes speak to two core ideas: that there is strength in the family voice in the process of supporting families with special needs, and the idea that professionals need to embrace a paradigm shift when working with these families from a pathological approach to a strength-based approach as is endorsed strongly by the families in this study.

Implication of novel themes. Although not strongly represented in this way in current literature, these themes highlight some of the main implications of the present research. While reviewing the novel themes, two key ideas became evident. The first of which was an emphasis on providing space and volume to the family voice, and the other was the idea of ecological amplification. The latter idea comes from the assertion of the family participants that the experience of having a child with special needs does not necessarily make the life events unique but it does exaggerate the impact of those life events on the family. By grasping these two concepts, professionals and other supportive individuals can better understand the needs of the family and offer support in appropriate ways.

Analysis of Family Type

This research started with professionally informed and described typologies with a view to utilizing these typologies to expedite service delivery for families. The factors that were taken into consideration were supported by literature and shown to be variables that could provide professionals with distinct categories with which they could gain understanding and insight into a family's discrete needs. The scope of this thematic framework, although useful in its simplicity, does not do justice to the complexity and richness of families with children with disabilities.

This idea does play out in the literature to an extent, but the real learning came from listening to the voices of the families. For instance, Luescher et al. (1999) and Trute (1990) found that positive family adjustment had little to do with the child's attributes including gender, level of disability, or temperament but that the marital adjustment and family functioning did have a positive effect. This speaks to the idea that played out with the families that the severity of the child’s disability had little effect on their ability to cope but that their own ability to keep the family together and functioning well did have a positive effect. Furthermore, the families very strongly spoke to the idea that the temperament and behaviour of their child were indeed factors in their ability to cope.

However, although the literature does speak to the idea of distinct types of families that reflect the levels of discrete variables like family functioning and level of satisfaction with resources, after listening to families these professionally defined types became less important than the researcher originally thought. Upon reflection of the themes and their importance in the different types of families, it was shown that there is little difference in what families view as important aspects of what helps and hinders their coping across the typologies. Within this research, the concrete typologies have, therefore, faded to the background. As with the needs of any given family, the typologies, if used, need to be flexible and individualized for each family. Furthermore, the most important idea with respect to the expediation of service delivery is for the professionals to take the time and give space for families to articulate their needs.

Ecological Models of Reflective Practice

As has been noted, historically, research has been based on assumptions that services and support should focus on the pathology of the child, often noting that there are limited capacities for coping within families who have children with special needs. Recent research and professional literature have emphasized the enhancement of family strengths more than remediating their assumed pathology. This idea highlights an early paradigm shift that occurred in the literature as well as in the practice of supporting families with children with special needs. This paradigm shift was identified as a positive shift to a focus on strengths and drew upon the resiliency models, coping models, and family functioning models. These models overlap to some degree and are defined by the professionals. The next major shift identified here, an ecological focus, matches persons and families to their environments. This shift created the necessary bridge from an exclusive focus on professional perspectives to collaborative approaches that include family voice-the last conceptual shift that is the focus of the current research.

Dyson (1991; 1996) identifies that although the parents with a family member with special needs did experience more stress than families who had no special needs in their family, the member with a disability was not the source of the family dysfunction. Furthermore, in the families with a disabled member, the families were found to be more positive and cohesive, to strive for more personal growth and to be more active in cultural and recreational activities than the normal families. This shift to a new paradigm which is not pathological but strength-and-resilience-based (Pettersson, 2001) included a shift in how professionals work with and even perceive families with children with special needs. At this point in the shift, some of the most prominent ideas were drawn from resiliency models, coping models, and family functioning models.

Deal, Trivette, and Dunst (1988) and Trivette and Dunst (1990) developed a model of family functioning that identified 12 characteristics of strong family functioning style. They later looked at responses from different families and found that responses to family scales indicated that fathers and mothers of children with developmental disabilities did not differ from each other or from fathers and mothers of children without disabilities in parental stress, family social support, or family functioning.

With respect to models of coping, the ABCX model of family adaptation, first developed by family sociologist Reuben Hill in 1958, provides interventionists with a conceptual framework that promotes a focus on strengths rather than deficits. This model was designed originally to explain the individual differences among families in their adaptation to stressful events. Because the information on resources and perceptions forms the basis for an intervention plan, strengths become the starting point for intervention. In addition, the model provides an integrated framework for directly linking assessment information with outcomes and implementation strategies. Basically, the model states that a stressor event (A) interacts with a family's crisis-meeting resources (B) and the definition that the family gives to the stressor event (C) to determine how the family adapts (X). This ABCX model suggests that how a family adapts to a critical event is shaped by the interaction between family resources and family perceptions (McCubbin & Patterson, 1983; Shin & Crittenden, 2003; Winton, 1990).

Another model that professionals use to work with families with children with special needs is the resiliency model. It has been defined in different ways but Patterson (2002) discusses the concept of family resilience from the perspective of family stress and coping theory (McCubbin & Patterson, 1983). This theory emphasises the active processes that the family engages in to balance family demands with family capabilities as these interact with family meanings to arrive at a level of family adjustment or adaptation. There is a major source of confusion about family resilience. This confusion lies in the two differing ways this term is used for practice and research. For practitioners, family resilience generally implies the capacity of a family to successfully manage challenging life circumstances. For researchers, resilience is a process involving interactions between risks and protective factors relative to a specified outcome. A major issue highlighted by Patterson and viewed differently in research and practice is how significant the risk must be before a good outcome can be considered evidence of resilience. The key to understanding family resilience is the identification of protective factors and processes that moderate the relationship between a family's exposure to significant risk and their ability to show competence in accomplishing family functions. Strategies for future research on family resilience include: (a) providing clear conceptual and operational definitions of key variables, (b) developing and testing conceptual models for risk and protective processes, and (c) studying populations of families experiencing significant risk (Hawley & Dehaan, 1996; McFarlane & Yehuda, 1996; Rutter, 1999; Walsh, 1996).

The next major shift, which includes ecological models of family development and resilience, also provides us with a bridge from the professional perspective to family voice. A phenomenological variant of ecological systems theory **(**PVEST) was introduced by Spencer, Dupree, and Hartmann (1997). More recently, Swanson, Spencer, Dell’Angelo, Harpalani, and Spencer (2002) suggest that identity formation comes from how the youth views themselves and their future prospects. Researchers and practitioners must comprehend and analyze relationships between the environments that the youth encounter, acknowledge their perceptions and reactions to these environments, and assess their consequent maturational and developmental trajectories. As in this research, when we look at the needs of families with special needs, we must look at identity, culture, and context. Ecological magnification suggests that it is the environment of the system within which families with children with special needs receive services that creates a mismatch between the families, needs from their perspective and the support that is offered. Furthermore, it is the professional aspect of the system that creates this environment. The idea that there needs to be a fit between the person and their environment is elaborated on in the research (i.e., PVEST) and the current research goes further to indicate that this fit needs to be from the perspective of the services recipient. This idea leads to the final shift that is the focus of this research, the shift from professional perspective to family voice.

As the current research has identified, predetermined typologies faded into the background as less effective in building collaborative relationships between families and professionals. As it turns out, addressing family voice is no longer a luxury but has become a crucial strategy for professionals adequately addressing family needs and service requirements. This realization mirrors the shift that is taking place in the literature. Family voice is now being incorporated as a fundamental component in collaborative professional practices identifying needs, functioning, coping, and resilience (Parette, Brotherson, & Blake Huer, 2000; Stricker, 2000; see Figure 1 below for a summary of a model of reflective practise and translation).

In this kind of model, it is suggested that there is incongruity between family perspective and professional perspective and this disparity leads to a mismatch of system resources and family needs. It is this neglect or negation of family voice that exacerbates the problems that families with children with special needs have in gaining access to appropriate and effective services. This dilemma is illustrated in the current research most clearly in the problems that families have with navigating the diagnostic trajectory. The needs that families identify have more to do with strengthening their internal resources through education, successful grieving, and focus on the strengths and gifts of the family members. The system, however, bases the support that is offered on the needs of the child with special needs paying little attention to the family needs. This mismatch also suggests that not only do coping, family functioning and resilience need to be looked at from the perspective of the family rather than from the perspective of professionals, but also that professionals cannot get an effective needs analysis without truly understanding family voice.

