“The moral test of a society is how that society treats those who are in the dawn of life, the children; those who are in the twilight of life, the elderly; and those who are in the shadow of life, the sick, the needy and the handicapped.”

Hubert Humphrey

University of Alberta

Parent's Perception of Professional Contacts during their Adaptation to Caring for a Child with Disabilities

by

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Dedicated to my beloved parents

Boonron & Ratana Ramingwong

Abstract

The key objective of this study was to identify and describe parents' perceptions of professional practices that enhanced or undermined their parental roles and their relationships with their children who have disabilities. In phase one, participants in a focus group were asked to generate responses to the two open-ended questions: (1) "Please describe the important things that professionals have said or done that made you feel better or more secure in your relationship with your child and your role as a parent of a child with a disability", and (2) "Please describe the important things that professionals have said or done that made you feel worse or less secure in your relationship with your child and your role as a parent of a child with a disability." Two lists of statements were generated, sorted, and rated by participants. Consequently, multidimensional scaling and hierarchical cluster analysis were used to analyze the data to create concept maps. The parents' positive perceptions of professional practices consisted of 5 themes: (1) Supportive services from health professionals, (2) Psychological support from health professionals, (3) Supportive care-workers, (4) Social services help with home-life balance, and (5) Supportive school professionals. The parents' negative perceptions of professional contacts consisted of 6 themes: (1) Inadequacy of school professionals, (2) Conflict with health professionals, (3) Professionals' ignorance, (4) Social service professionals' lack of empathy, (5) Fight for social services, and (6) Funding issues.

In phase two, an incidence survey was developed based upon parents' reported statements. Administering the survey to parents of individuals with disabilities who attended the Elves Special Needs Society programs in Edmonton, Alberta, determined the extent to which other parents perceived similar positive or negative experiences with professional contacts. All 5 clusters from the map on parents' positive perceptions of professional practices received a significant amount of agreement responses. Respondent variability existed at the level of individual items within "inadequacy of school professionals" and "conflict with health professionals" categories. The findings are important to guide practice for professionals in the field of disabilities services.

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CHAPTER I

Introduction

Statement of the Problem

In the past, parents of children with disabilities were seen as passive recipients of social support services from expert professionals. Neglecting parental perspectives and participation resulted in a failure to promote their involvement and adaptation in the enabling care of their children. Farrar (1942), a leading Canadian psychiatrist, wrote that good professional practice requires the destruction of any attachment between parents and children with severe disabilities. Ferguson (2002) described how, from roughly 1820 to 1920, medical and educational experts blamed most childhood disability on parents, especially mothers who were poor. These professionals argued that the only way to break the connection between poor parents and children with disabilities was to allow professionals to assume the parental role within institutions. Institutionalization and segregated services were then the dominant professional and social responses to parents and individuals with disabilities. The policy of institutionalization was driven by a combination of motives ranging from the benign desire to relieve families of the demands of care to the deeply objectionable desire to rid society of what was considered inferior stock. Professionals and society overlooked the feelings and voices of parents and individuals with disabilities while depriving them of their rights. Institutions segregated individuals with disabilities from the rest of society and reinforced notions of difference and inferiority (Asch, Blustein, & Wasserman 2008). As a result, parents had greater difficulty in maintaining contact with their institutionalized children. Furthermore, many individuals with disabilities were harmed by neglect, abuse, and even violence against them by institutional staff and by other residents (Law Commission of Canada, 2000). History has shown that professionals and their practices have sometimes done great harm to people with disabilities and their families.

The Convention on the Rights of the Child was adopted by the United Nations on November 20, 1989, and was adopted by Canada and most other nations shortly thereafter. The convention confirms that family is the natural and best environment for the growth and well-being of all children. Article 23 of the Convention states clearly that a child with a disability should live in an environment which ensures dignity, supports independence, and facilitates his or her active participation in a community (United Nations, 1996). Later, the United Nations Convention on the Rights of Persons with Disabilities was adopted on December 13, 2006 and indicated a significant movement of people with disabilities in response to the inequalities and discrimination that exist within society. The Convention marks the shift from viewing persons with disabilities as "objects" of charity, medical treatment, and social protection towards viewing persons with disabilities as "subjects" with rights, who are capable of claiming those rights and making decisions for their lives based on their free and informed consent as well as being active members of society (United Nations, 2006). The movement of the past decades has weakened the assumption that people with disabilities cannot function in ordinary community settings (Asch et al., 2008).

A policy of deinstitutionalization has been implemented over the past five decades, emphasizing families as a potential resource for providing good care to children with disabilities. The vast majority of people with disabilities now live with their families and integrate in society with nondisabled people. The U.S. Department of Health and Human Services (HHS) has developed the public health plan, Healthy People 2010. Among its goals, by 2010, Healthy People 2010 was to reduce to 0 the number of children with disabilities aged 17 years and younger living in congregate care facilities, consistent with permanency planning principles (US Department of Health and Human Services, 2000). Congregate care is defined as any setting in which four or more unrelated persons with disabilities reside together. Permanency planning emphasizes the use of supports necessary to enable a child to be raised in an ongoing secure family relationship (Johnson & Kastner, 2005). By the end of 2011, the goal had yet to be achieved. However, it appears that progress in reducing out-of-home placements of children and youth with disabilities is moving slowly toward the target. Larson et al. (2011) provided a report from the U.S. showing that between June 1977 and June 2009, the number of children (0-14) and youth (15- 21) with intellectual disabilities and developmental disabilities in out-of-home placements decreased from an estimated 90,942 to an estimated 20,753. Factors that clearly contribute to this progress were policy shifts toward inclusion and the availability of supportive services to families of individuals with disabilities. To achieve the goal of eliminating congregate care settings for children with disabilities, professionals in health care, social services, and school systems need to respond adequately and appropriately to meet the families' needs. A failure of any of these service systems certainly influences the experience of families of persons with disabilities.

Indeed, these policy shifts have promoted social integration and rights of people with disabilities and their parents. They clearly have great benefits for child development and family well-being. Research also reports many positive effects on parents as a result of parenting a child with disability, such as personal growth (Scorgie & Sobsey, 2000) and self-fulfillment (Lane et al., 2000). Nonetheless, having a child with significant physical and intellectual disabilities in the family typically requires collaborative relationships between parents and professionals. Parental use of professional resources is one way to manage and adapt to the demands and challenges associated with the child's complex and unique needs (Atkin & Ahmad, 2000). There is evidence that parenting a child with a disability is stressful and can have negative effects on family (Erwin & Soodak, 1995; Hoare et al., 1998). Society, including experts in social policy, recognizes the need to support families who are parenting children with disabilities and the need to strengthen families' support resources. Social support has been found to be an important factor in enhancing parents' acceptance of and adaptation to their child's disability. Social support is believed to act as a buffer against the psychological assault of social stigma and the stress arising from life transitions (Romer & Heller, 1983). Parents are the center of a child's supports and the coordinators of their child's support network services. Goodley and Tregaskis (2006) stated that contact with formalized care services is a key part of life for parents of children with disabilities. Supportive interactions that parents experience with professionals (e.g., doctors, teachers, social workers, therapists) enable them to better meet the needs of their children with disabilities and their families as a whole. However, researchers report that available supports are not always helpful and are often a constraint rather than a resource (Llewellyn, 1995; Llewellyn & McConnell, 2002).

Philips, Morrison, and Davis (2004) argued that many health professionals have limited knowledge and experience of the needs of people with intellectual disabilities and also feel uncomfortable when faced with caring for them. Bianco, Garrison-Wade, Tobin, and Lehmann (2009) found many parents of young adults with developmental disabilities in their study did not always feel that their relationships with agencies and service providers were welcomed or collaborative, and parents did not feel that agencies and service providers listened to them. Inappropriate responses from professionals can provoke anxiety; heighten feelings of guilt, isolation, and helplessness; and lead to feelings of distrust and hesitation in requesting help (Anionwu, 1993; Schoofs et al., 2004). Ray (2003) revealed that health, education, and social services systems were the source of frustration for parents of individuals with special needs. Many professionals failed to respect the central role of parents in providing and coordinating their child’s care. Under some circumstances, professional supports can be counterproductive and add more stress to the parents’ adaptive role to caring for a child with disabilities. For example, professional supports designed to teach parents more effective parenting skills may undermine the parents’ confidence in their own parenting. Similarly, social supports that characterize the child as the source of the parents’ troubles may alienate the parent from the child and threaten the bond between the parent and child. While these examples provide theoretical instances of attempts to be supportive that create problems, little is known of the actual experiences that parents undergo as genuinely supportive or counter-productive. If services are to be effective and responsive to the needs of parents and their children with disabilities, it is essential to understand the parents' perceptions of their experience with professional practices.

Purpose of the Study

The objective of this study was to identify and describe parents' perceptions of professional practices that enhanced or undermined their roles as parents and their relationships with their children with disabilities. The study focused on the parents' perceptions of their experiences with professional contacts regarding support services provided to them in caring for children with disabilities. The study employed a two-phase mixed-method research design. In the first phase, a focus group was used to collect qualitative data from participants that were analyzed using the concept mapping procedures described by Trochim (2002). The concept mapping process was used in addressing specific research questions which included: (1) What did parents report as their perception of their experiences with professional contacts in regard to services delivered to them and their children with disabilities? (2) What were the themes or categories underlying their identified experiences with professional contacts? In the second phase, the results of the first exploratory phase were used to construct a survey that determined the frequency of agreement and disagreement with the findings from the first phase. By measuring the prevalence of agreement and disagreement, the second quantitative phase provided a framework for determining how the findings from phase one can be applied to a larger population of parents.

Significance of the Study

This study solicited parents’ voices to provide a better understanding of their experiences and perceptions of professional contacts. It is assumed that if more can be understood about the way in which professional contacts have a positive or a negative impact on parents’ feelings and roles in caring for a child with disabilities, it will be possible to identify strategies that can be used to improve the quality of professional support services. The information also provides a foundation for social interventions that effectively serve parents of children with disabilities.

Findings from the study will advance current knowledge of: (a) the relationships between parents’ perceptions of professional practices and their adaptation to caring for a child with disabilities; and (b) types and sources of professional interactions perceived by the parents as supportive or unsupportive. The notion of supportive and unsupportive from professional contacts is important not only to assist parents with managing their psychological distress and adaptive skills but also to guide the provision of effective psychosocial, educational, and health services to strengthen positive family adaptation in caring for a child with disabilities.

The subsequent chapters of this thesis are organized as follows. Chapter 2 contains literature concerning professional practices that have influenced the lives of individuals with disabilities and their parents, the Double ABCX model and the Family Adjustment and Adaptation Response (FAAR) Model as the theoretical framework to enhance our understanding of the adaptation process among parents of children with disabilities, and conceptualization of social support. Chapter 3 contains a detailed description of the research method used in this study. An overview of the concept mapping methodology described by Trochim (2002) is also presented in this chapter. Chapter 4, the results of the study are presented in the form of concept maps and the findings of the incidence survey. Chapter 5 provides a summary and discussion of the major findings of the research, limitations of the study, and implications for practice and future research.

CHAPTER II

Review of Literature

This chapter defines the scope and meaning of disabilities and presents an overview of literature on the impact of professional practices on parents and their children with disabilities. It presents a critical review of research on negative assumptions about family pathology and on professional practices that can have adverse effects on parents' adaptation to caring for children with disabilities. Professionals' support has been widely accepted as important to enhance parents' adaptation to caring for their children with special needs. However, there has not been as much research about how efforts to provide support may undermine adaptation. The theoretical models used to guide this study are the Double ABCX model, and the Family Adjustment and Adaptation Response (FAAR) model are described in this chapter.

The Impact of Professional Practices on Children with Disabilities and their Parents

The Family Support for Children with Disabilities Act of Alberta (2007) defines disability as:

> A chronic developmental, physical, sensory, mental or neurological condition or impairment but does not include a condition for which the primary need is for medical care or health services to treat or manage the condition unless it is a chronic condition that significantly limits a child's ability to function in normal daily living. (p.2)

Also, in the United States, the Developmental Disabilities Assistance and Bill of Rights Act (2000) defines a developmental disability as a severe, chronic disability that:

> a) is attributable to a mental or physical impairment or a combination of both impairments;
>
> b) is manifested before the person attains age twenty two;
>
> c) results in substantial functional limitations in three or more of the following areas of major life activity: (1) self care, (2) receptive and expressive language, (3) learning, (4) mobility, (5) self-direction, (6) capacity for independent living, (7) economic self-sufficiency; and
>
> d) reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are of lifelong or extended duration. (p. 1677)

A national policy to institutionalize people with disabilities was once advocated in Canada, the U.S., and many other countries around the world. Many professionals and policy makers may have intended to provide support to these vulnerable people and their families, but the realities that their experience was different. The neglect of parental perspectives and insensitive approaches to delivering services to children with disabilities and their parents resulted in a lasting impact on their ability to adapt and adjust to typical lives. More recently, realizing the institutionalization policy was wrong, many countries have implemented a new policy: deinstitutionalization. Large residential facilities for children with disabilities in North America began closing their doors in the late

1960s, peaking from 1988 through 1999 (Coucouvanis, Polister, Prouty, & Lakin, 2003), but continuing at a slower rate since.

Professionals' attitudes and beliefs have strongly influenced policy decisions, their practices, and consequently the lives of persons with disabilities and their parents. This is demonstrated by another development that violated the human rights of people with disabilities. Between 1924 and the late 1930s, starting in Virginia, the majority of American states had passed laws permitting the state to sterilize individuals found to be incompetent because of mental retardation, mental illness, alcoholism, epilepsy, or other factors. This practice continued to some extent into the 1970s (Blacher & Baker, 2002). In Alberta, sterilization began in 1928 and continued until 1972.

Both institutionalization and forced sterilization were based in part on eugenic ideas that were fueled by primitive notions of natural selection, racial and ethnic prejudices, and unfounded beliefs in good and bad bloodlines. Advocates of eugenics came to believe that society must eliminate bad blood lines by arresting a person's capacity to reproduce through either incarceration in sexually segregated institutions throughout the reproductive years or through sexual sterilization.

In the past, people with disabilities and their families had no significant voices in society. They were passive recipients of whatever treatment professionals provided to them. Families' perceptions and real needs were often overlooked by professionals. The medical model of disability implies professionals know best, and has resulted in hardship and even harm to people with disabilities and their parents. Recently, the United Nations General Assembly (2006) adopted the Convention on the Rights of Persons with Disabilities, stating that every person with a disability has a right to respect for his or her physical and mental integrity on an equal basis with others. Another recent change is that the American College of Obstetrics and Gynecology (ACOG) (2007) stated in a position paper that hysterectomy should not be used as the primary and initial treatment for dealing with menstruation, or for non-voluntary sterilization for girls and women with disabilities. Indeed, professionals' practice and support for people with disabilities and their parents has gradually shifted toward a social model of disability.

Negative Assumptions about Family Pathologies

Society has moved from an institutional model of care toward community-based models of care. Parents are seen as important partners with professionals in the care of their children with disabilities. However, social values and beliefs about the causal connections between children with disabilities and damaged families still have a great influence on research and professional practice. Families who have children with disabilities have long been confronted by social stigma. For example, Brinchann (1999) compared having a child with severe disabilities at home with living in a prison because the child was so dependent on the parents that parental freedom was severely restricted. As a nurse and researcher, Brinchann supports withdrawing treatment for a severely disabled child in a neonatal ward because the child is a burden to the family and society. Fox and Wilson (1999) stated that attitudes of health professionals towards children with disabilities could be negative and medical decisions were sometimes made on the basis of a pessimistic view of the quality of their lives and value as citizens.