In the current research, voice is central to the researcher's understanding of the needs of families with children with special needs. Often, however, in the literature, even when family voice is taken into account, it is quickly pushed into the professional experience as it is redefined based on professional perspectives. The method by which the current research was carried out very quickly highlighted the necessity of truly hearing the family voice when identifying the needs (i.e., having a caring community to support them, having the means to educate themselves and others, etc.) and service needs of the family. In the current research, by being a practise-centred professional working in the field, the researcher was able to give space to the family voice.

The following diagram (Figure 1) illustrates the process of reflective practise or translation that is described in the above section. Specifically, it shows that although professionals and families traditionally have been thought to speak different languages, the ecological model can be a bridge of understanding. Vivid understandings of differing voices and perceptions of terms such as coping, family functioning, and resiliency become a centrepiece for collaboration. In this process, "translators" must understand the need for space for each of the voices as well as the specific support needs of the family (e.g., Do they need support to advocate for themselves in the current system or do they need system change?) and the professionals (i.e., system resources and constraints). By focusing on the ecological model (i.e. paying attention to the fit of the individual to their environment) as a bridge between professionals and families, this translator can join with both the family and the professionals to form a collaborative unit based on the needs and voices of both, in an environment of understanding.

Implications for Practice, Policy and Utility

There appears to be several noteworthy implications that come from the results of the present research with respect to how both professionals and non-professionals can support families with special needs. One of the strongest ideas that comes from this research is that professionals must give space to and listen to the family voice. Families in the current research indicated repeatedly that they felt competent to articulate their needs and ask for support but felt that they were not given the space in the professional milieu to do so. Furthermore, the voice of the family indicated their strengths as well as their needs, which is essential in accurately setting up support strategies for these families. If professionals listen to the voice of the families, they will better understand their resources like faith, a sense of and appreciation for community, their skills and gifts as well as their ability to educate themselves as well as their needs. (i.e., the need for accurate diagnosis, services that fit, etc.). An understanding of these resources and needs can help facilitate service delivery plans that not only fit the expressed needs of the family but also utilize the already present resources that the family brings by virtue of their own experience of caring for a child with special needs.

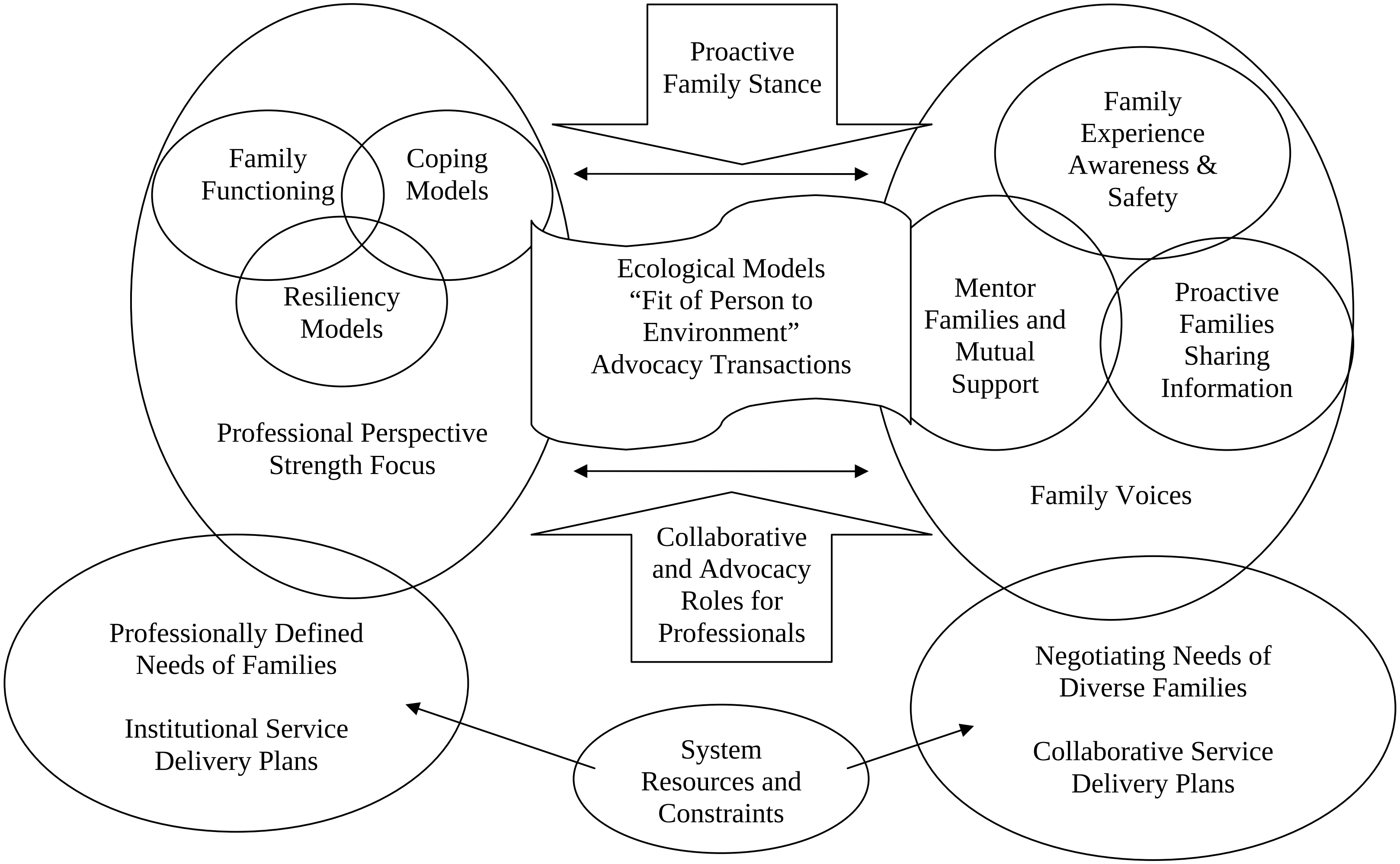

Figure 1. Guide for reflective practise: Map of the translation process between families and professionals.

Another noteworthy implication is that there is a definite drive for professionals to continue the paradigm shift from pathology of the family to strengths and resources and then to continue the shift from professional perspective to looking at the perspective of the family as the identifying feature for service delivery.

Once professionals understand the strength of what the family has to say, the coping models like ABCX come to life in a new way. The outcome is now driven by the meaning that the family makes of the life event, not merely by the fact that there is a child with special needs living in their midst. This inspires hope in the family system, which can only be strengthened by the support of the professionals that the family deals with.

Limitations of Current Research and Future Research

Some of the limits of the current research have to do with the chosen methodology. There are inherent limitations of qualitative research in that, although the data is rich, it is based on memory and relies on honest communication. As the researcher must build rapport with the family in order to carry out the research effectively, this may present a limitation based on the believability of the family. To please the researcher, the participants may strive for the right answer. Furthermore, as they are talking about the inner workings of their family, they may present themselves in an overall agreeable light, or, based on the idea that they are finally being heard, they may also over-catastrophize their situation. Although the repetitive nature of the interviews does speak to some of the concerns in this regard, believability is still a limitation of this study.

Another limitation revolves around the issue of applicability. Participants in this study were quite homogenous with respect to demographics. Although there was good representation based on the previously discussed typologies, factors such as race, religion, socio-economic status and geographic location were quite uniform. All of the participants were from British Columbia, classified themselves in the middle-to upper-middle class, most identified themselves as coming from a Christian background and with one exception, all of the participants were Caucasian.

Another limitation that has to do with the homogeneity of the sample size comes from the fact that all of the families in this study were accessing services at the time of the study. This again limits the applicability to families who access services and can not be generalized to the population of families with children with special needs who for whatever reason are not accessing services. These facts about the homogeneity of the population being known, one should take caution in applying these results to the greater population.

In addition to the relatively homogenous sample, the size of the sample was also quite small. For the purposes of this research, elements such as the saturation of themes were met but a larger sample size would have allowed for applicability that is more confident. It is also possible with such a small sample size that features unique to one family could be mentioned enough within their interview to skew the results.

While these limitations do require highlighting with respect to how one reviews the results, they are not limitations so large to significantly detract from the overall value of the study.

This project provides insight and clarification around what helps and hinders a families' coping when caring for a child with special needs, and it opens doors to a greater understanding of a paradigm shift that is beginning to take place in the practise and research of families.

One aspect of this study that was particularly interesting was the role of the researcher as professional and practitioner in coming alongside the family. This practise-based focus gave more space for the family voice than the typical research-based interactions and led to greater understanding. To further this research by utilizing that kind of dynamic would yield truer voice and go further in matching needs with services. This could, therefore, also lead to a change in system that would allow more room for families to talk about what they need from the system. By paying attention to this shift from professional perspective to family perspective, a more efficient system could emerge.

The families that participated in this study shed a great deal of light on the themes that were significant in their coping and it became clear that many of the families saw these themes as working hand-in-hand (such as education, skills and gifts and successful grieving). A suggestion for further research would be to explore the relationship of these constructs in greater detail by utilizing both quantitative and qualitative research methods. A greater understanding of these themes in relation to one another would give rise to more effective questions being asked and a truer interpretation of family voice as it relates to the family needs and service requirements.

In the current research, family voice was the core to understanding the needs of family. In the field of children with special needs it is often the case that practise precedes research. From this idea, a natural step for future research would be to look at policy making and how the system identifies the needs of the family. Furthermore, this research asks the question of whether the current system can evolve to a model closer to the one identified here where the family voice has precedence over the professionals' perspective. From this, we could look more into more effective ways of organizing service delivery for families based on this family voice centred model. Moreover, this movement will come from education of both professionals and families in the process of translation back and forth from professional to families. This could further lead to the discussion as to how much we need to support the family to advocate for themselves, and how much the system needs to bend to support the families in an efficient way.

Conclusion

This research is intended to address the unique needs of families with children with special needs within the context of their own family experience. While a great deal of attention has been paid in the literature to the effect that the child with special needs has on the family or the stress that their membership has in the family, there is significantly less information on the richness of the family experience with respect to the family in its entirety with each family member bringing to the picture their own unique set of strengths and needs. To further explore this richness, this research employed the qualitative approach to elicit information that pays respect to the unique context that each family offers. This approach to data collection not only highlights the participant's own voice but also allows the researcher to explore the uniqueness of each family within the context of the population.

As discussed in the first two chapters, the research in this area has started to shift from a pathological focus to one that is more respectful of the true experience of the family, with a focus on their strengths and unique appraisal of the situations that make up their lived experience. This change in paradigm sets this research up to further the focus of exploration into the experience of these families. By looking at what helps and hinders coping in intentionally focused types of families, this researcher can start to make qualified conjecture as to what their unique needs are from the family's perspective with respect to service delivery and support within the community of professionals as well as non professionals.

The research method involved interviews with 15 families (20 family members) of children with special needs. Critical incident technique was utilized to elicit incidents from the participants that focused around two pivotal experiences in their life with their family member, the diagnosis, and another turning point event. These particular events were chosen for their focus on transitional times in the development of the child. Seventeen themes were created from the analysis of all of the events reported. Applicability techniques were applied in order to test the soundness and comprehensiveness of the themes. In addition, efforts were made to examine the theme's fit to current literature and consultation with both family members and professionals provided a further check of validity. The themes reflected that coping factors had both useful and non-useful aspects and included: Faith, Community, Diagnosis as relief, Appreciation, Skills and Gifts, Fit with Services, Education, Successful Grieving, and Normalization as helpful themes and Isolation, Diagnostic Trajectory, Lack of Fit of Services, Ignorance from Others, Challenges with the Grieving Process, Child Characteristics and Behaviour, Constant Change, and Stress of Providing Support as themes that hindered coping.

In addition, these themes were looked at in the context of different types of families and factors that made a difference in the coping styles were identified. In the context of this research, the typologies faded into the background and became important only in the organization for recruitment of families with different backgrounds. The ecological model came to the forefront in the current research along with the importance of creating space for family voice and the bridging between families and professionals also called the reflective model of practise (or translation process) in this research.

The findings of this research contribute to the field of counselling psychology by providing a model for translation between family voice and professional speak that can be utilized to bridge the gap between the two and build a more effective service delivery plan that is based on the uniqueness of the members of this population from their own perspective. This gives a focus to implementation of services based on not only their unique needs but also on the strengths that are inherent to families with a member with a disability. Furthermore, the research suggests promising support for the ecological model and family voice as a focus to working with and supporting this population.

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APPENDIX A

Definitions of Terms

Professional speak: This term refers to the jargon and professional terms that professionals often use in there conversation with other professionals as well as with families.

Lay person speak language: This refers to the language used by a lay person, including families. It does not include jargon or professional words and is more simplistic and to the point then most professional speak.

Family Voice: This literally refers to the voice of the family members with no interpretation into professional speak. It is the truest representation of the needs, and experience of the family that is heard only when the family is given a safe and respectful space to talk about their journey. This is often but not always facilitated by someone who is with them in that space to hear and carry their words forward. In the terms of this study it this term is used to identify the words that are spoken by the family that come directly from their experience and journey with their child.

Space: This term refers to the ability of the family to have their voices heard. In the terms of this study space has two parts. One of the parts refers to the idea that the family is able to have a safe place (location and people) to talk about their experience, and the second part refers to the idea that their ideas and thoughts are met with validation and they are supported in getting their voices heard in the professional realm.

Resilience: This term is used as it is defined by professionals and refers to the model of resilience within families. It describes how families adapt to stress and bounce back from adversity

Ecological Model: This term refers to the fit of the person to their environment.

Qualitative Research: This is the type of research that this study has employed and involves detailed, verbal descriptions of characteristics, cases, and settings, typically uses observation, interviewing, and document review to collect data and focuses on the meanings and interpretations of the participants as opposed to its size or quantity (as in quantitative research). In the case of this study, the measures of research are based on interviews with participants and analysis of their experience as opposed to surveys that gather numerical information.

Family Systems Theory: An approach to families that emphasizes the interdependency of family members rather than focusing on individuals in isolation from the family. This suggests that the experience or process of one family member impacts and influences the experience of the other family members. This theory underlies the most influential forms of contemporary family therapy.

Reflective Practise: Reflective practice is a means by which practitioners can develop a greater self-awareness about the nature and impact of their performance, an awareness that creates opportunities for professional growth and development. Maximum benefits from reflection are said to occur when the process happens in community, in interaction with others; when participants value the personal and intellectual growth of themselves and others; and when participants have time to engage in slow, non-assumptive thinking (Boud & Walker, 1998).

Disability (Disabilities): A condition that curtails to some degree a person's ability to carry on his normal pursuits. For the purpose of this study this condition is a permanent part of the individual’s life.

Coping and Family Functioning(or what is the family doing and how well are they doing it): The degree to which the family is strained in meeting the challenges of caring for their special needs child and how well the family is able to stay cohesive under the strain.

Satisfaction with Services: The degree to which the family is satisfied with the supports that they receive to help care for their special needs child.

Diagnosis: An event described as the time when the family was made aware by a professional that their family member had a condition that classified them as special needs.

Turning Point Event: An event described as a time in the life of the child with special needs that had a significant effect on the family.

APPENDIX B

Family Context Survey

Family Context Survey

Welcome to the Family Context Survey (FCS)! The FCS is an information-gathering tool that helps parents to describe their experiences and home dynamics related to living with a child who has a physical or mental disability. The survey asks nearly 190 questions. Some are about your family background and structure, some aim to describe your child and his or her disability, and others ask you to consider your family dynamics and your satisfaction with the social supports that you currently receive. Only parents who are **CURRENTLY LIVING WITH THEIR DISABLED CHILD** should fill out the FCS.