Many researchers have suggested that parents of children with developmental disabilities experience high levels of stress and dysfunction. Crnic, Friedrich, and Greenberg (1983) indicated that families of children with disabilities often experience greater stress than families with non-disabled children. Mothers of children with autism have reported significantly higher stress levels, lower levels of perceived parenting competency, higher frequency of depression, and more struggles with challenging behaviors than mothers of children without disabilities (Rodrigue, Morgan, & Geffken, 1990). Frude (1992) found that some parents experience feelings of helplessness, inadequacy, anger, shock, guilt, and self-blame. Siblings might also experience feelings of guilt, shame, and embarrassment. Rezendes and Scarpa (2011) suggested that child behavior problems might increase parenting stress, which then interfered with parenting self-efficacy and consequently increased feelings of anxiety or depression in mothers of children with autism spectrum disorders. Although there is unquestionably some validity in research suggesting that many families of children with disabilities experience stress or other negative outcomes, there is indication that research has selectively focused on and over-emphasized the negative aspects while ignoring positive aspects of the parenting experience.

These negative assumptions that researchers and professionals make about family pathologies have raised concerns about the practices that the professionals promote. Kirschner, Brashler, and Savage (2007) argued that judgmental professionals, who tend to criticize parents who seek solutions to care-giving challenges, have harmed parental caregivers. Often, the parents are left with inadequate resources and information to meet their needs. The attitude that having a child with disabilities in the family is a tragedy certainly has an impact on the way families adjust to the situation. This attitude may encourage families to perceive themselves as victims.

Helff and Glidden (1998) investigated published research from the 1970s to the 1990s on adjustment in families of children with disabilities. They stated that researchers still focus excessively on negative rather than positive assumptions and hypotheses in their research. Another negative assumption that professionals and researchers expressed was that parents of children with disabilities had much higher divorce rates than other parents because of the extreme stress they experienced. This expectation of family breakdown sometimes reached the extreme of forecasting that most families of children with severe disabilities would break down. For example, Pabst (1995) claimed, "…feelings of guilt, loneliness, and despair lead to broken marriages in the majority of families of severely handicapped, medically fragile children" (p. 3). This description and others like it suggest that families of children with disabilities are extremely different from other families, that those differences result from the child's disability, and that the outcome is both negative and certain. In fact, the observed differences in the divorce rates appear to be small. Risdal and Singer (2004) used meta-analytic methods to reexamine literature on comparative levels of divorce in parents of children with and without developmental disabilities. A total of 13 studies were conducted in North America from 1975 to 2003, with combined group sizes totaling 48,254 in comparison participants and 6,270 in the disability group. Taken together, these studies found that families of children with disabilities were 5.97% more likely to divorce. This increase in divorce rate is much smaller than previously suggested, and it does not support an older view that children with disabilities cause severe family strain in almost all families. It is also important to note that even this small difference in divorce rates is a correlation and does not demonstrate causality. For example, poverty, family violence, parental substance abuse problems, and a variety of other factors that increase risk for both family breakdown and childhood disability could produce this difference. To determine whether the child's disability is a causal factor, a prospective study that matches parents before they have children with or without disabilities would be required. Fortunately, such a study exists. The Wisconsin longitudinal study has periodically followed a large cohort of individuals from 18 to 54 years old. Among this large group of individuals were many that had families and some of whom had children with disabilities. This longitudinal study makes it possible to compare individuals who were matched at age 18 on various socio-economic characteristics and had children with or without disabilities. Families of children with disabilities had lower incomes than the counter group due to career impacts on one or both parents. There was no difference in divorce rates between families with and without children with disabilities (Seltzer, Greenberg, Floyd, Pettee, & Hong, 2001). Nonetheless, the results do indicate the existence of marital difficulties and the need for better forms of family support for some families of children with disabilities. While Hodapp and Krasner (1994-1995) reported a higher divorce rate among parents of eighth graders with disabilities than among those without, they pointed out that the differences might be explained by other variables. They reported that the families of children with disabilities in the study had significantly lower incomes and were more likely to come from minority groups, both factors which may be important predictors of divorce rates. Joesch and Smith (1997) noted that many studies had found no difference in divorce rates or mixed results, with some subgroups showing increases and others showing decreases. Hence, the claim of high divorce rates among families of children with disabilities has not been supported consistently in empirical studies.

While many studies capture certain aspects of parenting a child with a disability, the negative focus and bias toward expecting deleterious or pathological outcomes in the family may be counter-productive. Contextual variables such as the family’s socio-economic status, parental characteristics, social-support system, and beliefs are important and need to be investigated. The Japan League on Developmental Disabilities (2009) conducted a study on depression in mothers of children with developmental disabilities in four countries; Brazil, Colombia, Malaysia, and Thailand. The researchers found differences between the group of depressed and non-depressed mothers. The depressed mothers lacked home and community support. They were under financial strain, their social and recreational lives were limited, and they viewed their situations negatively. On the contrary, the mothers who were not depressed received support from family members and the community. They had fewer financial problems, and recognized their capacity to cope well with their situations. The study shows that mothers' stress and depression is associated with many factors other than having a child with a disability.

Positive Experiences in Parenting Children with Disabilities

A growing number of studies have emerged documenting positive or beneficial outcomes and experiences in parenting children with disabilities. Greenberg et al. (2004) investigated the physical and psychological well-being of mothers age 55 or older caring for an adult child with Down syndrome, schizophrenia, or autism. They found no relationship between behavior problems and the well-being of mothers of children with different types of disabilities. Interestingly, the study reported that in caring for a child with disabilities, younger mothers experienced positive feelings of personal growth, self-acceptance, and purpose in life more often than older mothers.

Erwin and Soodak (1995) and Hornby (1992) found that parents who advocate for their children with disabilities reported stressful experiences and negative feelings but also strong positive feelings and claims of personal growth. Scorgie, Wilgosh, and McDonald (1996, 1997, 1999) and Scorgie and Sobsey (2000) identified a range of transformational outcomes associated with parenting children with disabilities. The outcomes included personal growth, improved relations with others, and changes in philosophical or spiritual values. Researchers had argued that key transformational outcomes could take time to emerge and might not be so evident early on when stresses within the family might be more evident (Scorgie & Sobsey, 2000).

McCubbin, Cauble, and Patterson (1982) also argued that non-normative stressors were often unforeseen, families might not have available the social, psychological, or material resources needed to manage such events. It is possible that families struggling with stressors may emerge less healthy and more vulnerable than before. However, changes during family crises may also move members toward increased health, maturity, and an opportunity for growth. It is important to acknowledge that it is possible for negative and positive effects to occur simultaneously. For instance, parents describe the deep love they feel for their children with disabilities, and the ways they have grown and changed through their parenting and advocacy experiences. The changes often bring fulfillment to their lives, and help them cope well with the situation (Iversen, Graue, & Clare, 2009; Kenny & McGilloway, 2007). At the same time, a constant need to advocate for services and resources that their children require may be a greater source of stress than actually caring for their children (Roeher Institute, 2000)

Researchers and professionals now recognize that many families of children with disabilities not only adapt well, but also report positive effects of caring for these children, including personal growth, increased tolerance for differences in others, learning valuable life lessons, being part of a strong family unit, appreciation of their child’s contributions to the quality of family life, and that the child is a source of joy, (Hastings & Taunt, 2002; Poston et al., 2003). Similar findings were also reported in a study in Ireland. Parents of children with intellectual disabilities report that gratifying aspects of caring for their children include bonding with the children, deriving a sense of personal fulfillment, and growing creativity and increasing selflessness while acknowledging the need for effective and appropriate service provision (Kenny & McGilloway, 2007). Clearly, there exists evidence of both positive and negative effects of parenting a child with a disability, but increasingly researchers and professionals are focusing more on exploring the ways families adapt to the care of children with disabilities rather than investigating the pathology of families and the burdens of care. This approach has the merit of emphasizing the creative aspects of human services and the facilitative role of resources; it does not characterize parents as passive victims of their circumstances nor reduce the role of individuals with disability to that of a burden (Zarit, 1989).

Theoretical Framework of the Study

Recognizing the impact of professional support on parents' adaptation and the key roles of parents in the lives of children with disabilities, this study explores the experience of professional support from the unique perspectives of parents of children with disabilities in Edmonton, Alberta. The theoretical framework of the study was based upon the Double ABCX Model (McCubbin & Patterson, 1983), and the Family Adjustment and Adaptation Response (FAAR) model (Patterson, 1993). These models are useful and appropriate to the study for many reasons. First, they do not assume pathology in the parents just because the parents have children with disabilities. Second, the models consider the role of the parents' appraisal of the demands and resources that influence their adapting roles to caring for children with disabilities. Finally, they are useful for exploring effective ways of supporting parents while they try to fulfill their on-going roles in the lives of their children with disabilities.

The Double ABCX model.

Hill (1949) originally formulated the ABCX Family Stress Model. The model postulates that a family's reaction (X) to a stressful event (A) is mitigated by the family's resources (B) and its perceptions of the significance of the event (C). In the original model the family's appraisal was dealing with a single stressful event (Patterson, 1993). In reality, families often experience a pile-up of stressors or demands over time, particularly in the aftermath of a major stressor, such as caring for a disabled family member (McCubbin & Patterson, 1982). Thus, the process of reacting to a stressful event is not seen as a reaction to a single event but as a series of responses to many intervening events related to family adaptation. McCubbin and Patterson (1983) expanded the original ABCX model to the Double ABCX model that adds post-crisis variables in an attempt to describe family efforts over time to recover from a crisis situation.

In this model, McCubbin and Patterson (1982) expanded the "a" factor to the "aA" factor, which is defined as the pile-up of stressors. There are at least three types of stressors contributing to the family system in a crisis situation: (1) the initial stressful event that moves the family into a crisis state; (2) normative family life changes; and (3) stressors that are associated with the family's effort to cope with the hardships of the crisis situation. The "bB" factor refers to family's resources. There are two general types of resources: (1) resources already available to the family that minimize the impact of the initial stressor; and (2) new resources (personal, family, and social) strengthened or developed in response to the additional demands. The "cC" factor is family's perception of the original stressful event, plus the pile-up of other stressors and strains ("aA" factor), plus "bB" factor its perceptions of its resources (Patterson, 1993). The "xX" factor is defined as the family's post-crisis adaptation. McCubbin and Patterson (1983) describe bon-adaptation of family would result in: (a) the maintaining or strengthening family integrity; (b) the continued promotion of both member development and family unit development; and (c) maintaining family independence and its sense of control over environmental influences. This model is focused on family crisis and post-crisis adaptation.

The Family Adjustment and Adaptation Response (FAAR) model fits with the Double ABCX model.

Patterson (1993) describes two phases in the FAAR Model: adjustment and adaptation, separated by family crisis. In the adjustment phase, families make only small changes to achieve balance between demands and capabilities. Demands mean all of the stressors, strains, and hardships experienced by the family unit and its members. Capabilities include resources and coping behaviors. The adjustment phase is homeostatic, in the sense that the family's goal is basically to preserve routines, roles, and relationships as they existed before the new challenge. Crisis occurs when demands exceed capabilities and an imbalance persists. Then adaptation is needed to resolve the crisis. During the adaptation phase, families restructure their system by changing boundaries, roles, and/or rules in order to restore balanced functioning in families. The adaptation phase is transformative in the sense that the family attempts to establish new routines, roles, and relationships to achieve a new balance of demands and resources. In this model, individual and family outcomes are conceptualized as the result of a process whereby a family balances its demands with family capabilities, and this balance is influenced by the interpretations and meanings the family gives to its circumstances (Patterson, Holm, & Gurney, 2004). Patterson (1993) explains that family's efforts to develop its patterns of functioning intended to adapt to a crisis situation such as having a child with disability will shape and be shaped by the family's appraisal at three levels. She purposes the three levels of meaning which are interrelated and influence how a given situation is appraised:

> ***Level one*** – The individual appraises the situation, which involves appraising the stressor event or the pile-up of demands and of capabilities for managing the demands.
>
> ***Level two*** – The family rules of relationship, which describe how family members relate to each other and, as a unit, relate to the world outside the family. These rules are usually implicit such as, the degree of togetherness or apartness tolerated among members, or the degree of change versus stability that they will tolerate.
>
> ***Level three*** – The individual's beliefs about the purpose and meaning of life or world view. (Patterson, 1993, p. 230-233)

The Double ABCX model and FAAR model are useful because they focus on the factors, particularly cognitive appraisal and social support, which facilitate family adaptation to a hardship situation (McCubbin, Thompson, & McCubbin, 1996). The double ABCX model focuses on family crisis. Post-crisis adaptation is the outcome factor. Family adaptation is seen as “a continuum of outcomes ranging from the balanced ‘bon-adaptation’ to the ‘mal-adaptation’, which is characterized by a continued imbalance in family functioning” (Saloviita, Italinna, & Leinonen, 2003, p. 301). The FAAR model focuses on families’ ongoing processes of lifelong adjustment and adaptation, which can be shaped and reshaped according to the families’ perceptions of the stressful event and resources. Three basic phenomena have been noted in both models: the stressful event, the outcome of the stress, and the intervening factors between the two (Lavee, McCubbin, & Patterson, 1985). Figure 1 shows how the two models are fitted together and guide this study.

The Family Adjustment and Adaptation Response (FAAR) Model
Fits with the Double ABCX Model

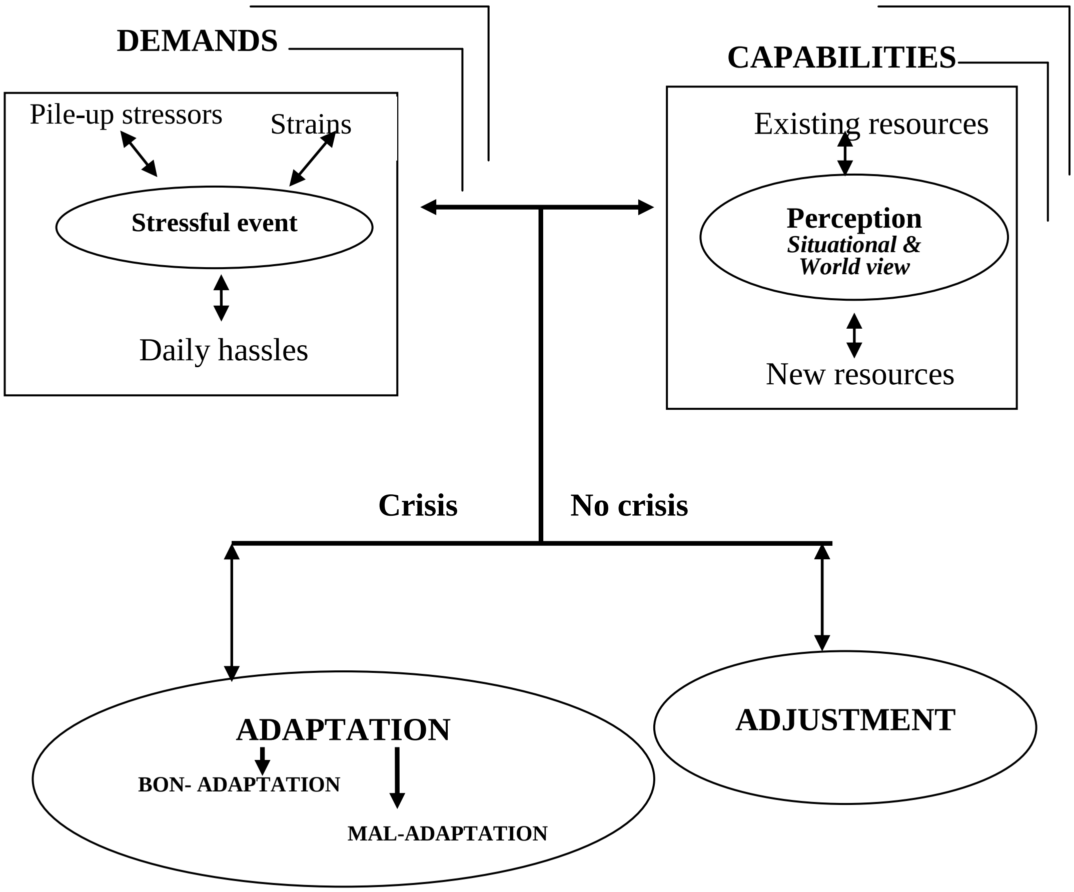


Figure 1. The top left square represents “Demands.” It consists of existing piled-up stressors, strains, and daily hassles in the family system. A stressful event always has influences on the existing demands, and vice versa. The right square represents “Capabilities.” A family’s capabilities consist of the family’s perception of the “Demands,” existing resources, and availability of new resources. Families utilize their “Capabilities” to cope with the “Demands.” A family may need only to adjust to the situation if small changes are required to achieve balance between demands and capabilities. Crisis occurs in families when demands outweigh capabilities; then adaptation is needed to resolve the crisis. Bon-adaptation occurs when capabilities exceed demands, and mal-adaptation occurs when demands exceed capabilities.

The Role of Cognitive Appraisal on Adaptation

McCubbin and McCubbin (1993) describe three levels of appraisal that may influence how members of a family judge the impact of a stressful event. The first involves an immediate judgment by focusing on characteristics of the event such as its intensity and expected duration. The second focuses on the family's perception of its own ability to meet the demands created by the stressful event, resulting in attributions of adequacy or inadequacy. The third level deals with the meanings the family as a unit attaches to the stressful event.

It has been argued that an individual's thoughts, feelings, and perceptions about an event are more significant in determining outcome than the actual factors present in the event itself (Gordon & Song, 1994). For example, Lawson (2001) examined 165 diverse samples of women's perceptions of raising a child with a serious disability and attitudes toward using prenatal diagnostic testing (PDT). The findings indicated that women who noted rewarding aspects of raising a child with a disability were less likely or willing to use PDT. Women who associated no rewards with raising a child with a disability indicated a strong desire to use PDT in the event of a future pregnancy. McCubbin and Patterson (1983) point out that subjective interpretation is a key element that can determine whether an event constitutes a family crisis. If parents or family appraise the event as posing little threat or danger, then the occurrence of that event does not constitute a crisis to the family. Parents' cognitive appraisals of themselves, their situations, and their family members have been shown to be a key element in preventing high levels of stress and facilitating optimal adjustment in families of children with significant disabilities. Trute and Hiebert-Murphy (2002) conducted a study on parents' primary appraisal of the entry of their child with a disability into the family system and its impact on the family as an entity. Over the 7-year interval in their longitudinal study, they found no average change in parents' cognitive appraisal of the impact that childhood disability had on family life. The result indicates that the appraisal of the family impact of childhood disability that parents hold is formed early in the life of the child and tends to remain unchanged through to the child's preadolescence. Their finding suggests that professional helping networks should pay attention to parents' cognitive appraisal regarding the impact of a child with developmental disabilities on family life. It is recognized that professional encounters affect parents' perspectives and roles. Hence, understanding parents' negative and positive appraisals of professional contacts is important in predicting how parents adapt to caring for children with developmental disabilities. It is obvious that different cognitive interpretations shape families' responses and strategies. Folkman and Moskowitz (2000) proposed that the positive appraisal of the efforts involved in care-giving may be particularly important in enhancing people's ability to sustain such efforts over long periods. Hastings and Taunt (2002) reviewed five published studies on the positive perceptions and experiences of families of children with developmental disabilities. They suggest that positive perceptions enhance a family's ability to adapt to or cope with the experiences of raising a child with disabilities.

Social Support for Families of Children with Disabilities

McCubbin and McCubbin (1993) suggest that social support is one of the most important factors referenced in their study of family adaptation, as it enhances parents' acceptance of and adaptation to their child's disability. Studies find that appropriate social support can have a positive impact on parental functioning, help reduce stress, facilitate adjustment, and benefit parents' well being (Beresford 1994; Parker & Wright 1997; Sloper & Turner, 1992). Romer and Heller (1983) believe that social support acts as a buffer against the psychological assault of social stigma and the stress arising from life transitions. Saloviita, Italinna, and Leinonen (2003) found that when predicting parental stress, availability of family resources is a more important variable than the characteristics of the child with disabilities.

Recognizing the vital roles of parents in caring for children with disabilities and social supports, the Families of Children with Disabilities Support Act of 1994 was implemented in the United States. The principles of the Act state that the support must:

> (1) focus on the needs of the entire family; (2) support families to determine their own needs concerning necessary, desirable, and appropriate services; (3) be flexible and respond to the unique needs, strengths, and cultural values of family; and (4) support families in promoting the integration and inclusion of their children with disabilities into the community. (Singer, Powers, & Olsen, 1996, p. vi)

Also, the new Family Support for Children with Disabilities (FSCD) Act in Alberta, Canada, which has been in force since August 1, 2004, emphasizes the family-centered model and focuses on the interaction between service providers and families. Service providers are expected to build positive relationships and supports to empower and strengthen families of children with disabilities (Alberta Children's Services, 2004). This Act is an important development in the field of social support services for families and children with disabilities. It was developed with the involvement of many key stakeholders. The draft regulations were developed with input from parents of children with disabilities, advocates, service providers, and professionals in childhood disability (Alberta Children's Services, 2004). The intent is to be certain that families and children will be provided with the most appropriate supports and services. The new FSCD legislation's key aspects include: providing family-centered supports; empowering families; preserving and strengthening families; and preventing families from experiencing hardship in getting necessary supports and services. Dunst (2002) emphasizes that the best family support programs are guided by five family-centered principles that encompass beliefs and practices: (1) treat families with empathy and respect; (2) include individualized, flexible, and responsive practices; (3) encourage family to be actively involved in decisions and choices regarding intervention options; (4) consider parent-professional collaboration to achieve desired goals; and (5) provide resources and supports necessary for families to raise their children in ways that produce well-being of family members.

Conceptualization of Social Support

There are many conceptualizations of social support. Cobb (1976) defines social support as information exchanged at the interpersonal level that provides: (1) emotional support, leading individuals to believe that they are cared for; (2) esteem support, leading individuals to believe that they are respected and valued; and (3) network support, leading individuals to believe that they belong to a network of communication involving mutual support and understanding. Similarly, Weinert and Brandt (1987) define social support in five dimensions:

> (1) provision for attachment/intimacy; (2) social integration (being an integral part of a group); (3) opportunity for nurturing behavior; (4) reassurance of worth as an individual and in role accomplishments; and (5) the availability of informational, emotional, and material help. (p. 591)

Many researchers describe three important components of family support models which include: (1) social-emotional support (e.g., perceived availability, and feeling cared for), (2) instrumental support (e.g., time, resources, financial assistance, equipment, or tangible support), and (3) informational support (e.g., receiving advice or information) (Guralnik, 2000, 2001; McWilliam & Scott, 2001; Rueger, Malecki, & Demaray, 2010). Obviously, family support services should assist families in reducing the personal and family stress experienced when caring for a child with developmental disabilities. Nevertheless, many studies have shown that attempts at social supports can also harm parenting abilities if they are inappropriately and insensitively provided. Bernheimer and Weisner

(2007) argue that in order to successfully implement family-centered practices, professionals need to develop new skills and new attitudes.

Professional Support may Undermine Parents’ Roles in Caring for Children with Disabilities

White and Hastings (2004) postulate that the most effective adaptive forms of coping strategies employed by parents of children with disabilities are seeking social supports and having access to formal support services. Using professional support resources is an attempt by parents to manage and adjust to the condition in caring for a child with chronic illness (Atkin & Ahmad, 2000). Goodley and Tregaskis (2006) argue that care is a key part of life for parents of children with disabilities. They describe parents of a 1-year-old boy who had met with 124 health and social care professionals since their son’s birth. Drummond, McDonald, MacKenzie-Keating, and Fleming (2004) found in their longitudinal study that most Alberta families of children with or at risk for disabilities accessed services more frequently as their children’s lives progressed.

Social support networks are designed to mediate the effect of family stress and to enhance a family’s ability to have control over their lives. On the other hand, social support efforts can also adversely affect families. Researchers find that parents often report feeling powerless and helpless when faced with unfamiliar procedures and unexpected barriers in adult services for persons with developmental disabilities (Cooney, 2002). They are also frustrated with the perceived incompetency of service providers, and with the way that educators devalue their contributions as collaborators with the school (Bianco, Garrison-

Wade, Tobin, & Lehmann, 2009). Sloper (1999) reported that parents of children with severe disabilities feel increased pressure when they are faced with insufficient support from professionals. Likewise, Statham and Holtermann (2004) discussed negative comments that parents made about social work support including: (1) services withdrawn earlier than expected, which left families feeling let down; (2) families were not treated as individuals or felt they were not valued; (3) families felt that they were not being kept informed; and (4) services were irrelevant to their needs. In a study of the disclosure process and its impact on south Asian families with a child with severe intellectual disabilities, many parents reported experiencing the use of complex and confusing medical terminology, feeling dissatisfied, and suffering because there was little to no support during or after the disclosure process (Hatton et al., 2003). The authors note that the absence of good practice in the disclosure process can result in parental emotional distress, a lack of understanding and acceptance of the child's disability, and lack of awareness and uptake of support services. Many years after disclosure of their child's disability, parents frequently are clear about which communications helped them and which left them feeling upset and angry (Fallowfield & Jenkins, 2004). Edelson (2001) described this in her book about the disclosure of her son's diagnosis in a hospital. A doctor surrounded with medical students in the crowded public hallway of an emergency department told her and her husband that their son had a rare brain condition that would cause him to be severely retarded and have a shortened lifespan. The doctor's impatient and mechanical attitude left the parents feeling shocked, angry, and confused.

Fallowfield and Jenkins (2004) reported that what parents most appreciate is when informants show some concern and distress at the news rather than cold professional detachment. An insensitive or unkind professional can make things more stressful. For instance, a mother reported her frustration with a service provider, who told her that he could always find other parents for her daughter if she found it was too tough to take care of her (Roeher Institue, 2000). Clearly, professionals' involvement makes a difference in whether or not families receive the supports they need. Frequently parents report that it is more important to them that professionals listen to them and show concern than to spend a lot of time with them or provide in-depth information (Darrah, Magil-Evans, & Adkins, 2002; Roeher Institute, 2000). They need clear, truthful, and relevant information (Brazy, Anderson, Becker, & Becker, 2001).

Harden (2005) discusses the key points of dissatisfaction with healthcare encounters as reported by parents of young children with mental health problems. Parents expect healthcare professionals: (1) to listen to them, not dismiss their experiences; (2) to provide them with greater emotional and practical support and take their involvement in child's care into account; and (3) to be more sensitive in addressing the question of cause in relation to their child's condition. Redmond and Richardson (2003) interviewed 17 mothers who had young children with severe/profound and sometimes life-threatening disabilities and were receiving services from a foundation in the Republic of Ireland. The mothers frequently referred to the process of gaining useful information about services as disorganized and to most of the services offered to them as uncoordinated, unreliable, and difficult to access. Negative and unsympathetic responses from professionals, or professional incompetence can be anxiety-provoking and heighten feelings of guilt, isolation, and helplessness (Anionwu,1993; Schoofs et al., 2004). These issues can also lead to the feeling of distrust or hesitation about using the services (McNally et al., 1999; Midence & Elander, 1994; Schoofs et al., 2004). At the same time, a number of mothers expressed that they have to be very careful in advocating enough to get their children the needed supports, but not so much that they will risk retaliation by professionals in the systems (Roeher Institute, 2000). For example, a mother reported that she found herself being investigated by child protection authorities after she complained of abusive treatment she had witnessed her daughter suffering at school. In another case, a mother indicated that when she told the principal about her daughter being abused in the school, she was told to call child welfare. Such non-supportive responses from professional sources of support inevitably add stress to the role of caring for children with disabilities.

Tucker and Johnson (1989) note that social support can inhibit parents' competence and adjustment, such as when others belittle the parent's efforts or intervene for the child's benefit only. They suggest that promoting parents' competence needs to be developed in the context of a low level of environmental strain in the support system, a positive perception of parental caretaking competence, and systems that provide support directly to the parent, rather than only to the child. Moreover, culturally inappropriate responses can further contribute to the vulnerability of parents' coping strategies (Ahmad & Atkin, 1996).

Many studies have found that social support can be counterproductive and a source of stress for the parents. Therefore, service providers are required to have a thorough understanding of family stress, appraisal, and the adaptation process in order to provide effective services to meet family needs. There is less research based on explicit conceptual frameworks designed to explore Edmonton parental perceptions of their direct experiences with professional contacts, and how these contacts impact their roles to caring for children with disabilities. This study underscores the need to investigate parents' perceptions of professional practices that enhanced or undermined their parental roles and their relationships with their children who have disabilities.

Support for families from professionals and service providers have the potential to play a critical role for family adjustment in both the Double ABCX and Family Adjustment and Adaptation models. In the Double ABCX model, these supports are viewed as resources that minimize the impact of the situational stressors. In the Family Adjustment and Adaptation model, these resources are viewed as facilitating more positive appraisals and leading families toward "bon-adaptation." These concepts of professional support, however, are based on an assumption that interactions with professionals and services actually serve to reduce stress and facilitate bon-adaptation. If families actually experienced their interactions with professionals and service agencies as stressful or burdensome, the services described as "supports" might actually increase stress and contribute to mal-adaptation. This study explores parents' perceptions of their interactions with professionals to determine if they experience these interactions as supportive or not.

Summary

This chapter addressed three topics. First, it reviewed research literature on how having children with disabilities affects parents. It pointed out that much of the early research emphasized negative effects and tended to present a bleak and often pathological picture of families with children with disabilities. Second, it reviewed the literature on the role of professionals in providing family support with an emphasis on findings showing that efforts to provide supports can have negative as well as positive effects on families. Finally, it described two frequently used models of family adjustment and adaptation: the Double ABCX Model and the Family Adjustment and Adaptation Response (FAAR) Model.

CHAPTER III

Method

Parents of children with disabilities come in contact with many professionals over the years because of their children’s unique needs and, in many cases, chronic health conditions. A review of the literature on services that professionals delivered to children with disabilities and their parents demonstrated a need to examine the parents’ personal perceptions of their experiences with professionally delivered support services. The purpose of this study was to identify and describe parents’ perceptions of professional practices that enhanced or undermined their roles as parents and their relationships with their children with disabilities. The study employed a mixed-method research design that can be categorized as a sequential mixed design (Teddlie & Tashakkori, 2009).

Mixed Methods Research

Tashakkori and Creswell (2007) define mixed methods research as “research in which the investigator collects and analyzes data, integrates the findings, and draws inferences using both qualitative and quantitative approaches or methods in a single study or program of inquiry” (p.4).