Instructions:

There are four things to keep in mind as you fill out the FCS: Firstly, in most of the questions you are trying to describe your **FAMILY**; that is, the people who are currently living with the child with the disability. As such, have your answers reflect the general experience or dynamic of **THE FAMILY AS A WHOLE**, rather than letting your answers describe just you or your experience.

Secondly, it is likely that your experience of life and of your family dynamics will change over time. This will make some questions seem more true of your family now than at other times. Because of this, it is important that you try to describe your family as it is **RIGHT NOW**, letting the answers reflect each of the "ups and downs" that make up your family life as it is today.

Thirdly, since each family is unique, each family will have their own unique constellation or profile of answers to the FCS. As such, you should try to remember that there is **NO RIGHT OR WRONG ANSWER**, only the answers that best describe your family right now.

Lastly, **ANSWER ALL OF THE QUESTIONS**. For questions that do not apply to your family, simply circle the "NA" for Not Applicable. For example, a single parent living alone with one or more children would not answer questions about marriage. Similarly, parents who have only one child would not answer questions that ask about sibling relationships. Each of these types of questions should be answered as "zero – Not Applicable". Also, please note that the terms "Mother" and "Father" are meant generally to describe any adult female (mother, step-mom, father's girl-friend) and any adult male (father, step-dad, mom's boy-friend) who lives with and actively participates in the challenges of raising the family.

Family Context Survey

General family characteristics

1. Today's Date: *year=*________ *month=*________ *day=*________
2. Relationship of survey participant to child
   - A Birth/biological Mother
   - B Adoptive Mother
   - C Foster Mother
   - D Step-Mother
   - E Dad's girl-friend
   - F Birth/biological Father
   - G Adoptive Father
   - H Foster Father
   - I Step-Father
   - J Mom's boy-friend
3. Number of adults currently living with the child with the disability: ________________
4. Primary ethnic group of family members (Select with an "X" only one):
   - A Caucasian,
   - B Asian,
   - C Indo-Canadian,
   - D Hispanic,
   - E Black,
   - F First Nations,
   - G Other.
5. Primary language spoken in the home:________________________________
6. Education level of **Mother** (Select with an "X" only one):
   - A Did not finish grade 12
   - B Graduated grade 12
   - C Attended college/university
   - D Finished undergraduate degree (eg., BA)
   - E Finished Graduate degree (eg., MA)
   - F Finished Doctoral degree (eg., MD, PhD)
   - G Other (please specify) ________________________________
7. Education level of **Father** (Select with an "X" only one):
   - A Did not finish grade 12
   - B Graduated grade 12
   - C Attended college/university
   - D Finished undergraduate degree (eg., BA)
   - E Finished Graduate degree (eg., MA)
   - F Finished Doctoral degree (eg., MD, PhD)
   - G Other *(please specify)* ________________________________

Characteristics of child with disability

8. Age: _____years old

9. Gender: ☐ A Male ☐ B Female

10. Birth order: (Indicate gender of each child born from to youngest to oldest and circle the child with the disability)

Example family has 4 children. The oldest is a Girl. Next came a Boy with a disability, then a Girl, the youngest is another Boy.
Example family: Youngest: Boy Girl (Boy) Girl Oldest

Your family: Youngest______________________________Oldest

11. Sibling ages: (Following the same pattern as above, indicate the age of each "B" or "G" you listed in question 10 above)

Your family: Youngest__________________Oldest

12. Age of first diagnosis: _________

13. Classification of your child's disability (Select with an "X" only the ones that apply. May be more than one.)

☐ A ADHD & ADD
☐ B Aspergers
☐ C Auditory impairment
☐ D Autism
☐ E Behavioural disturbance
☐ F Cerebral Palsy
☐ G Conduct disorder
☐ H Developmental delay
☐ I Down syndrome
☐ J Eating disorders
☐ K Elimination/bathroom disorders
☐ L Emotional disturbance
☐ M Fetal Alcohol Syndrome (FAS)
☐ N Learning disability
☐ O Vision impairment
☐ P Oppositional Defiance Disorder
☐ Q Physical disability
☐ R Prader Willie's Syndrome
☐ S Rett's disorder
☐ T Sensory disability
☐ U Tourette Syndrome
☐ V None of the above *(please specify)*_______________________

14. Severity of your child's disability (Select with an "X" only ONE)

☐ A Undesignated ☐ B Mild ☐ C Moderate ☐ D Severe ☐ E Profound

This section makes statements about family dynamics and about specific relationships within a family. Your task is to **RATE** how well each statement describes or is true of your family. Try to select the exact number that best describes your **FAMILY** as it is now, that way you will likely have some statements that score 7 – “Very true & descriptive of our family”, some that score 1-“Not true or descriptive of our family”, and some statements that score between these extremes. TIP: Use the full scale (i.e., each number from 1 to 7) when appropriate, to describe the subtle differences between statements about your family. Don’t just use 1’s and 7’s.

Statement about family dynamics or relationships	**Not true or descriptive of our family**						**Very true & descriptive of our family**
15. We often spend time together as a family even with our busy schedules	1	2	3	4	5	6	7
16. We take great pride in our family accomplishments	1	2	3	4	5	6	7
17. We often get too overwhelmed to talk through our problems	1	2	3	4	5	6	7
18. As a family we are clear about what is acceptable behaviour for family members	1	2	3	4	5	6	7
19. We try not to worry about uncontrollable events since that just causes more stress	1	2	3	4	5	6	7
20. We have good friends and family who help us to succeed as a family	1	2	3	4	5	6	7
21. I find it hard to believe that my child has a disability	1	2	3	4	5	6	7
22. I often feel sad, mad, guilty, embarrassed, hopeless about my child with a disability	1	2	3	4	5	6	7
23. I have difficulty parenting / managing the behaviours of my kids	1	2	3	4	5	6	7
24. There is almost constant tension in our home; family members just don’t get along	1	2	3	4	5	6	7
25. We often take each other for granted and forget to show appreciation for what others do	1	2	3	4	5	6	7
26. We believe family relationships will outlast material possessions	1	2	3	4	5	6	7
27. Our family members share concerns and feelings with each other; we express ourselves well	1	2	3	4	5	6	7
28. As a family we can depend upon each other in difficult times, we always pull through	1	2	3	4	5	6	7
29. We feel comfortable letting friends and relatives help us out	1	2	3	4	5	6	7
30. Other professionals stand up for our rights and help us get what we need	1	2	3	4	5	6	7
31. I often think that nothing is really wrong with my child	1	2	3	4	5	6	7

Statement about family dynamics or relationships	**Not true or descriptive of our family**						**Very true & descriptive of our family**
32. I feel like I'm not living my own life anymore. The disability clouds out the old real me	1	2	3	4	5	6	7
33. I'm not sure/confident about how to be helpful to my disabled child	1	2	3	4	5	6	7
34. Most family members do not help out with regards to the disability	1	2	3	4	5	6	7
35. We value and enjoy spending time together as a family. We are committed to each other	1	2	3	4	5	6	7
36. We often make personal sacrifices for the benefit of the family	1	2	3	4	5	6	7
37. We remind each other that there is good in the worst situations	1	2	3	4	5	6	7
38. Our decision making is done to benefit the entire family	1	2	3	4	5	6	7
39. We try to look at the bright side of things and not let ourselves get too down	1	2	3	4	5	6	7
40. As a family, we fight to ensure we get all the support we are entitled to	1	2	3	4	5	6	7
41. I feel overwhelmed about the disability	1	2	3	4	5	6	7
42. Having a child with a disability has not changed my life or my sense of self	1	2	3	4	5	6	7
43. I don’t mind having strangers watch me as I discipline and direct my child	1	2	3	4	5	6	7
44. Each family member has appropriate social relationships outside the home	1	2	3	4	5	6	7
45. We often pitch in and help each other with tasks and struggles	1	2	3	4	5	6	7
46. Difficulties often separate and pull apart family members	1	2	3	4	5	6	7
47. Our family members listen to both sides of disagreements	1	2	3	4	5	6	7
48. We solve our own problems before asking others for help	1	2	3	4	5	6	7
49. We have rules and structure to help cope with unacceptable behaviour	1	2	3	4	5	6	7
50. We often just take what we are given rather than fight for more	1	2	3	4	5	6	7
51. Thinking of my child with a disability does not upset or shock me	1	2	3	4	5	6	7
52. I often wonder why this has happened to me	1	2	3	4	5	6	7
53. I often feel inadequate or incompetent as a parent	1	2	3	4	5	6	7
54. Our family is accepting of support professionals as part of our daily life	1	2	3	4	5	6	7

Statement about family dynamics or relationships	**0-NA means “not applicable”**	**Not true or descriptive of our family**						**Very true & descriptive of our family**
55. We rarely make time for the important things in our family life		1	2	3	4	5	6	7
56. Our family members can depend upon each other		1	2	3	4	5	6	7
57. We often talk about different ways of dealing with problems		1	2	3	4	5	6	7
58. As a family, we often don’t know how to respond to problems or crises		1	2	3	4	5	6	7
59. We have a hard time coping with the challenges of our family		1	2	3	4	5	6	7
60. We often disagree when making important decisions for the family		1	2	3	4	5	6	7
61. My partner and I spend quality time together away from children	0-NA	1	2	3	4	5	6	7
62. I’m happy with how my partner and I share tasks of raising the family	0-NA	1	2	3	4	5	6	7
63. My partner and I agree about how to discipline the children	0-NA	1	2	3	4	5	6	7
64. My partner and I agree on how to manage family money	0-NA	1	2	3	4	5	6	7
65. My partner and I share common goals and dreams about family	0-NA	1	2	3	4	5	6	7
66. The siblings interact with and enjoy our special needs child	0-NA	1	2	3	4	5	6	7
67. The siblings enjoy the benefits of living with a disabled child	0-NA	1	2	3	4	5	6	7
68. Siblings help each other out so that every one "wins" and things get shared	0-NA	1	2	3	4	5	6	7
69. Siblings hate having to live with a special needs child	0-NA	1	2	3	4	5	6	7

Turn to the next page and continue …

Since you have a child with a disability, you likely have several professionals and support services in your life to help you with your child. This section makes statements that might describe **YOUR SATISFACTION** or **EVALUATION** of these professionals or services. Please note that the scale has changed from the options that you had before. Now, the scale has an **AVERAGE MIDDLE SCORE**. That means that any professional or service that **JUST MEETS YOUR EXPECTATIONS** would score 4-Just Meets My Expectations. This way you can clearly indicate which services are performing above your expectations and which are performing below.

	0-NA means “not applicable”	**Very low / Poor**			**meets my expectations (average)**			**Very good / Exceptional**
70. Our school is the best in the area for my child	0-NA	1	2	3	4	5	6	7
71. Our classroom is the best in the school for my child	0-NA	1	2	3	4	5	6	7
72. My child’s teacher(s) is meeting all my expectations this year	0-NA	1	2	3	4	5	6	7
73. The other teaching assistants are all meeting my expectations	0-NA	1	2	3	4	5	6	7
74. I am as involved with the school, class, and planning as I want to be	0-NA	1	2	3	4	5	6	7
75. As a parent, I receive enough counselling and personal support	0-NA	1	2	3	4	5	6	7
76. My family gets enough counselling and support as a family	0-NA	1	2	3	4	5	6	7
77. We receive enough money to pay for the supports we need	0-NA	1	2	3	4	5	6	7
78. We have adequate help with transportation for our disabled child	0-NA	1	2	3	4	5	6	7
79. My family has adequate legal support regarding disability rights	0-NA	1	2	3	4	5	6	7
80. My family receives adequate financial support from the government	0-NA	1	2	3	4	5	6	7
81. We have enough financial planning and tax information regarding disabilities	0-NA	1	2	3	4	5	6	7
82. We have a lot of interaction with other parents with similar children	0-NA	1	2	3	4	5	6	7
83. We have adequate support for the siblings of our disabled child	0-NA	1	2	3	4	5	6	7
84. We have access to a parent support group for families like us	0-NA	1	2	3	4	5	6	7

Turn to the next page and continue …

Next, you will be asked to evaluate or rate each of the professionals you see, or support services that you receive. Please consider each of the following definitions in your rating, if it applies. In other words, you will **RATE EACH** professional or service **IN TERMS OF** a) amount of time, b) their availability and flexibility, c) the quality of care they provide, d) the importance of their service to you, and e) their competency. Note that some of these areas of evaluation may not apply to each of the professionals that you see. If not, simply circle “0- Not applicable”. TIP: Read over the list of professionals and services to see which ones apply to your family.

Amount of time from service: This describes HOW MUCH service you get, per meeting or per week or month. Do you get enough time from this person/service? Do they see you, talk to you, or deliver the service often enough? Do you feel rushed or that this person doesn’t have time for you?

General Availability & Flexibility: Describes how well this person/service can be reached by phone, returns calls, books appointments when needed, adjusts to meet your schedule, etc. How hard does this person/service try to accommodate your needs?

Quality of care: Describes the NATURE of the support delivered to you / your child or family. Their “nice-ness” in personal relationship; shows respect; listens/attends to your needs; friendly. E.g. A doctor with good bed-side manner.

Importance of service: This describes how VALUABLE the person/support is to you/your family at this time. E.g. “I really need this person or support right now” or, “This person/support provides a great benefit to our life right now”.

Competency of provider: Describes how well the provider DEMONSTRATES KNOW-HOW. Acts on qualifications; is well trained to do job; does job well; gives appropriate service/support.

	Family Doctor	Does Not Apply	**very low/ Poor**			**meets my expectations**	**average**			**exceptional/ very good**	
85.	Amount of time	0	1	2	3	4	5	6	7	8	9
86.	Availability & flexibility	0	1	2	3	4	5	6	7	8	9
87.	Quality of care	0	1	2	3	4	5	6	7	8	9
88.	Importance of service	0	1	2	3	4	5	6	7	8	9
89.	Competency of provider	0	1	2	3	4	5	6	7	8	9

Turn to the next page and continue …

	Psychiatrist	Does Not Apply	**very low/ Poor**				**meets my expectations average**			**exceptional/ very good**	
90.	Amount of time	0	1	2	3	4	5	6	7	8	9
91.	Availability & flexibility	0	1	2	3	4	5	6	7	8	9
92.	Quality of care	0	1	2	3	4	5	6	7	8	9
93.	Importance of service	0	1	2	3	4	5	6	7	8	9
94.	Competency of provider	0	1	2	3	4	5	6	7	8	9

	Psychologist	Does Not Apply	**very low/ Poor**				**meets my expectations average**			**exceptional/ very good**	
95.	Amount of time	0	1	2	3	4	5	6	7	8	9
96.	Availability & flexibility	0	1	2	3	4	5	6	7	8	9
97.	Quality of care	0	1	2	3	4	5	6	7	8	9
98.	Importance of service	0	1	2	3	4	5	6	7	8	9
99.	Competency of provider	0	1	2	3	4	5	6	7	8	9

	Family Counsellor / therapist	Does Not Apply	**very low/ Poor**				**meets my expectations average**			**exceptional/ very good**	
100.	Amount of time	0	1	2	3	4	5	6	7	8	9
101.	Availability & flexibility	0	1	2	3	4	5	6	7	8	9
102.	Quality of care	0	1	2	3	4	5	6	7	8	9
103.	Importance of service	0	1	2	3	4	5	6	7	8	9
104.	Competency of provider	0	1	2	3	4	5	6	7	8	9

	Social Worker / Case manager	Does Not Apply	**very low/ Poor**				**meets my expectations average**			**exceptional/ very good**	
105.	Amount of time	0	1	2	3	4	5	6	7	8	9
106.	Availability & flexibility	0	1	2	3	4	5	6	7	8	9
107.	Quality of care	0	1	2	3	4	5	6	7	8	9
108.	Importance of service	0	1	2	3	4	5	6	7	8	9
109.	Competency of provider	0	1	2	3	4	5	6	7	8	9

Turn the page and continue .