Sequential mixed designs are defined as:

> Designs in which at least two strands occur chronologically (QUAN → QUAL or QUAL → QUAN). The conclusions based on the results of the first strand lead to the formulation of design components for the next strand. The final inferences are based on the results of both strands of the study. The second strand of the study is conducted either to confirm

> or disconfirm inferences from the first strand or to provide further explanation for its findings. (Tashakkori & Teddlie, 2003, p.715)

Concept Mapping Process

Trochim (2002) defines concept mapping as “a structured process, focused on a topic of interest, involving input from participants that produces an interpretable pictorial view of their ideas and concepts and how these are interrelated” (p.1). This approach can be applied appropriately to analyze a large number of statements generated from many participants when the researcher is seeking to clarify the domain, constituent elements, and underlying structure of the individual’s experiences. An important feature of this method is that it provides few opportunities for a researcher’s bias to affect the results. The methodology allows participants to describe their unique experiences in a manner that is unconstrained by the researcher’s specific criteria or previous conceptions. During the investigation process the investigator has to avoid over-directing or prompting the participants. The concept system, a specialized computer program is required for analysis and mapping procedures to assure that the results are accurate. Trochim and Linton first described the concept mapping methodology in 1986.

Concept mapping has been used for a variety of purposes in a number of diverse fields in theory development (Forbes, 1999) and in psychology (Florio, Donnelly, & Zevon, 1998; Schuck & Liddle, 2004). Some studies in the field of social services have also used concept mapping. Biegel, Song, and Milligan (1995) used concept mapping to investigate the barriers that impede African-

American families’ involvement in the treatment and support of a family member with mental illness. Biegel, Johnsen, and Shafran (1997) used the technique to examine the needs of African-American family members of persons with severe mental disabilities. Wiener, Wiley, Huelsman, and Hilgemann (1994) used the methodology to organize input from key informants about how a crisis service agency could provide mental health services to meet the needs of the clients. Trochim, Cook, and Setze (1994) used concept mapping to develop a conceptual framework of staff views of a supported employment program for individuals with severe mental illness. Forbes (1999) used two research methods on a study of hope in the older adult with chronic illness. The same research question was studied using both phenomenology and concept mapping. Although each method used different participants, the studies had similar findings. Forbes suggested that concept mapping was superior in the areas of time investment, number of participants needed, and preference for participant-focused data analyses.

The results of concept mapping projects have been shown to be reliable. When examined across 38 concept mapping projects, the method has yielded reliable results as estimated by a number of acceptable reliability indicators: the average individual-to-individual sort reliability value was .815; the average individual-to-total matrix value was .929; the average split-half total matrix reliability was .833; the average of the reliability estimate that involved rating values was .78; and the average value of the relationship between individuals’ sorts and the final map configuration was .863 (Trochim, 1993).

Trochim (2002) describes four distinct features of this method. First, it is primarily a group process, and stakeholders have to work together. Second, there is a specific structure of steps for facilitating a group's expression of its opinions and understanding them clearly. Third, the process utilizes many state-of-the-art multivariate statistical methods that analyze the input from all of the individuals and yields a collective group product. And last, in the concept system, a specialized computer program is required for accomplishing the analysis and mapping procedures.

Six steps are involved in developing a group concept map (Trochim, 1989): 1) prepare the project; 2) generate ideas; 3) structure ideas; 4) compute concept maps; 5) interpret maps; and 6) utilize maps. A detailed description of each step follows.

Preparation. There are three tasks at this stage. First, identify the participants. There is no limit on the number of participants in concept mapping. Practically, a group between 10 and 20 stakeholders is enough to ensure a variety of opinions and enable good interpretation. The number of participants at each step may not be the same. A relatively small number of participants may participate in the generation step, and a larger group performs the structuring step. Second, develop the study's specific focus or domain. The open-ended research question must have a clear focus for all participants. Finally, set an appropriate schedule for the focus group meeting.

Generate ideas. Participants are encouraged to generate as many statements as they can based on their perceptions of the research question. Many methods can be used at this stage including traditional brainstorming, brain-writing, nominal group techniques, focus groups, and qualitative text analysis (Trochim, 2002). Once all the participants' responses are collected, statements should be edited for clarification and to remove redundancies. Whenever possible, the final number of generated statements should be limited to100 or fewer because larger numbers of statements impose serious practical constraints (Trochim, 1989).

Structure ideas. Participants, who may or may not be the same individuals in the statements-generating group, are chosen to do two things. First, each participant receives a set of cards that has one statement on each card. Each participant sorts the cards into piles based on similar themes or ideas. Participants can have as many piles as they want. They give each pile a short descriptive label. There are restrictions on this procedure: (a) each statement can be placed in only one pile; (b) all statements cannot be put into a single pile; and, (c) no statement can be put in a separate pile by itself, although some statements may be sorted alone (Trochim, 1989). For the second task, each participant rates each statement on some type of scale. Usually the statements are rated on a Likert-type response scale (e.g., 1 to 5, or 1 to 7 rating) for their relative importance (Trochim, 1989). The potential for researcher bias and subjective variability is reduced because the participants and not a researcher are grouping and rating each data set.

Compute maps. The sort and rating input is analyzed and displayed in the form of a map in this step. Two major statistical analyses are used to produce the map: (1) multidimensional scaling is a multivariate analysis which locates each statement as a separate point on the map with closely associated statements located near each other; (2) hierarchical cluster analysis is used to group each participant's statement on the map into clusters of statements to represent the conceptual domain (Trochim, 1989). Using these statistical techniques it allows researchers to objectively categorize statements into themes.

Interpret maps. Four different types of maps are interpreted at this stage: (1) The numbered point map that shows the statements as they were placed by multidimensional scaling; (2) The cluster map that shows how statements were grouped by the cluster analysis; (3) The point rating map with average statement ratings overlaid; and (4) The cluster rating map with average cluster ratings overlaid (Trochim, 1989). These maps show the important ideas and how they are interrelated. The facilitator and participants develop the labels and interpretations for the maps.

Utilization of maps. The result of a concept mapping process provides a better understanding of the issue addressed in the study's original focus. The results may be used for program planning or evaluating intervention effort. Also, they may be used to construct a future research measurement.

The intent of this study was to apply the concept mapping process in addressing two specific research questions: 1) How did the parents perceive their experiences with professional contacts in regard to services delivered to them and their children with disabilities; 2) What were the themes or categories underlying their identified experiences with professional contacts. The conceptual domains derived from the maps were used to construct an incidence survey. This study received ethical approval from the Faculties of Education, Extension, and Augustana Research Ethics Board (EEA REB) at the University of Alberta.

The study had two major phases. In phase one, a focus group comprised of parents of children or adults with developmental disabilities identified things that professionals had done or said that they felt supported or undermined their parental roles and relationships with their children. Concept mapping was then used as method to identify themes among the supportive and non-supportive interactions. In phase two, parent statements generated in phase one were used as the basis for a survey that was completed by a larger group of parents. Survey participants indicated their agreement or disagreement for each statement, and the results of this survey were analyzed to determine how the findings from the focus group could be applied to a larger group of parents.

Phase One: the Concept Mapping Procedures

The following section is a detailed explanation of how the concept mapping process that William Trochim developed (1989) was used. The process consisted of three steps. Step one, parent focus groups generated statements based on their experiences with professionals. Step two, the participants rated the generated statements and sorted them into groups based on conceptual similarity. Step three, the researcher analyzed these groups using the Concept System computer software (Trochim, 1993) to develop a concept map.

Participants

The participants were recruited for this study on the basis of the following criteria: 1) they were biological parents, adoptive parents, foster parents, or legal guardians of a child or adult with disabilities, 2) they were actively involved in caring for an individual with disabilities, and 3) they had a long-term relationship of at least two years with the child or adult with disabilities. Participants in two phases of this study were recruited with the cooperation of Elves Special Needs Society's organization in Edmonton. The Elves Special Needs Society is a non-profit organization, which offers preschool, school and adult day programs for individuals with severe developmental disabilities ages 2.5 to 6, 6 to 18, and 18 and over, respectively. The school program is designated by Alberta Education as an independent special education program. Individuals with disabilities who attend the Elves' programs have various diagnoses, such as cerebral palsy, developmental delays, Down syndrome, autism, and fetal alcohol spectrum disorder (FASD). Parents of individuals with disabilities of all ages and categories of disability were included in this study. Many researchers have recommended a non-categorical approach to studying psychosocial services (Perrin et al., 1993; Campbell & Patterson, 1995). The rationale for this approach is that there are many differences among many specific types of chronic health conditions and there also can be variability in how any specific condition manifests itself even within the same disability. As a result, there can be as much variability among individuals with the same diagnostic labels as between groups with different diagnostic labels. Therefore, a categorical approach is neither pragmatically nor conceptually sound, and a generic approach, which focuses on elements shared by many conditions, children, and families, has been recommended (Perrin et al., 1993). Pless and Perrin (1985) describe commonalities in the experience of these families, such as a need for community and professional services, heightened challenges to self-concept, and optimal emotional development, extra financial hardships, and disruption of family and social activities. Patterson, Holm, and Gurney (2004) report that most of the strains, resources, and coping behaviors of parents of children with cancer are similar to those described in studies of families experiencing other childhood chronic conditions. They suggest that the psychosocial impacts of childhood chronic conditions are more similar across conditions than unique to any specific diagnosis. In addition, Gonzalez, Steinglass, and Reiss (1989), argue that non-categorical psychosocial intervention for a family that involves several different conditions enhances a focus on family issues rather than on the type of condition itself. Saloviita, Italinna, and Leinonen (2003), indicate that parents of children with disabilities perceive that the social supports available to them are more important in predicting parental stress than the disabling conditions of their children. Martin and Baker (2001) examine the lifelong challenges to families of a child with severe disabilities. They indicate that families deal with the same issues regardless of the child’s age.

The Elves Special Needs Society granted permission to recruit prospective participants, who were parents of persons with disabilities at the Society. A social worker at the organization helped to recruit participants in order to protect the clients’ confidentiality, identity, and privacy. Initially, purposive sampling of participants was used to achieve a diversity of participants and maximum information about the phenomena. The criteria for participants’ inclusion were developed to ensure participation of parents of different genders, ages, marital statuses, types of disabilities of the child, and ages of the child. The social worker sent an invitation letter with brief information about the study (Appendix A) to the selected parents (n = 30). The researcher's contact telephone number was provided in the invitation letter. When the prospective parents called the researcher, they were provided with pertinent information about the study, and any questions they had were answered. Within one month, 7 parents (23.3%) accepted the invitation to participate in the study. A 2.5 hour meeting time was scheduled at the participants' convenience. A meeting room was arranged at the Elves' School because it was easy to access, and familiar to all the participants. At the time of the meeting, however, only 3 mothers came, and 4 parents did not arrive due to a snow storm that morning. These mothers deserved an opportunity to voice their opinion; hence the focus group interview was conducted according to the schedule. Unfortunately, the information obtained from this focus group was not used in the study because the participant group was not sufficiently diverse and maximum information about the phenomena was lacking. Hence, a second recruitment process took place a month after the first one. This time the social worker sent invitation letters to a larger number of parents of children with disabilities at Elves (n=61), and hoped to receive enough responses from prospective participants. Within one month after the letters were sent out, at cut-off time for responses, 10 parents (16.4%) had volunteered to participate in the focus group interview. On the scheduled day of the focus group, two parents did not attend due to sickness in one case and transportation problems in the other. Hence, a total of 8 parents participated in the focus group. Vaughn, Schumm, and

Sinagub (1996) indicate that the best number of participants in a focus group is about 8 to 10 persons. This range provides an opportunity for all members of the group to express unique perceptions and is an appropriate size for the researcher to facilitate and encourage dialogue in the group. Forbes (1999) uses the concept mapping procedure for her research on hope among older adults with chronic illness. She had 8 participants in the study. Table 1 shows the demographic data reflecting the sufficient variability of the focus group sample.

When participants arrived at the meeting room, they were given information sheets about the nature of the study and detailed instructions for generating statements in response to the research questions (Appendix B). Parents were asked to participate in a two-and-a-half hour focus group interview that would be recorded in writing and audio-recording. They were informed that their responses would be confidential. Then, written consent forms (Appendix C) were signed and demographic information questionnaires (Appendix D) were completed.

Table 1

Demographic Characteristics of the Focus Group Participants

Variable	Number	%
Gender		
Male	3	37.5
Female	5	62.5
Marital Status		
Married	5	62.5
Single parent	3	37.5
Age of the parent		
31-40 years	3	37.5
41-50 years	1	12.5
50+ years	4	50.0
Age of the child		
2.5-6 years	1	12.5
6.1- 12 years	3	37.5
18+	4	50.0
Live in		
City	6	75.0
Rural	2	25.0
Relation to the child		
Biological parent	6	75.0
Adoptive parent	2	25.0
Diagnosis of the child		
Cerebral Palsy	1	12.5
Cerebral Palsy & Visually Impaired	1	12.5
Micro Cephalic & Spastic	1	12.5
Fetal Alcohol Spectrum Disorder	2	25.0
Autism	1	12.5
Developmental Delays	2	25.0

Description of the focus group sample.

Parents who participated in the focus group included 3 males (37.5%), and 5 females (62.5%). Six were biological parents (75%) and 2 were adoptive parents (25%). Three were single parents (37.5%) and 5 were married (62.5%). Three (37.5%) parents' ages were in the 31 to 40 year range, 1 (12.5%) parent's age fell into the 41 to 50 year range, and other 4 (50%) parents were more than 50 years old. Six (75%) participants lived in the city and 2 (25%) lived in a rural area. One parent (12.5%) had a child with disabilities in preschool years (2.5 to 6 years). Three parents (37.5%) had children in their school years (6.1 to 12 years), and four parents (50%) had children over 18 years old. Diagnoses of their children included 2 (25%) with cerebral palsy, 2 (25%) with developmental delays, 2 (25%), with FASD, 1 (12.5%) with microcephaly and spasticity, and 1 (12.5%) with autism.

Generation of statements.

In the Generation step all participants were encouraged to take part and generate as many statements as possible in response to each of the following open-ended research questions:

1) Please describe the important things that professionals have said or done that made you feel better or more secure in your relationship with your child and your role as a parent of a child with a disability.
2) Please describe the important things that professionals have said or done that made you feel worse or less secure in your relationship with your child and your role as a parent of a child with a disability.

Participants were asked to respond to one research question at a time. They had a 15-minute coffee break between addressing the first and second questions. As the participants generated the statements, the statements were recorded and numbered as a list on a white board so that they were visible to all the participants. A research assistant, who had signed a confidentiality agreement (Appendix E), also entered the statements into a computer program (MS-Word) during the meeting. This helped to prepare for the structuring step. The group brainstormed 39 and 34 statements in response to the first and second questions respectively. It took approximately an hour for participants to generate statements for each question until there were no more original responses. Before concluding each question of the focus group interview, the participants were asked to review their group list of statements. The generated statements were edited for clarity, and the redundant ones were deleted from the lists if the participants agreed. All the participants were satisfied with their own lists. Osborn (1948) states that the generation step is accomplished by simply brainstorming a large number of statements related to the focus question. The focus group interview lasted for 2.5 hours as scheduled. Upon completing the focus group, the participants were asked to volunteer to participate in the structuring step. All eight participants agreed to have a complete set of final statement slips and a rating sheet sent to their addresses for sorting and rating.

Structuring of conceptual domain.

In the structuring step the participants were involved with two distinct tasks, rating how important specific statements were to their idea and sorting the generated statements into categories by theme. For the rating task, the 39 and 34 final statements in response to the two questions in the focus group were listed in questionnaire form and each participant in the focus group was asked to rate each statement on a 5-point Likert-type response scale in terms of how important they perceived it to be, where “1” denoted relatively unimportant (compared with the rest of the statements) and “5” denoted extremely important (Appendix F). The participants were asked to make a relative judgment of the importance of each statement to all the other statements on the questionnaire. Eight rating questionnaires were sent out, and 7 participants (87.5% response rate) returned completed ones. The rating values were then averaged across the 7 participants for each statement (Appendix G). The average rating values range in scores from 2.57 to 4.57. One of the parents made a comment that it was difficult for her to rate the statements because every statement seemed important to her, which was why the parents generated them in the focus group to begin with.

For the sorting task, each statement was printed on an individual slip of paper. Two sets of final statement slips (one set for each question) were put in two different envelopes and sent in a package to the volunteer sorters along with a cover letter (Appendix H) and an instruction sheet (Appendix I). The sorters were instructed to use their own judgment to group their set of final statement slips into piles that contained common themes or similar content. After sorting the statements into piles, the sorters were asked to label each of their groupings with a word or phrase that they thought most accurately represented the statements in that pile. Each sorter gave each pile a short descriptive label. In addition to the parent sorters, a convenience sample of 21 full-time rehabilitation instructors, who had worked directly with individuals with disabilities and parents at the Elves Adult program for at least two years, were invited to volunteer in the sorting task. They were provided with invitation letters with information about the study. Twelve staff (57.1%) volunteered to take part in the sorting task. A total of 19 sorts were returned, 7 sorts from the parents in the focus group, and 12 sorts from the rehabilitation instructors. This response represented an 87.5% return rate for parent sorters and a 100% return rate for staff sorters. Trochim (1993) conducted a reliability study of 38 concept mapping projects, focus on the sort data and of the two-dimensional MDS map. Results indicate that the concept-mapping process is reliable.

Data analysis.

After the participants had completed the rating and sorting tasks, the data analysis was conducted. The Concept System computer program that William Trochim developed (1993a) was used to perform statistical analyses and to construct concept maps. This was accomplished in many steps. After the sorting, information from all the participants was entered into the computer program, and individual binary symmetric similarity matrices were created from each participant’s sorting results. These matrices had as many rows and columns as there were statements in each domain (i.e., 39 x 39 for the generated statements to the first research question of this study and 34 x 34 for the generated statements to the second research question). The value in each cell of the binary matrices was 1 or 0. For any two statements, if a participant sorted them in separate piles, the cell for those two statements contained a ‘0’. If sorted in the same pile, the cell contained a ‘1’. Then all the individual matrices were combined to obtain a group-similarity matrix. The total similarity matrix from the group was analyzed using nonmetric multidimensional scaling (MDS) analysis with a two-dimensional solution. Kruskal and Wish (1978) indicate that when a MDS configuration is desired as the basis on which to display clustering results, a two-dimensional configuration is easy to work with and more useful than one involving three or more dimensions. Two-dimensional multidimensional scaling of the aggregate data created a two dimensional (x, y) point map in which statements were represented as points. Statements that were closer together on the point map were more often sorted into the same piles by the participants. Statements that were further apart were less likely to be sorted together.

A stress value was computed to indicate the goodness of fit of the two-dimensional map to the original dissimilarity matrix that served as input (Trochim, 1993b). A stress value ranges from 0 to 1. A lower stress value indicates a better fit. Trochim (1993b) states that in typical field-based concept mapping projects, the level of stress value expected is normally higher than the multidimensional scaling literature recommends. This is because the suggestions in the literature are based on experience with more stable phenomena, fewer entities, and more precise measurement methods. In a study of the reliability of concept mapping projects, Trochim (1993b) recommends that benchmarks for the level of stress values in typical concept mapping projects can be expected to range from 0.155 to 0.352, with an average value of 0.285.

Bridging indices for statements and clusters are values between 0 and 1. The bridging value for a statement shows the degree to which the statement was sorted together with other statements. A statement that has a value closer to one is more often sorted with statements in other regions of the map. This indicates that the statement is not highly related to statements that are close to it. A statement with a low bridging value is more likely to be sorted with statements that are close to it on the map. This indicates that the statement is highly related to statements that are close to it. A statement with a low bridging index value usually provides the best clue about the general concept in that area of the map (Trochim, 1989). A cluster bridging value for a category was calculated by averaging bridging values of all statements in the particular category. A low cluster bridging value indicates that statements within a category are more often sorted together, and are more likely to be conceptually similar. A high cluster bridging value indicates that statements within a category are frequently sorted with statements belonging to other categories, and are less likely to be conceptually similar. Cluster bridging values were used to identify a categorical solution that provided many categories with low bridging values.

After MDS, the program groups statements into clusters on the map. Hierarchical cluster analysis takes the point-map output from the multidimensional scaling and groups statements on the map into non-overlapping clusters that are intended to represent underlying themes. Labels for these concept-cluster categories provided by the participants are examined to determine which final labels best describe the statements in the categories. Finally, the generated concept maps that show the critical relationships among the input statements are used to organize and develop an incidence survey instrument in the second phase of study.

Phase Two: the Incidence Survey

While concept maps serve as useful tools to determine themes and ideas expressed by a small group of individuals, they cannot determine the extent of the findings from this small group to a larger segment of society. A survey provides a framework for determining how the findings from the original focus group can be applied to a larger population of parents. In this case, a survey study was conducted to determine which statements about parents' perceptions of professional practices were most frequently endorsed by a larger group of parents.

An incidence survey (Appendix J) was developed from statements in each of the themes generated in the concept mapping study. The investigator and her supervisor conducted a final edit of the statements. Statement lists were edited to remove any specific reference to persons, gender, or positions. The essential meaning of each statement was retained using the participant's wording of the statement to the greatest extent possible. This editing process was employed to ensure that the statements were clear and understandable for parents of persons with disabilities. The statements were randomly numbered so statements were not grouped by cluster and combined into a questionnaire. Survey participants were asked to rate their degree of agreement or disagreement with each of the statements derived from the concept mapping study. The ratings on a 6 point Likert-type response scale were: 1 = Strongly Disagree, 2 = Disagree, 3 = Neutral, 4 = Agree, 5 = Strongly Agree, and 0 = Not Applicable. The “not applicable” choice was intended for statements that participants viewed as irrelevant to their experience. A package of the demographic and survey questionnaires, along with the information about the study, was sent to 133 parents of persons with disabilities who attended the programs at Elves. Parents who had already participated in the focus group study were not invited to participate in the survey study. The prospective participants were chosen based on criteria as biological, adoptive, or foster parents; or legal guardians who had established a long-term relationship and were actively involved in caring for a person with disabilities. Only one parent from each family was asked to respond to the survey, which required about 20 minutes to complete. Information letters clearly stated that a parent’s decision to participate in the study was strictly voluntary. To return the survey packages to the Elves’ social worker, the parents put them into the backpacks belonging to the individuals with disabilities. Participants returned 48 completed survey packages, a return rate of 36.1%.

Data analysis.

There were three components to the data analysis on the survey instrument. First, descriptive statistics (frequencies, percentages, means, and standard deviations) were calculated. Second, subgroups based on demographic variables were compared. Third, statements that were most frequently endorsed by parents were examined in relation to the previously identified concept clusters in order to assign importance ratings to clusters.

CHAPTER IV

Results

Results from the concept mapping process and incidence survey are presented in this chapter. The early part of the chapter includes the parents' statements from the focus group interviews when they talked about their perceptions of professional contacts that made them feel more secure or less secure in their roles as parents of children with disabilities. Then, the results of multidimensional scaling and cluster analysis are presented. The chapter also includes the rationale for selecting final cluster/categorical solutions, a description of categories and statements comprising the categories, and concept maps. Finally, it describes the results obtained from the incidence survey and demographic information about the participants.

Phase One Master Lists of the Generated Statements

In the focus group interview, 3 male and 5 female parents (n=8) were asked to generate statements in response to two specific open-ended requests. The first was "Please describe the important things that professionals have said or done that made you feel better or more secure in your relationship with your child and your role as a parent of a child with a disability." The second request was "Please describe the important things that professionals have said or done that made you feel worse or less secure in your relationship with your child and your role as a parent of a child with a disability." Parents responded to one request at a time. Before concluding discussion on each topic, the participants reviewed their list of statements. The statements were edited for clarity, and redundant statements were deleted with the participants’ agreement. Consequently, two final master lists were obtained. The first list consisted of 39 positive statements in response to question one, professional contacts that made parents feel better or more secure in their relationship with their children with disabilities. The second list consisted of 34 negative statements in response to question two, professional contacts that made parents feel worse or less secure in their roles as parents of children with disabilities. Tables 2 and 3, respectively, present these lists of statements with identifying numbers (ID. No.) indicating the order in which they were included during brainstorming.

Table 2

Final Master List of Parents' Positive Statements of Professional Contacts

ID. Number	Statement
1.	There have been many health professionals in our child's life, who have been empathetic and done what we asked them to.
2.	Many professionals really go the extra mile to do what we asked them to do.
3.	The hospital referred our two-and-a-half-year-old child to a special needs program. We had someone to turn to.
4.	My pediatrician continues to see our son well into his adult years.
5.	A hospital has been helpful in giving supplies, wheelchairs, orthotics for shoes, and prosthetics.
6.	Care-workers work one-on-one with my son and put their whole hearts into making sure he learns.
7.	Care-workers have the means to learn the best way how to help my child.
8.	A staff person provided me with the skills required to help my son myself.
9.	A staff person gave me hope by showing me how to focus on the positive gains my son was making. I have more good days with my child.
10.	Funding by FSCD have helped to make a home program and supportive services possible.
11.	Teachers have supported me and have advocated services needed by both my son and me.
12.	Teachers prompted me to access services I was unaware of.
13.	A social worker at my child's school has helped us to access services for any needs my child has had. She puts us in touch with many organizations.
14.	Social worker acts as an intermediary between a family and staff members to see positive change.

Table 2 (continued)

ID. Number	Statement
15.	A care-worker has developed a strong bond with my son and chose to transition with him to the school setting.
16.	Because of a dedicated professional, my son’s transition to school has been less stressful.
17.	I have been very impressed by some teachers who stretch their creativity to reach my child with different teaching methods.
18.	Therapists provide me with skills to assist my son at home. Through this he makes more gains than only seeing them twice a month.
19.	Therapists provided knowledge that we needed. We are able to use it in a way that my child could understand.
20.	My child’s care-worker has gone above and beyond by helping to advocate for more funding.
21.	A program supervisor at school is going to try to implement the home video about our family situation as a teaching tool so that staff can be more empathetic to what families are going through.
22.	Some doctors are willing to see my child more frequently to maintain adequate care because of her needs.
23.	Teachers praise your effort as a parent to help you remember that you do good jobs.
24.	The multi-disciplinary team in the hospital told me that I did not do anything wrong during pregnancy to cause my child to become an autistic. This helped me to come out of my depression.
25.	Care-workers prompt me to do other activities besides just caring for my child. They helped me to lead my life in a normal way.
26.	They ask me regularly if I am fine. They really care about me.
27.	She taught my child at home. This helped lessen my tension and gave me strength when I was exhausted.

Table 2 (continued)

ID. Number	Statement
28.	My pediatrician said that she will do what my child needs regardless of what I have and she will take my problems seriously.
29.	My pediatrician listened to me patiently. I really appreciate him.
30.	A second opinion from a pediatrician supported me for not having my son go through unnecessary testing.
31.	Knowing the diagnosis made me understand the odd behaviors of my child.
32.	Therapy for children with autism at school with a consistent routine has helped my child gain different skills in activities of daily living.
33.	Social workers at the school were helpful with money issues (for example, by providing gift cards for food). This gave me more positive energy when I had financial difficulty.
34.	Social workers were very respectful and provided a lunch program for my child.
35.	A therapist went on to contact other people to help complete my child's assessment.
36.	A therapist called me to offer help in case I needed it. She went beyond her duties to help me.
37.	A neurologist reassured me that my son's seizures were not caused by anything that I was doing.
38.	When my son was connected with many wires at the hospital, a nurse observed him closely and gave him a book he wanted. This made my son and I feel very happy.
39.	A FSCD staff asked me "why we [FSCD staff] stressed you out?" At least she tried to identify what can keep me from having too much stress, when I am in contact with FSCD.

Table 3

Final Master List of Parents’ Negative Statements of Professional Contacts

ID. Number	Statement
1.	I felt pre-school assessment services could have warned me better about the outcome.
2.	We identified the fact that there was a problem with our child, but the doctor told us there was nothing wrong, that this was normal.
3.	The initial pediatrician told us to give our daughter up because he also had a child with disability and his personal relationship broke up.
4.	A doctor mentioned that our child would put us in difficult situations.
5.	Social services wanted us to give back our adopted child when we found out later that she had cerebral palsy. We were pestered by them for quite awhile for refusing to give her back.
6.	Multidisciplinary team at a hospital persuaded the parents to use tube feeding for their children over mouth feeding.
7.	A social program at a women’s shelter refused services due to my son’ diagnosis of autism.
8.	I had to fight to get services from the social program.
9.	I had to use my son’s diagnosis of autism to get help from the police in an abusive situation.
10.	We have to go through the constant battles from different government agencies to get the needed help for our children that can be financially, manpower, equipment, services, on and on.
11.	The constant change of personnel at school causes frustration because we have to deal one day with one person and another day with another person.
12.	With these children it takes a long time to form a bond that assists them to progress. The rate of pay from the government for staff in this field is not enough to keep them.

Table 3 (continued)

ID. Number	Statement
13.	The rate of pay is not enough to hire people to work at home. I have financial resources, but have difficulty finding help.
14.	The government provides funding for help, but it is not enough to be effective.
15.	AISH regulation limits the amount of money that parents can leave to or save for their children with disabilities.
16.	With FSCD, it’s almost impossible to get funding and when we do get funding it is minimal.
17.	A service worker told me if I could not control and calm my child I would not get my cheque on that day.
18.	There is a lack of tolerance and understanding about children with disabilities in society.
19.	A school supervisor told me not to expect my son to get any better, or expect progress so I left that school.
20.	It is rude for professionals to say to parents to put their children aside or give up on them. They should be encouraging parents to help their children.
21.	Professionals have a lot of knowledge but lack experience.
22.	I feel disappointed when professionals promise me services that they cannot deliver.
23.	Professionals are not forthcoming about all services that are available.
24.	A mother once said to me “This is my first visit with FSCD which a staff member did not make me cry.”
25.	Some professionals are rude, condescending.
26.	A social worker told me to downplay my child’s function in order to get more funding.