	Behaviour Therapist	Does Not Apply	**very low/ Poor**				**meets my expectations average**			**exceptional/ very good**	
110.	Amount of time	0	1	2	3	4	5	6	7	8	9
111.	Availability & flexibility	0	1	2	3	4	5	6	7	8	9
112.	Quality of care	0	1	2	3	4	5	6	7	8	9
113.	Importance of service	0	1	2	3	4	5	6	7	8	9
114.	Competency of provider	0	1	2	3	4	5	6	7	8	9

	Speech/Language Therapist	Does Not Apply	**very low/ Poor**				**meets my expectations average**			**exceptional/ very good**	
115.	Amount of time	0	1	2	3	4	5	6	7	8	9
116.	Availability & flexibility	0	1	2	3	4	5	6	7	8	9
117.	Quality of care	0	1	2	3	4	5	6	7	8	9
118.	Importance of service	0	1	2	3	4	5	6	7	8	9
119.	Competency of provider	0	1	2	3	4	5	6	7	8	9

	Physio/Occupational therapy	Does Not Apply	**very low/ Poor**				**meets my expectations average**			**exceptional/ very good**	
120.	Amount of time	0	1	2	3	4	5	6	7	8	9
121.	Availability & flexibility	0	1	2	3	4	5	6	7	8	9
122.	Quality of care	0	1	2	3	4	5	6	7	8	9
123.	Importance of service	0	1	2	3	4	5	6	7	8	9
124.	Competency of provider	0	1	2	3	4	5	6	7	8	9

	School Teacher	Does Not Apply	**very low/ Poor**				**meets my expectations average**			**exceptional/ very good**	
125.	Amount of time	0	1	2	3	4	5	6	7	8	9
126.	Availability & flexibility	0	1	2	3	4	5	6	7	8	9
127.	Quality of care	0	1	2	3	4	5	6	7	8	9
128.	Importance of service	0	1	2	3	4	5	6	7	8	9
129.	Competency of provider	0	1	2	3	4	5	6	7	8	9

Turn the page and continue …

	Child Care Worker	Does Not Apply	**very low/ Poor**				**meets my expectations average**			**exceptional/ very good**	
130.	Amount of time	0	1	2	3	4	5	6	7	8	9
131.	Availability & flexibility	0	1	2	3	4	5	6	7	8	9
132.	Quality of care	0	1	2	3	4	5	6	7	8	9
133.	Importance of service	0	1	2	3	4	5	6	7	8	9
134.	Competency of provider	0	1	2	3	4	5	6	7	8	9

	Respite Care Provider	Does Not Apply	**very low/ Poor**				**meets my expectations average**			**exceptional/ very good**	
135.	Amount of time	0	1	2	3	4	5	6	7	8	9
136.	Availability & flexibility	0	1	2	3	4	5	6	7	8	9
137.	Quality of care	0	1	2	3	4	5	6	7	8	9
138.	Importance of service	0	1	2	3	4	5	6	7	8	9
139.	Competency of provider	0	1	2	3	4	5	6	7	8	9

	Group home/special housing **STAFF**	Does Not Apply	**very low/ Poor**				**meets my expectations average**			**exceptional/ very good**	
140.	Amount of time	0	1	2	3	4	5	6	7	8	9
141.	Availability & flexibility	0	1	2	3	4	5	6	7	8	9
142.	Quality of care	0	1	2	3	4	5	6	7	8	9
143.	Importance of service	0	1	2	3	4	5	6	7	8	9
144.	Competency of provider	0	1	2	3	4	5	6	7	8	9

	After school care/baby sitter	Does Not Apply	**very low/ Poor**				**meets my expectations average**			**exceptional/ very good**	
145.	Amount of time	0	1	2	3	4	5	6	7	8	9
146.	Availability & flexibility	0	1	2	3	4	5	6	7	8	9
147.	Quality of care	0	1	2	3	4	5	6	7	8	9
148.	Importance of service	0	1	2	3	4	5	6	7	8	9
149.	Competency of provider	0	1	2	3	4	5	6	7	8	9

Turn the page and continue …

	Supported work Placement	Does Not Apply	**very low/ Poor**				**meets my expectations** **average**			**exceptional/ very good**	
150.	Amount of time	0	1	2	3	4	5	6	7	8	9
151.	Availability & flexibility	0	1	2	3	4	5	6	7	8	9
152.	Quality of care	0	1	2	3	4	5	6	7	8	9
153.	Importance of service	0	1	2	3	4	5	6	7	8	9
154.	Competency of provider	0	1	2	3	4	5	6	7	8	9

	Special Medical Support/Equipment	Does Not Apply	**very low/ Poor**				**meets my expectations** **average**			**exceptional/ very good**	
155.	Amount of time	0	1	2	3	4	5	6	7	8	9
156.	Availability & flexibility	0	1	2	3	4	5	6	7	8	9
157.	Quality of care	0	1	2	3	4	5	6	7	8	9
158.	Importance of service	0	1	2	3	4	5	6	7	8	9
159.	Competency of provider	0	1	2	3	4	5	6	7	8	9

	Other: ____________________ **(specify)**	Does Not Apply	**very low/ Poor**				**meets my expectations** **average**			**exceptional/ very good**	
160.	Amount of time	0	1	2	3	4	5	6	7	8	9
161.	Availability & flexibility	0	1	2	3	4	5	6	7	8	9
162.	Quality of care	0	1	2	3	4	5	6	7	8	9
163.	Importance of service	0	1	2	3	4	5	6	7	8	9
164.	Competency of provider	0	1	2	3	4	5	6	7	8	9

Turn to the next page and continue …

Please rate each of the following areas in terms of whether it is a **CURRENT CONCERN** or a **FUTURE CONCERN**, as well as how urgent this issue is to you as a parent. **CURRENT CONCERNS** are issues that are important to you now, that need to be addressed now or soon. **FUTURE CONCERNS** are issues that will become more important later in time. **URGENCY** describes how important that current or future issue is to you **NOW**. Above all, the goal is for you to identify the issues and topics that most critically need to be addressed now. As such, *topics with lower scores* should be ones that *can be "set aside"* for now, where as *topics with higher scores need to be addressed very soon!* Each item can have only one score.

Issue of concern	**0-NA means Does Not Apply**	**Future Concern** Rank from *Not urgent* to *Urgent*			**OR**	**Current Concern** Rank from *Not urgent* to *Urgent*		
165. Transition planning	0-NA	1	2	3		4	5	6
166. Child's progress at school	0-NA	1	2	3		4	5	6
167. Receiving appropriate medical support	0-NA	1	2	3		4	5	6
168. Securing adequate respite	0-NA	1	2	3		4	5	6
169. Securing appropriate housing for child	0-NA	1	2	3		4	5	6
170. Social skill development	0-NA	1	2	3		4	5	6
171. Teaching appropriate behaviours	0-NA	1	2	3		4	5	6
172. Child safety	0-NA	1	2	3		4	5	6
173. Language development	0-NA	1	2	3		4	5	6
174. Building friendships	0-NA	1	2	3		4	5	6
175. Puberty and teen transitions	0-NA	1	2	3		4	5	6
176. Sexual / relationship development	0-NA	1	2	3		4	5	6
177. Building a support team	0-NA	1	2	3		4	5	6
178. Financial security of child as adult	0-NA	1	2	3		4	5	6
179. Housing of child as adult	0-NA	1	2	3		4	5	6
180. Finding job for child when out of school	0-NA	1	2	3		4	5	6
181. Finding care workers (eg. Child care and respite)	0-NA	1	2	3		4	5	6
182. Finding professional supports (Dr, counsellor, etc.)	0-NA	1	2	3		4	5	6

183. What do you consider to be the most important goals for yourself or your family regarding your child with a disability?

184. In your opinion, what are the most important steps that need to be taken next for your family to become more healthy and happy?

185. Do you have any other concerns or experiences about your life with a child with a disability that you want to share?

186. Using any number from 1 to 100, how would you rate your family's **current overall functioning** in relation to having a child with a disability?

1 10 20 30 40 50 60 70 80 90 100

●——————————————————●

We are in total despair.
We will not make it as a family,
if we continue this way.