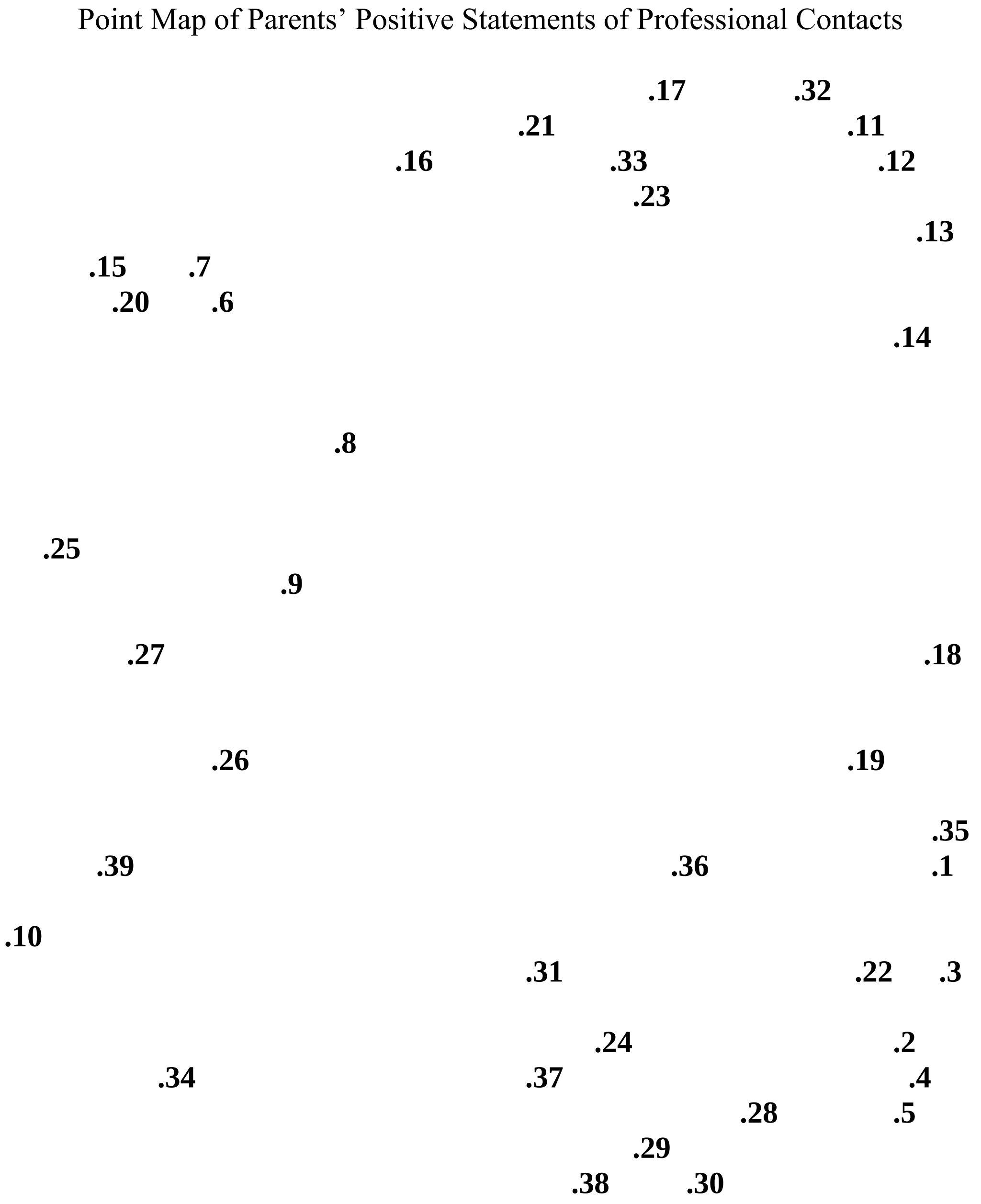
Table 3 (continued)

ID. Number	Statement
27.	I was starting with my three-year-old son to get him into a program and services. I tried to take one agency at a time so that I could digest all the information they gave to me. It’s so much.
28.	Professionals do not have the relational skills necessary to deal with parents and children with disabilities.
29.	Professionals protect their territory and their funding, particularly in a school system.
30.	Lack of accountability on how professionals spend the funding they receive.
31.	Parents are often excluded from important discussions and decision-making in school.
32.	Parents have to fight for services and government supports. There has not been much change for decades.
33.	Teachers are not willing to use strategies in school that were developed and already work at home.
34.	Teachers are not willing to take into account the parents’ personal experience with the child.

The Parents' Concept Maps

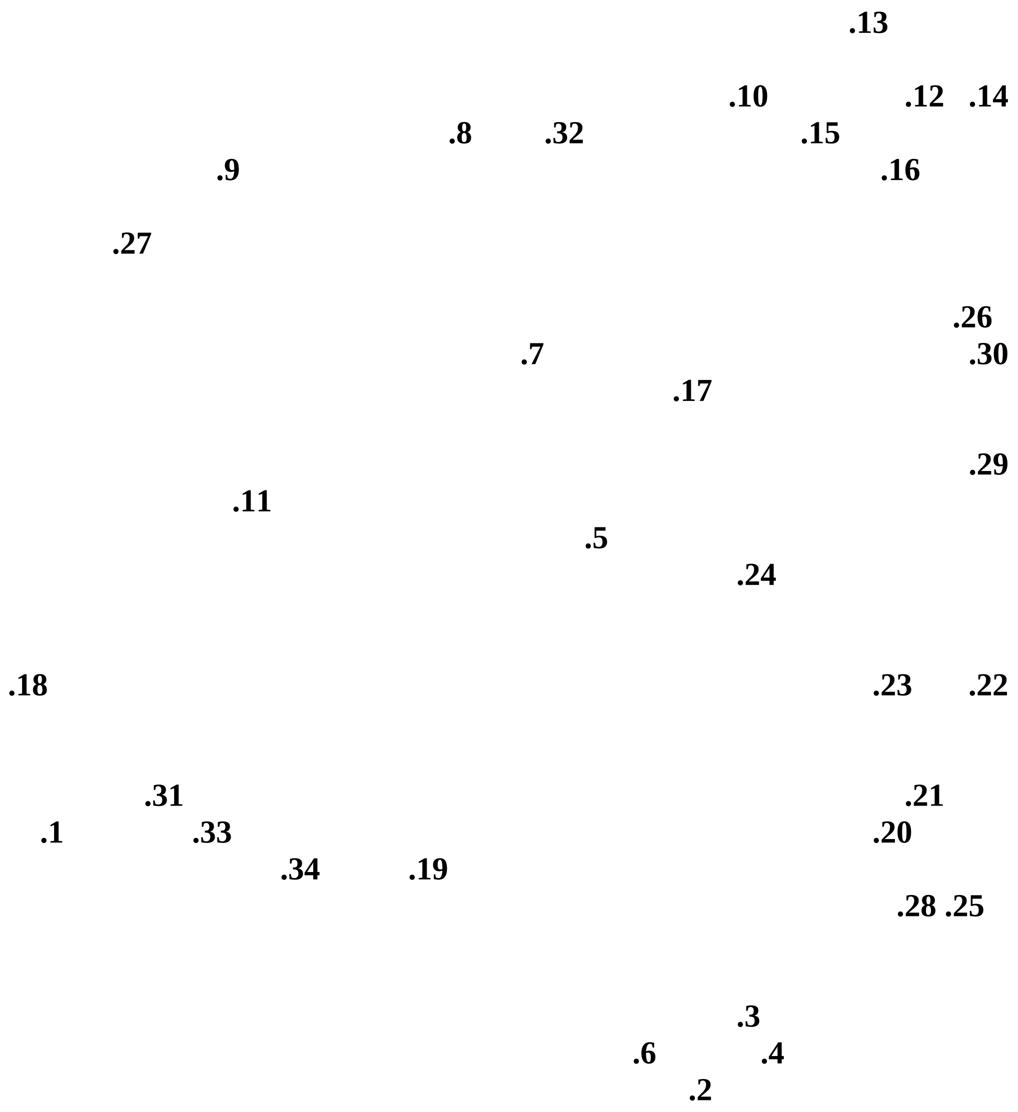
In this step, the conceptual structuring process commenced with rating the importance of each of the statements in the master lists and sorting the statements into themes. The 39 parents' positive statements of professional contacts and 34 parents' negative statements of professional contacts were rated by 7 parents who participated in the focus group, and sorted by 19 sorters (7 parents and 12 rehabilitation instructors). Then the concept system (Trochim, 1993a), a computer software program, was used to analyze the rated and the sorted data.

The two resulting point maps are presented in Figure 2 and Figure 3, respectively. These figures represent each statement as a point with a number beside it identifying the statement. Statements most often grouped together in the participants' sorts are located closer to each other on the map, whereas those piled together less frequently are further apart. Statements closer to each other usually were more closely related. For example, on the point map (Figure 2), statement 18 (Therapists provide me with skills to assist my son at home. Through this he makes more gains than only seeing them twice a month.), and statement 19 (Therapists provided knowledge that we needed. We are able to use it in a way that my child could understand.) were located closely together, as expected, given their high conceptual similarity. On the other hand, statement 10 (Funding by FSCD have helped to make a home program and supportive services possible.), located on the far left of the map, lacks conceptual similarity to statements 18 and 19. Finally, the analysis resulted in a stress value for each of the two point maps. The final stress values were 0.2402 for the parents' positive perception of professional contacts point map, and 0.1993 for the parents' negative perception of professional contacts point map. These stress values represent acceptably stable solutions.



Point Map of Parents' Positive Statements of Professional Contacts

Figure 2. Point map of 39 parents' statements of professional contacts that made them feel better or more secure in their relationships with their children with disabilities. Statements closer to each other were more closely related.



Point Map of Parents' Negative Statements of Professional Contacts

Figure 3. Point map of 34 parents' statements of professional contacts that made them feel worse or less secure in their relationships with their children with disabilities. Statements closer to each other were more closely related.

It is difficult to identify underlying clusters that represent conceptual themes based only on a visual inspection of the point maps. Therefore, the x-y coordinate data from the MDS solutions were used as the input, and the computer program conducted hierarchical cluster analyses. Ward's algorithm (Ward, 1963) was performed to partition the MDS configuration into non-overlapping clusters in two-dimensional space. Ward's algorithm is designed to minimize the variance within clusters and optimize the distinctiveness across clusters. The hierarchical cluster analysis grouped each statement on the MDS point map into clusters of similar statements. The end product of this analysis showed clusters of individual statements enclosed in numbered polygons. The numbers assigned to clusters reflect the order in which they were constructed, not importance or frequency. There is no mathematical rule for selecting an optimal number of clusters for the concept map. Trochim and Linton (1986) advised that a range of cluster solutions be examined when deciding the final number of clusters for the map, using both statements content and the cluster-average bridging values. The researcher tried to minimize the cluster-average bridging values and preserve the distinct interpretability of the cluster. As commonly practiced in concept mapping, the computer program begins by generating cluster solutions with an average of one-fifth of the total number of statements in each cluster, then sequentially merges clusters until all statements are in one cluster. Hence, many possible cluster solutions are created. The procedure used here was to examine an initial default cluster solution of each of the concept maps. Then, successively lower and higher cluster solutions were investigated. A judgment was made at each level about whether the merged or split clusters seemed distinctively interpretable and yielded lower bridging values. Consequently, independent determinations were made for the final number of clusters for the parents' positive perceptions of professional contacts concept map, and the parents' negative perceptions of professional contacts concept map.

The computer program provided a bridging index for each statement as well as an average bridging index for each cluster. Bridging values can range from 0.0 to 1.0. Statements with lower bridging values were sorted together often. Statements with higher bridging values were more frequently sorted together with statements in other clusters. Similarly, clusters with lower average bridging indices have greater coherence of the statements within the clusters. Clusters with higher bridging average values indicate "linking" clusters between neighboring clusters (Trochim, 1993a). The following section will contain descriptions of each cluster of the final maps and the process used to determine the final cluster solutions for parents' positive perceptions of professional contacts and their negative perceptions of professional contacts.

The Parents' Positive Perceptions of Professional Contacts Concept Map

Initially, the default number of clusters for this concept map was seven. The researcher tried increasing and decreasing the number of clusters. Upon examination, the 7- and 8-cluster solutions created clusters that seemed reasonably coherent. In both cases, however, some clusters contained too few statements and had very high cluster average bridging values. This made it clear that a further increase in the cluster number solution failed to improve the structure of the configuration. Consequently, the researcher examined what would happen if the number of cluster solutions was reduced to 6, 5, and 4 successively. The 6-cluster solution was an improvement over the 7-cluster solution, providing a distinct concept in each cluster and lower cluster average bridging values. Further reduction of the cluster solution to 5 and then 4 clusters was examined to determine the most appropriate number of clusters. The 4-cluster solution clearly lumps too many distinctly independent concepts together. Inspection of the 5-cluster solution suggested an improvement over the 6-cluster solution. Combining cluster number 5 and cluster number 6 seemed to be more coherent than splitting them apart, and the bridging value was improved slightly but not significantly. The final decision favored the 5-cluster solution as the one that provided the greatest interpretability of the parents' perception of professional contacts that made them feel better or more secure in their role as a parent of a child with disabilities data set. The final 5-cluster solution concept map is shown in Figure 4.

Five-Cluster Solution Concept Map of 39 Parents' Positive Statements of Professional Contacts

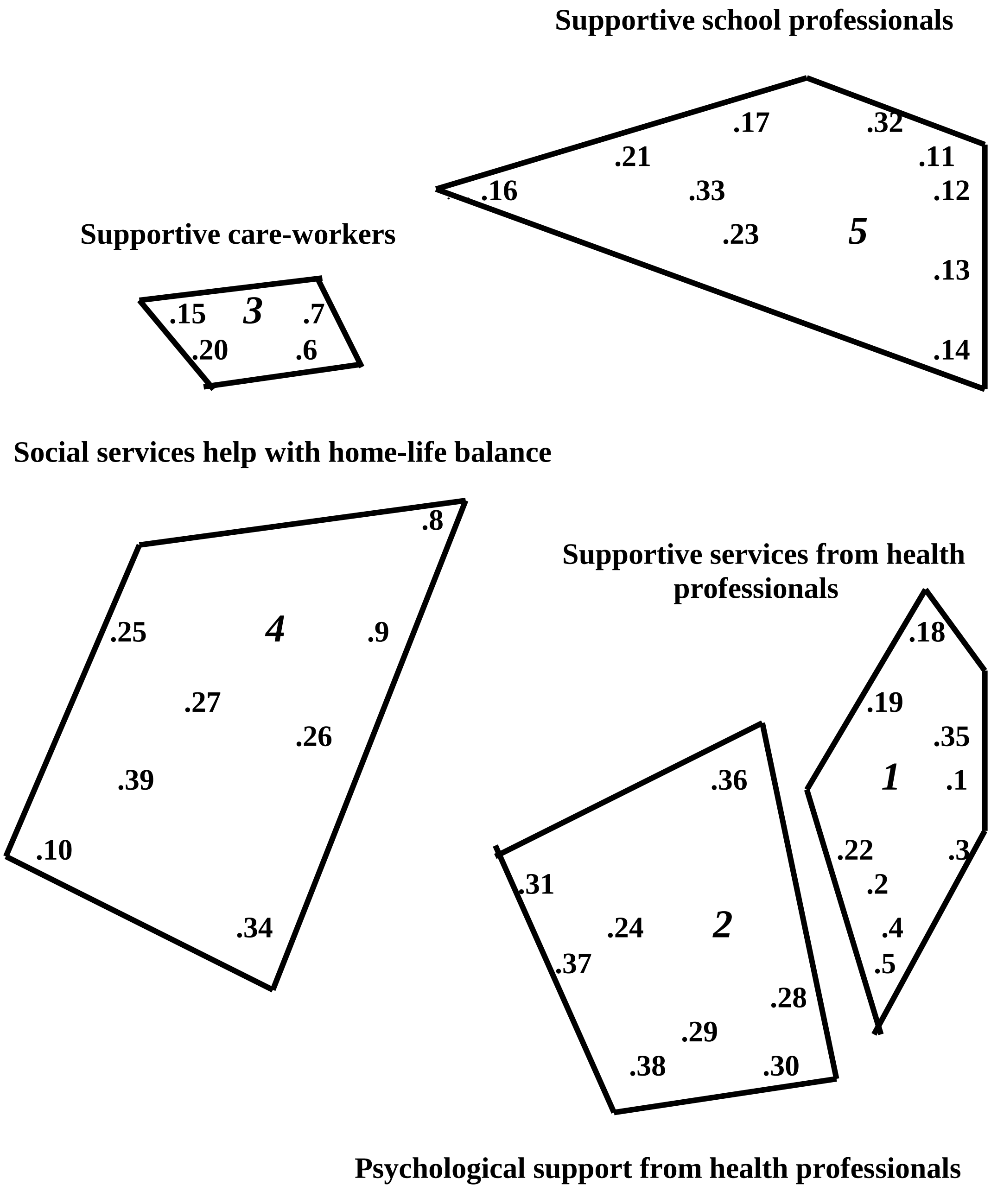


Figure 4. The 5 clusters were assigned the 5 positive labels that best corresponded to each theme: 1) Supportive services from health professionals, 2) Psychological support from health professionals, 3) Supportive care-workers, 4) Social services help with home-life balance, and 5) Supportive school professionals.