We are doing exceptionally well!
There is nothing that we could do
better as a family.

187. Using any number from 1 to 100, how would you rate your **current overall satisfaction** with the services and social supports that you receive?

1 10 20 30 40 50 60 70 80 90 100

●——————————————————●

0% satisfied
We get no useful support to
help us with our disabled
child.

100 % satisfied!
Our support system is
exceptional! There is nothing
more that we need as a family.

THE END.
Thank you for completing the Family Context Survey. Please be sure to return this form AS SOON AS POSSIBLE to:
Steve Cunningham. Put in envelope.

APPENDIX C

Researcher Background

In the past 12 years I have had the honour of working with families with children with special needs in various capacities. I have been a support worker and caregiver to the children, counsellor for the family and siblings, respite for the families, and other roles that I happily took on in the lives of these very special people. In other words, I have had the role of both a professional and a caregiver. In these two roles I saw very different things, and was treated very differently. As a professional I was treated with respect and given information in a professional manner. As a caregiver however, I was given a small taste of what families encounter. I was not given the information that I needed to care for the children and furthermore, I had to fight to get what I knew (from being a professional) was available to the children.

It was these experiences that lead inspired me to write this paper. From my experience, I knew that parents were a wealth of knowledge on special needs and their children in particular but they struggled to be heard. I also knew that in many ways, even well meaning professionals missed the mark with respect to providing services that the families needed. So I wanted to give these families a voice, a space to have their needs and thoughts heard. And that is what I have attempted to provide by doing this study.

In the process of doing this study, my own thoughts and ways of practise have shifted. I realized that families and professionals are speaking different languages. In listening to the voices of the families, the experts on their children with special needs I gained a real appreciation for what the families have to give to the field. But they needed a translator or a bridge to be able to speak to the professionals about what they needed by way of support. So, in this study I not only was able to provide space for their voice, but with my background in the field of special needs as both caregiver and professional I was able to provide a bridge from the families to the professionals and back so that they can begin the conversation that will lead to better support to these families.

This shift in me has also enriched my own practise as I brought what I learned from these families to the field and have applied it to my own work. The feedback has been very encouraging as families respond with appreciation for feeling heard.

APPENDIX D

Typologies of Families with Children with Disabilities

Type 1: High needs, low coping/family functioning, low resources

Type 2: High needs, high coping/family functioning, high resources

Type 3: High needs, high family functioning/coping, low resources

Type 4: Low needs, high family functioning/coping, low resources

Type 5: Low needs, low family functioning/coping, low resources

Type 6: Low needs, high family functioning/coping, high resources

Note: High needs is conceptualized as severity of disability, resources is conceptualized as how much support the family receives, financially, emotionally, and professionally, and family coping being conceptualized by Folkman et al. (1986), as a persons cognitive and behavioural efforts to manage the internal and external demands of the stressful situations.

APPENDIX E

Recruitment Poster

Don't be left out!!

I am working on a research project, **"Living with a Child with Disabilities: The Family Experience"** and I would like your help. Together we will explore the gifts and the challenges that go hand in hand with having a family member with special needs. I would like to hear your story!

During your participation in the research you will be asked to answer a series of questions relating to your experience of being a family member of a child with special needs. Your participation will last approximately 1.5 hours. As well as the audio taped interview, I will be asking you to fill out a few surveys relating to demographics and the Family Context Survey.

This research is intended to give families such as yours a voice and to help professionals understand your experience more fully and I am hoping to hear about the challenges and triumphs that you go through as a family. As such, to ensure your privacy, identifying information about your family will never be associated with any report and all information will be kept confidential.

As a thank you for your participation in this study, your family's name will be entered in a draw for a gift certificate for dinner at a restaurant in the area.

So…

If you are a family member of a child with disabilities who is living at home with you…

I would like to hear your story!!

If you are interested in participating or have any questions about this study please contact the researcher, Tracy Wilkins, at (604)316-1474 or *twilkins1@shaw.ca* .

Thank you.

APPENDIX F

Typology Development Procedure

Variables from the Cunningham data set will be selected to help describe different levels of needs and resources characterizing families' experiences. In addition, key informants as well as literature will be consulted to evaluate preliminary descriptions, with the coping model being based on Folkman's et al (1986) model. Process outline: literature, consultation, Cunningham, consultation & revision. The data from the respondents of the Cunningham survey will be looked at and based on literature, clinical experience, and consultation with other professionals it is hypothesized that eight types will emerge from the responses provided by the parents in the Cunningham survey. These groups may include: a) high disability, low coping/family functioning, low satisfaction with resources, b) high disability, high coping/family functioning, high satisfaction with resources, c) high disability, high coping/family functioning, low satisfaction with resources, d) high disability, low family functioning/coping, low satisfaction with resources, e) low disability, high coping/family functioning, low satisfaction with resources, f)low disability, low coping/family functioning, low satisfaction with resources, g) low disability, high coping/family functioning, high satisfaction with resources, h) low disability, low family functioning/coping, high satisfaction with resources (with high disability being conceptualized as severity of disability, satisfaction with resources being conceptualized as how satisfied the family is with the support the family receives, financially, emotionally, and professionally, and family coping being conceptualized by Folkman et al. (1986), as a persons cognitive and behavioural efforts to manage the internal and external demands of the stressful situations).

APPENDIX G

Script for Initial Recruitment

My name is Tracy Wilkins and I am a graduate student in Counselling Psychology at Trinity Western University. I am inviting families such as yourself to talk with me and share your experiences of having a child with special needs in your family. The interview will take approximately 1.5 hours and will be conducted by myself with as many of your family members that wish to participate present. I will give you a list of the questions before hand so that you know what we will be talking about. After the interview I would invite you to share some more information with me by filling out a questionnaire about your family. At the end of the research I will contact you again to share with you the results. I would really appreciate the opportunity to speak with you and your family about your experiences.

APPENDIX H

Informed Consent

August 4, 2004

Dear Research Participants,

Thank you for your interest in the research project, “Living with a Child with Disabilities: The Family Experience”. Together we will explore the gifts and the challenges that go hand in hand with having a family member with special needs. I would like to hear your story!!

During your participation in the research you will be asked to answer a series of questions (given to you in advance) relating to your experience of being a family member of a child with special needs. Your participation will last approximately 1.5 hours and may include follow-up questions. As well as the audio-taped interview, I will be asking you to fill out a few surveys relating to demographics and the Family Context Survey.

As this research is intended to give families such as yourself a voice and to help professionals understand your experience more fully, I am hoping to hear about your experiences. As such, to ensure your privacy, all identifying information about your family will be kept separate from your interview question answers and furthermore, your name, address, or phone number will never be associated with any report. All information will be kept confidential and after the completion of the study, the audiotapes will be destroyed.

During your involvement in this study, some of the topics that we discuss may bring up feelings in you that may be uncomfortable. I would encourage any of the family to talk with me about this and I would be happy to offer you referrals to counsellors that can help you work through these feelings.

Please keep in mind that your participation in this study is voluntary, and you may discontinue at any time for any reason. If you have any questions about your participation in this study, or the questions, please contact either myself Tracy Wilkins at (604)316-1474 or call Dr. McDonald at (604)888-7511.

As a thank you, your families name will be entered into a draw for a gift certificate for dinner at a restaurant in the area.

If you have any questions about the ethical issues involved in this project you may contact Ms. Sue Funk in the Office of Research at (604)513-2142.

I have read and understand the description of the study and I willingly consent to the participation of my family in this study

I acknowledge that my responses may be put in an anonymous form and kept for further analysis after this study in completed

Participant	Participant

APPENDIX I

Protocol for Interview

General Questions:

1. Please tell me about your family.
2. Can you give me an example of a time/incident when you coped well as a family?
3. What things would you identify help and hinder your coping as a family?
4. What strategies do you employ as a family or individuals to help the family cope (family strengths)?

Incident Specific Questions:

Diagnosis:

1. How old was your child when he/she was diagnosed/how long ago?
2. How did you react to the news of the diagnosis?
3. What did you do as a family or individually at this time?
4. Who, if anyone did you ask for help?
5. What roadblocks did you face as a family as you coped at this time?
6. What helped your family cope at this time (strengths)?