Description of the Parents' Positive Perception of Professional Contacts Clusters

The clusters on the concept map reflect how the participants sorted their statements and how their opinions were formed. The stress value of this map was 0.2402. The final 5 clusters represent the component statements from which they originated. The researcher labeled these clusters. In order to develop appropriate labels, an attempt was made to use key words or phrases from labels that participants provided (Appendix K) in their grouping during the sorting task. The clusters were assigned the following five labels: 1) Supportive services from health professionals, 2) Psychological support from health professionals, 3) Supportive care-workers, 4) Social services help with home-life balance, and 5) Supportive school professionals. Table 4 shows the statements of each cluster in the 5-cluster solution along with their bridging indexes, labels, and the average rating values of the statements' importance.

Table 4

Cluster Statements, Bridging Values, and Rating of Importance for the Five Clusters of Parents' Positive Perception of Professional Contacts

Item Number	Statements	Bridging Index	Rating Values
Cluster 1: Supportive Services from Health Professionals			
1.	There have been many health professionals in our child's life, who have been empathetic and done what we asked them to.	0.16	4.43
35.	A therapist went on to contact other people to help complete my child's assessment.	0.28	3.71
19.	Therapists provided knowledge that we needed. We are able to use it in a way that my child could understand.	0.24	4.00
18.	Therapists provide me with skills to assist my son at home. Through this he makes more gains than only seeing them twice a month.	0.38	4.43
2.	Many professionals really go the extra miles to do what we asked them to do.	0.15	3.57
22.	Some doctors are willing to see my child more frequently to maintain adequate care because of her needs.	0.09	4.14
3.	The hospital referred our two and a half year old child to a special needs program. We had someone to turn to.	0.16	3.71
4.	My pediatrician continues to see our son well into his adult years.	0.02	4.00
5.	A hospital has been helpful in giving supplies, wheelchairs, orthotics for shoes and prosthetics.	0.12	4.29
	Cluster Bridging Average	0.18	
	Cluster Rating Average		4.03
Cluster 2: Psychological Support from Health Professionals			
24.	The multi-disciplinary team in the hospital told me that I did not do anything wrong during pregnancy to cause my child to become an autistic. This helped me to come out of my depression.	0.15	4.14

Table 4 (continued)

Item Number	Statements	Bridging Index	Rating Values
37.	A neurologist reassured me that my son’s seizures were not caused by anything that I was doing.	0.17	4.00
31.	Knowing the diagnosis made me understand the odd behaviors of my child.	0.25	4.29
36.	A therapist called me to offer help in case I needed it. She went beyond her duties to help me.	0.20	3.14
28.	My pediatrician said that she will do what my child needs regardless of what I have and she will take my problems seriously.	0.00	3.57
30.	A second opinion from a pediatrician supported me for not having my son went through unnecessary testing.	0.03	3.43
29.	My pediatrician listened to me patiently. I really appreciate him.	0.05	3.00
38.	When my son was connected with many wires at the hospital, a nurse observed him closely and gave him a book he wanted. This made my son and I feel very happy.	0.28	3.43
	Cluster Bridging Average	0.14	
	Cluster Rating Average		3.63
Cluster 3: Supportive Care-workers			
6.	Care-workers work one-on-one with my son and put their whole hearts into making sure he learns.	0.37	3.57
7.	Care-workers have the means to learn the best way how to help my child.	0.34	3.43
15.	A care-worker has developed a strong bond with my son and chose to transition with him to the school setting.	0.36	3.14
20.	My child’s care-worker has gone above or beyond by helping to advocate for more funding.	0.50	3.71
	Cluster Bridging Average	0.39	
	Cluster Rating Average		3.46

Table 4 (continued)

Item Number	**Statements**	**Bridging Index**	**Rating Values**
Cluster 4: Social Services Help With Home-Life Balance			
8.	A staff person provided me with the skills required to help my son myself.	0.41	4.71
9.	A staff person gave me hope by showing me how to focus on the positive gains my son was making. I have more good days with my child.	0.41	4.57
26.	They asked me regularly if I am fine. They really care about me.	0.39	3.14
27.	She taught my child at home. This helped lessen my tension and gave me strength when I was exhausted.	0.42	4.00
25.	Care-workers prompt me to do other activities besides just caring for my child. They helped me to lead my life in a normal way.	0.38	3.14
10.	Funding by FSCD have helped to make a home program and supportive services possible.	1.00	4.00
39.	A FSCD staff asked me "Why we [FSCD staff] stressed you out?" At least she tried to identify what can keep me from having too much stress, when I am in contact with FSCD.	0.58	2.86
34.	Social workers were very respectful and provided a lunch program for my child.	0.97	2.86
	Cluster Bridging Average	0.57	
	Cluster Rating Average		3.66
Cluster 5: Supportive School Professionals			
11.	Teachers have supported me and have advocated services needed by both me and my son.	0.31	4.14
12.	Teachers prompted me to access services I was unaware of.	0.28	4.29

Table 4 (continued)

Item Number	**Statements**	**Bridging Index**	**Rating Values**
32.	Therapy for children with autism at school with a consistent routine has helped my child gain different skills in activities of daily living.	0.31	4.43
13.	A social worker at my daughter‘s school has helped us to access services for any needs my daughter has had. She puts us in touch with many organizations.	0.45	4.43
14.	Social worker acts as an intermediary between a family and staff members to see positive change.	0.59	3.29
16.	Because of a dedicated professional my son’s transition to school has been less stressful.	0.50	3.71
17.	I have been very impressed by some teachers who stretch their creativity to reach my child with different teaching methods.	0.24	4.00
21.	A program supervisor at school is going to try to implement the home video about our family situation as a teaching tool so that staff can be more empathetic to what families are going through.	0.45	3.00
23.	Teachers praise your effort as a parent to help you remember that you do good jobs.	0.43	3.43
33.	Social workers at the school were helpful with money issues (for example, by providing gift cards for food). This gave me more positive energy when I had financial difficulty.	0.54	3.86
	Cluster Bridging Average	0.41	
	Cluster Rating Average		3.86

A detailed description follows with each cluster and the statements contained in the parents’ positive perception of professional contacts concepts map.

Cluster 1- Supportive services from health professionals.

Cluster one was labeled “Supportive Services from Health Professionals” and reflected the positive perception of parents toward health professionals’ practices that made them feel better or more secure in their relationships with their children and their roles as parents of children with disabilities. This cluster had an average importance rating across statements of 4.03. It had the highest rating value of all the clusters on the map, suggesting that parents viewed this category as the most important. It also had a low cluster average bridging value of 0.18, suggesting that the statements within this category were coherent and had a distinct concept. The statements in this category were clearly related to services that health professionals provided and that parents perceived as helpful. Parents reported their positive experiences with health professionals who were empathetic and accountable. They mentioned health professionals who not only provided services to meet parents’ needs, but also did more than they were required. Here are some statements providing evidence of positive experiences: “There have been many health professionals in our child’s life, who have been empathetic and done what we asked them to” (#1), “Many professionals really go the extra miles to do what we asked them to do” (#2), “A therapist went on to contact other people to help complete my child’s assessment” (#35), and “Some doctors are willing to see my child more frequently to maintain adequate care because of her needs" (#22). Parents felt secure with health professionals who were trustworthy, caring, and established good, long-term relationships with them. These ideals were reflected in statements such as "the hospital referred our two-and-a-half-year-old child to a special needs program. We had someone to turn to" (#3), and "my pediatrician continues to see our son well into his adult years" (#4). There was a theme of competent health professionals who provided skill and knowledge to parents, empowering them to help their children and thus enhancing their adaptation to caring for their children. This was evidenced by statements such as "therapists provided knowledge that we needed. We are able to use it in a way that my child could understand" (#19), and "therapists provide me with skills to assist my son at home. Through this, he makes more gains than only seeing them twice a month" (#18). Parents appreciated receiving medical supplies and equipment to meet their children's needs. This was evidenced by statements such as "a hospital has been helpful in giving supplies, wheelchairs, orthotics for shoes and prosthetics" (#5).

Cluster 2 – Psychological support from health professionals.

Cluster 2 is adjacent to cluster 1 on the concept map. This category contains statements regarding psychological and emotional support that health professionals provide to parents. Parents perceived that assurance from trustworthy health professionals enhanced their psychological and emotional well-being. The following statements clearly illustrated this theme: "the multi-disciplinary team in the hospital told me that I did not do anything wrong during pregnancy to cause my child to become an autistic. This helped me to come out of my depression” (#24); “A neurologist reassured me that my son’s seizures were not caused by anything that I was doing” (#37); “A therapist called me to offer help in case I needed it. She went beyond her duties to help me” (#36), and “My pediatrician said that she will do what my child needs regardless of what I have and she will take my problems seriously” (#28). Information from knowledgeable and competent health professionals enhanced parents’ decision-making and their understanding of issues arising with their children as indicated in the following statements: “A second opinion from a pediatrician supported me for not having my son went through unnecessary testing” (#30), and “Knowing the diagnosis made me understand the odd behaviors of my child” (#31). Parents indicated satisfaction with attentive health professionals as reflected in the statements: “My pediatrician listened to me patiently. I really appreciate him” (#29), and “When my son was connected with many wires at the hospital, a nurse observed him closely and gave him a book he wanted. This made my son and I feel very happy” (#38). This cluster had the lowest average bridging value of the 5 clusters on this map. The value of 0.14 indicated that the statements were perceived to have a high degree of similarity and formed a distinct, coherent cluster of the map. The cluster rating average of importance was 3.63, which would be considered an important category to parents. This cluster was labeled “Psychological support from health professionals.”

Cluster 3 - Supportive care-workers.

Statements in this cluster are located on the far left upper portion of the concept map. The cluster contained four statements that directly concerned care-workers.

The statements reflected the kind of care-workers whom parents felt had been supportive to them and their children. Parents provided positive comments about skillful care-workers as indicated by statements such as ”care-workers have the means to learn the best way how to help my child” (#7), and “my child’s care-worker has gone above and beyond by helping to advocate for more funding” (#20). Parents recognized the positive experience with care-workers who developed bonds with their children as identified in the statements “care-workers work one-on-one with my son and put their whole hearts into making sure he learns” (#6), and “a care-worker has developed a strong bond with my son and chose to transition with him to the school setting” (#15). Hence, this category was labeled “Supportive care-worker.” This cluster had an average bridging value of 0.39. The cluster average rating of importance value was 3.49 and was rated the least valuable of the five categories on the map.

Cluster 4 - Social services help with home-life balance.

This cluster is located in the lower left corner of the map and next to cluster number 3. This cluster had the highest average bridging value (0.57) of the five clusters, and was judged to be the weakest of the map. The statements “funding by FSCD have helped to make a home program and supportive services possible” (#10), and “social workers were very respectful and provided a lunch program for my child” (#34) had a very high bridging index of 1.0 and 0.97 respectively. They appeared to be linking statements, which had been sorted frequently into different piles. This category’s average rating of importance value was 3.66. It was considered to be the third most important category of all 5 categories on the map.

Statements in this category encompassed parents' positive experiences with social service and home support professionals. Therefore, this cluster was titled "Social services help with home-life balance." Parents identified that attention and supportive communication from professionals had helped them to keep their lives in balance. They reported "A staff person gave me hope by showing me how to focus on the positive gains my son was making. I have more good days with my child" (#9), "Care-workers prompt me to do other activities besides just caring for my child. They helped me to lead my life in a normal way" (#25), "They ask me regularly if I am fine. They really care about me" (#26), and "A Family Service for Children with Disability (FSCD) staff asked me 'why we [FSCD staff] stressed you out?' At least she tried to identify what can keep me from having too much stress, when I am in contact with FSCD" (#39). Skill enhancement and practical supports from professionals affected parents' adaptation to caring for their children as reflected in the statements "She taught my child at home. This helped lessen my tension and gave me strength when I was exhausted" (#27), and "A staff person provided me with the skills required to help my son myself" (#8).

Cluster 5 - Supportive school professionals.

This cluster is located in the top right corner of the map. All statements in this category involved positive experiences that parents had with school professionals. The cluster average rating of importance was 3.86, which made it the second most important category among the five categories in the map. However, this cluster had a relatively high average bridging index of 0.41. The statements with highest bridging values were "social worker acts as an intermediary between a family and staff members to see positive change" (#14), "social workers at the school were helpful with money issues (for example, by providing gift cards for food). This gave me more positive energy when I had financial difficulty" (#33), and "because of a dedicated professional, my son's transition to school has been less stressful" (#16). The bridging values of these statements were 0.59, 0.54, and 0.50, respectively. The values indicated that these statements were linking statements, which were often sorted into different clusters. Parents frequently reported that the multidisciplinary team at school had done many important things to meet parents' and children's needs. Parents acknowledged the supports from school professionals in statements such as "Teachers praise your effort as a parent to help you remember that you are doing a good job" (#23). Parents valued teachers who were creative in their teaching method, as reflected in statements such as "I have been very impressed by some teachers who stretch their creativity to reach my child with different teaching methods" (#17). Parents reported that teachers also took a role in helping them out with many issues such as: "Teachers have supported me and have advocated services needed by both my son and me" (#11), and "Teachers prompted me to access services I was unaware of" (#12). Parents identified that a school social worker also played an important supportive role, stating "A social worker at my child's school has helped us to access services for any needs my child has had. She puts us in touch with many organizations" (#13). Parents also indicated their positive perceptions of a school therapist and program supervisor in the statements "therapy for children with autism at school with a consistent routine has helped my child gain different skills in activities of daily living" (#32), and "a program supervisor at school is going to try to implement the home video about our family situation as a teaching tool so that staff can be more empathetic to what families are going through" (#21).

These five themes from the parents' positive perception of professional contacts concept map were arranged from the highest to lowest ratings of importance as follows: 1) Supportive services from health professionals (4.03), 2) Supportive school professionals (3.86), 3) Social services help with home-life balance (3.66), 4) Psychological support from health professionals (3.63), and 5) Supportive care-workers (3.46). The categories, "Supportive services from health professionals" and "Psychological support from health professionals" had the lowest bridging values of .18 and .14 respectively. This indicated that the statements in these two categories formed distinct concepts and were rarely sorted into different piles. The category, "Social services help with home-life balance" had the highest bridging value of .57, followed by "Supportive school professionals" (.41), and "Supportive care-workers" (.39), indicating that these categories contained some linking statements which were frequently sorted into different piles.