Another critical incident in the life of your child:

1. Please tell me of a time in the life of your child with special needs that stands out to you (stressful).
2. How old was your child at this time?
3. How did you react as a family and/or individually?
4. Who, if anyone did you ask for help?
5. What roadblocks did you face as a family as you coped at this time?
6. What helped your family cope at this time?

APPENDIX J

Advice for Families

When asked to talk about the advice that the participant families would give other families with children with special needs, the participants gave the following statements:

- Persevere
- Demand respect for your child
- Question the experts
- Research the diagnosis
- Appreciate the gifts
- Be creative in teaching
- Work on what you see as important
- Challenge your child
- You need to develop resources to give you a breather
- Self care is important and lack of support leads to burnout
- Believe in your child and hope for the future
- Don’t let them treat your like a 2nd class citizen
- Understand the difference between the public and private sector (i.e. in the private sector you deal with waitlists but get more choice)
- Make your own plans
- Don’t rely on waitlists, let it be a happy surprise when things come up
- You are not always offered what you need
- Support not meddling; define what you support means to you
- Give advice to others
- Be aware of the grieving process and how you are progressing through it
- Parent need to look forward and not get stuck in the past; learn from it and pass wisdom on to others

APPENDIX K

Questionnaire of Types

Typologies of Families with Children with Disabilities

(To be given to the family after the interview)

Please choose the phrase that best describes your family:

1. (a) The financial strain of taking care of our special needs child is not difficult for our family to manage.
(b) The financial strain of taking care of our special needs child is difficult but manageable for us.
(c) The financial strain of taking care of our special needs child is so difficult that it hurts the family.

2. (a) We receive no support outside of our immediate family in caring for our special needs child.
(b) We have some support available to us outside our immediate family but we choose to care for our special needs child on our own.
(c) We have all the support that we need outside our immediate family and we ask for help when we need it.

3. (a) Our family is challenged in positive and negative ways by caring for our special needs child, but overall, we are growing from the experience/thriving and doing well.
(b) Our family is challenged in positive and negative ways by caring for our special needs child, and overall we are feeling the strain but holding together as a family.
(c) Our family is challenged in positive and negative ways by caring for our special needs child, and overall I am concerned about the well-being of my family, whether my family can hold together over the long run.

With your answers to the above statements in mind please choose which description best fits with your family.

A. Our special needs child has severe difficulties in most areas of his life as a result of his disabilities. In caring for our special needs child we are challenged and individuals and/or the family as a whole feel unable to meet the challenges presented. The strain of their care causes me concern over whether we can hold together as a family. Outside of our immediate family we have little or no support in caring for our special needs child.

B. Our special needs child has severe difficulties in most areas of his life as a result of his disabilities. In caring for our special needs child we are challenged but we feel able to meet the challenges and are growing and thriving as a family. Outside of our family we have many people supporting us and we can ask for help when we need it.

C. Our special needs child has severe difficulties in most areas of his life as a result of his disabilities. In caring for our special needs child we are challenged but we feel able to meet the challenges and we are growing and thriving as a family. Outside of our immediate family we have little or no support in caring for our special needs child.

D. Our special needs child has difficulties in some areas of his life as a result of his disabilities. In caring for our special needs child we are challenged but we feel able to meet the challenges and we are growing and thriving as a family. Outside of our immediate family we have little or no support in caring for our special needs child.

E. Our special needs child has difficulties in some areas of his life as a result of his disabilities. In caring for our special needs child we are challenged and individuals and/or the family as a whole feel unable to meet the challenges presented. The strain of their care causes me concern over whether we can hold together as a family. Outside of our immediate family we have little or no support in caring for our special needs child.

F. Our special needs child has difficulties in some areas of his life as a result of his disabilities. In caring for our special needs child we are challenged but we feel able to meet the challenges and are growing and thriving as a family. Outside of our family we have many people supporting us and we can ask for help when we need it.

APPENDIX L

Website

Living with a Child with Special Needs: The Family Experience

A. GIVING FAMILY MEMBERS A VOICE

If you have information to add to the interview for your family please fill in the following survey or if your family has not been interviewed at all you are invited to fill out this survey as well.

Click "Next" if you agree to participate in this study. If you'd like to leave the survey at any time, just click "Exit this survey".

B. BACKGROUND QUESTIONS

1. What is the participant number of your family? (the number on your survey and in your e-mail message from the researcher.) If no one in your family has been interviewed please leave this question blank.

2. Where do you live?
Abbotsford
Chilliwack
Delta
Tswassan
Vancouver
Langley
Vancouver
Burnaby
New Westminster
Richmond
Aldergrove
Maple Ridge
Coquitlam
Other (please specify)

3. What is your child’s diagnosis?

4. How many children do you have?
1
2
3
4
5
6
7
8

More than 8 children

5. Have you already been interviewed as part of this project?
- Yes we have met already

No, we have not already discussed these questions

C. INTRODUCTION TO FAMILY EXPERIENCE PROJECT

Thank you for your interest in the research project, “Living with a Child with Disabilities: The Family Experience”. Together we will explore the gifts and the challenges that go hand in hand with having a family member with special needs. I would like to hear your story!!

During your participation in the research you will be asked to answer a series of questions relating to your experience of being a family member of a child with special needs.

As this research is intended to give families such as yourself a voice and to help professionals understand your experience more fully, I am hoping to hear about your experiences. As such, to ensure your privacy, all identifying information about your family will be kept separate from your survey answers and furthermore, your name, address, or phone number will never be associated with any report. All information will be kept confidential.

During your involvement in this study, some of the topics that we discuss may bring up feelings in you that may be uncomfortable. I would encourage any of the family to talk with me about this and I would be happy to offer you referrals to counsellors that can help you work through these feelings.

Please keep in mind that your participation in this study is voluntary, and you may discontinue at any time for any reason. If you have any questions about your participation in this study, or the questions, please contact either myself Tracy Wilkins at (604)316-1474 or twilkins@shaw.ca or call Dr. McDonald at (604)513-2034.

If you have any questions about the ethical issues involved in this project you may contact Ms. Sue Funk in the Office of Research at (604)513-2142.

I acknowledge that my responses may be put in an anonymous form and kept for further analysis after this study in completed

By clicking on the "next" button below, I agree that I have read and understand the description of the study and I willingly consent to the participation of my family in this study

If you decide not to participate in this survey, just close your browser window.

D. COPING STRATEGIES

Like the interview, this section addresses your experience of living with a child with special needs. When answering each question, keep in mind that there is no right or wrong answer. The questions are guides to help you talk about what helps and hinders your coping personally and/or as a family with a child with special needs.

6. Please tell me a bit about your family.

7. Please give me an example of a time/incident when you feel that you coped well as a family.

8. What kinds of things help you cope?

9. What kinds of things hinder or limit your ability to cope?

10. What coping strategies do people in your family use to help the family cope?

11. What strengths do you see in the people in your family?

12. What do you personally or as a family do in times of stress?

13. Who, if anyone, do you ask for help in times of stress?

14. What roadblocks do you or your family face when trying to cope with stressful times with your family member with special needs?

15. Where do you personally or as a family find the strength to cope in stressful times?

16. Please comment on your satisfaction with the availability of services to help you care for your family member with special needs.

17. If you had any advice for a family member of a child with special needs when they are first starting out on their journey, what would it be?

18. Is there anything else that you would like to share about your experience in a family with a child with special needs?

E. LOOKING TO THE FUTURE

19. What would be on your "wish list" for the future to help you cope with the challenges or to help accentuate the gifts of living with a family member with special needs?

F. THANKS!

I appreciate the time and emotion that you have put into helping me with this study. Thank you for sharing your story with me!!!

Tracy Wilkins

e-mail: twilkins1@shaw.ca

NOTE: If your family has not been interviewed by this researcher and would like to take further part in this research project please contact me at (604)316-1474 or twilkins1@shaw.ca to set up a personal interview.