The Parents' Negative Perception of Professional Contacts Concept Map

Initially, the default number of clusters for this map was six. Then the researcher had to determine the final number of clusters. Each statement contained in each cluster was examined one by one from cluster one to cluster six. The researcher tried increasing and decreasing the number of clusters. It was obvious that the 7- and 8-cluster solutions of the map were too conceptually discrete and visually fragmented. In both cases, some categories contained only 2 or 3 statements and appeared to conceptually overlap with other clusters. Further, enlarging the cluster-solution number would fail to improve the configuration's structure. Thus, no attempt was made to continue increasing the number of clusters. Subsequently, reducing the number to 4- and 5-cluster solutions was examined. The 4-cluster solution seemed to lump too many distinct concepts together. Hence, this solution was rejected in favor of a better interpretable solution. The 5-cluster solution was an improvement over the 4-cluster solution. When comparing the 5-cluster solution with the 6-cluster solution, the bridging values were insignificantly different. Finally, the decision was made at 6 clusters. Therefore, the 6-cluster solution (Figure 5) appeared to provide the most distinct and concise description of the data set encompassing parents' perceptions of professional contact that hindered their roles in caring for their children with disabilities. The 6 clusters were assigned 6 labels that best corresponded to each theme: 1) Inadequacy of School Professionals, 2) Conflict with Health Professionals, 3) Professionals' Ignorance, 4) Social Service Professionals' Lack of Empathy, 5) Fight for Social Services, and 6) Funding Issues.

Six-Cluster Solution Concept Map of 34 Parents' Negative Statements of Professional Contacts

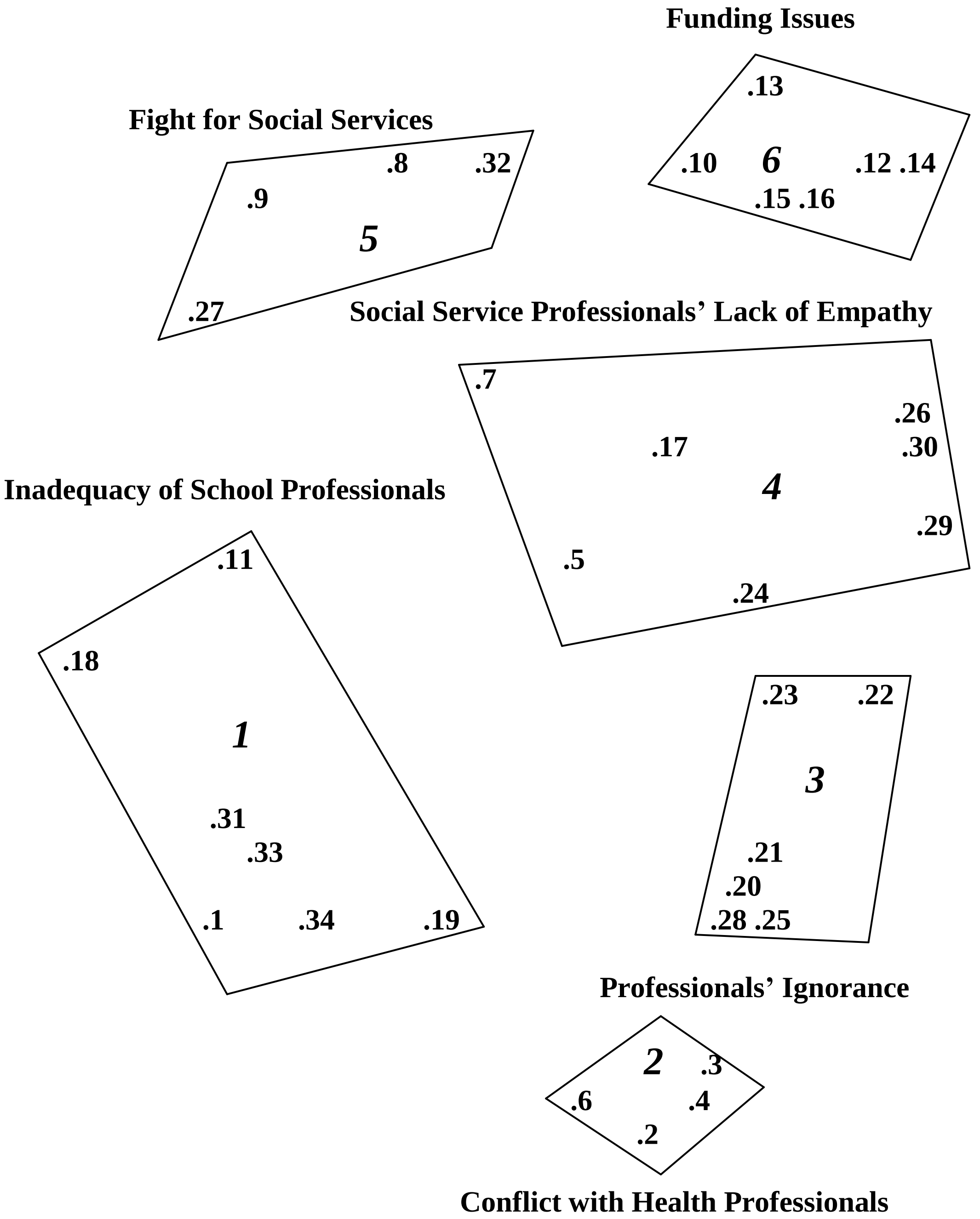


Figure 5. The 6 clusters were assigned 6 negative labels that best corresponded to each theme: 1) Inadequacy of school professionals, 2) Conflict with health professionals, 3) Professionals' ignorance, 4) Social service professionals' lack of empathy, 5) Fight for social services, and 6) Funding issues.

Description of the Parents' Negative Perception of Professional Contacts Clusters

The final six clusters were examined and labeled to represent the component statements from which they were constructed. Each category was labeled with key words or phrases from labels that the participants provided (Appendix L) for their grouping in the sorting task. Table 5 contains the statements in each cluster in the 6-cluster solutions, along with their bridging indexes, the average rating values of importance of the statements, and the labels. The Stress value of this map was 0.1993.

Table 5

Cluster Statements, Bridging Values, and Rating of Importance for the Six Clusters of Parents' Negative Perception of Professional Contacts

Item Number	Statements	Bridging Index	Rating Values
Cluster 1: Inadequacy of School Professionals			
1.	I felt pre-school assessment service could have warned me better about the outcome.	0.77	2.71
31.	Parents are often excluded from important discussions and decision-making in school.	0.49	3.71
19.	A school supervisor told me not to expect my son to get any better, or expect progress so I left that school.	0.49	3.71
33.	Teachers are not willing to use strategies in school that were developed and already work at home.	0.41	3.43
34.	Teachers are not willing to take into account the parents' personal experience with the child.	0.45	3.57
11.	The constant change of personnel at school causes frustration because we have to deal one day with one person and another day with another person.	0.90	3.71
18.	There is a lack of tolerance and understanding about children with disabilities in society.	0.98	3.57
	Cluster Bridging Average	0.64	
	Cluster Rating Average		3.49
Cluster 2: Conflict with Health Professionals			
2.	We identified the fact that there was a problem with our child, but the doctor told us there was nothing wrong, that this was normal.	0.35	3.71
6.	Multidisciplinary team at a hospital tried to persuade the parents to use tube feeding for their children over mouth feeding.	0.39	3.14
3.	The initial pediatrician told us to give our daughter up because he also had a child with disability and his personal relationship broke up.	0.29	3.43

Table 5 (continued)

Item Number	Statements	Bridging Index	Rating Values
4.	A doctor mentioned that our child would put us in difficult situations.	0.28	2.57
	Cluster Bridging Average	0.33	
	Cluster Rating Average		3.21
Cluster 3: Professionals' Ignorance			
20.	It is rude for professionals to say to parents to put their children aside or give up on them. They should be encouraging parents to help their children.	0.33	4.00
21.	Professionals have a lot of knowledge but lack experience.	0.35	2.71
25.	Some professionals are rude, condescending.	0.36	3.14
28.	Professionals do not have the relational skills necessary to deal with parents and children with disabilities.	0.32	3.29
22.	I feel disappointed when professionals promise me services that they cannot deliver.	0.54	3.29
23.	Professionals are not forthcoming about all services that are available.	0.53	4.43
	Cluster Bridging Average	0.40	
	Cluster Rating Average		3.48
Cluster 4: Social Service Professionals' Lack of Empathy			
5.	Social services wanted us to give back our adopted child when we found out later that she had cerebral palsy. We were pestered by them for quite awhile for refusing to give her back.	0.53	3.29
24.	A mother once said to me "this is my first visit with FSCD which a staff member did not make me cry."	0.50	2.57
7.	Social program at a women's shelter refused services due to my son's diagnosis of autism.	0.59	3.71
17.	A service worker told me if I could not control and calm my child I would not get my cheque on that day.	0.50	3.29

Table 5 (continued)

Item Number	Statements	Bridging Index	Rating Values
26.	A social worker told me to downplay my child's function in order to get more funding.	0.37	3.14
29.	Professionals protect their territory and their funding, particularly in a school system.	0.74	3.71
30.	Lack of accountability on how professionals spend the funding they receive.	0.52	4.00
	Cluster Bridging Average	0.53	
	Cluster Rating Average		3.39
Cluster 5: Fight for Social Services			
8.	I had to fight to get services from the social program.	0.47	3.86
9.	I had to use my son‘s diagnosis of autism to get help from the police in an abusive situation.	0.99	3.14
32.	Parents have to fight for services and government supports. There has not been much change for decades.	0.36	4.29
27.	I was starting with my three-year-old son to get him into a program and services. I tried to take one agency at a time so that I could digest all the information they gave to me. It's so much.	1.00	3.14
	Cluster Bridging Average	0.70	
	Cluster Rating Average		3.61
Cluster 6: Funding Issues			
10.	We have to go through the constant battles from different government agencies to get the needed help for our children that can be financially, manpower, equipment, services, on and on.	0.15	4.00
12.	With these children it takes a long time to form a bond that assists them to progress. The rate of pay from the government for staff in this field is not enough to keep them.	0.00	4.14

Table 5 (continued)

Item Number	Statements	Bridging Index	Rating Values
13.	The rate of pay is not enough to hire people to work at home. I have financial resources, but have difficulty finding help.	0.04	4.00
14.	The government provides funding for help, but it is not enough to be effective.	0.01	4.43
15.	AISH regulation limits the amount of money that parents can leave to or save for their children with disabilities.	0.05	3.57
16.	With FSCD, it's almost impossible to get funding and when we do get funding it is minimal.	0.01	4.29
	Cluster Bridging Average	0.04	
	Cluster Rating Average		4.07

What follows is a detailed description of each category and the statements contained in the parents' negative perception of professional contacts concepts map.

Cluster 1 - Inadequacy of school professionals.

Cluster 1 is located on the lower left side of the concept map. These statements reflected the challenges parents faced with school professionals. Specific statements that indicated parents' negative experiences with school professionals that made them feel worse or less secure in their relationship with their children were: "A school supervisor told me not to expect my son to get any better or expect progress so I left that school" (#19), "Teachers are not willing to use strategies in school that were developed and already work at home" (#33), "Teachers are not willing to take into account the parents' personal experience with the child" (#34), and "Parents are often excluded from important discussions and decision-making in school" (#31). The following two statements were not directly related to teachers but reflected challenges parents had with school services: "Pre-school assessment services could have warned me better about the outcome" (#1), and "The constant change of personnel at school causes frustration because we have to deal one day with one person and another day with another person" (#11). These two statements had very high bridging values of 0.77 and 0.90 respectively. Also, the statement number 18, that "there is a lack of tolerance and understanding about children with disabilities in society," had the highest bridging index of 0.98. This statement clearly indicated the societal issue in general. Hence, there was a high possibility for the statement to be sorted into many different piles by sorters. The higher bridging values of statements indicated less agreement in the way they were sorted, or that they were linking statements in the map. The high bridging values of these three statements resulted in the high bridging average value of 0.64 for this entire cluster. The importance ratings average across statements in this category was 3.49. It was ranked to be the third most important within the six clusters in this concept map. It was labeled "Inadequacy of School Professionals."

Cluster 2 - Conflict with health professionals.

Cluster 2 is located in the bottom of the map and on the right side of cluster 1. The statements in this cluster obviously reflected parental conflicts with health professionals' opinions. Parents felt that health professionals excessively focused on problems that the child would cause the parents, rather than supporting the family, as represented in the statements: "The initial pediatrician told us to give our daughter up because he also had a child with disability and his personal relationship broke up" (#3), "A doctor mentioned that our child would put us in difficult situations" (#4), and "Multidisciplinary team at the hospital persuaded the parents to use tube feeding for their children over mouth feeding" (#6). Another statement also suggested that the parents' opinion was in conflict with the doctor's: "We identified the fact that there was a problem with our child, but the doctor told us there was nothing wrong, that this was normal" (#2). This category was then labeled "Conflict with Health Professionals." This cluster had the lower bridging value of 0.33. This value indicated the statements were sorted together frequently to form a cohesive grouping. However, the average rating of importance value was 3.21, which was the lowest value of the six clusters.

Cluster 3 – Professionals' ignorance.

This cluster was located in the bottom right side of the concept map. The statements reflected parents' stress around dealing with professionals in general. Parents expressed dissatisfaction with professionals who lack competence in communicating and relating with parents or children with disabilities: "Professionals do not have the relational skills necessary to deal with parents and children with disabilities" (#28), "Professionals have a lot of knowledge but lack experience" (#21), and "Some professionals are rude, condescending" (#25). Parents also felt disappointed with professionals whose performance could not meet their expectations: "Professionals are not forthcoming about all services that are available" (#23), "I feel disappointed when professionals promise me services that they cannot deliver" (#22), and "It is rude for professionals to say to parents to put their children aside or give up on them. They should be encouraging parents to help their children" (#20). This category had average rating of importance of 3.48. The cluster average bridging value was 0.40. Statements number 22 and number 23 had the highest bridging values of 0.54 and 0.53 respectively in this cluster. This suggested that these two statements were often sorted in different piles by the sorters. This cluster was labeled "Professionals' Ignorance."

Cluster 4 – Social service professionals' lack of empathy.

This cluster was located in the upper right side next to cluster 3. Statements in this cluster reflected parents' negative experiences with social service professionals.

Parents perceived that they were treated with lack of empathy or sensitivity as represented by the statements: “Social services wanted us to give back our adopted child when we found out later that she had cerebral palsy. We were pestered by them for quite awhile for refusing to give her back” (#5), “A social program at a women’s shelter refused services due to my son’s diagnosis of autism” (#7), “A service worker told me if I could not control and calm my child I would not get my cheque on that day” (#17), and “A mother once said to me ‘this is my first visit with FSCD which a staff member did not make me cry” (#24). Parents also felt lack of trust in professionals concerning funding issues as seen in the statements “A social worker told me to downplay my child’s function in order to get more funding” (#26), “Professionals protect their territory and their funding, particularly in a school system” (#29), and “Lack of accountability on how professionals spend the funding they receive” (#30). The average rating of importance for this category was 3.39. The average bridging index for this cluster was 0.53. This value indicated that these statements were linking statements, and were sorted in different piles frequently. They did not form a cohesive grouping. This category was labeled as “Social Service Professionals’ Lack of empathy.”

Cluster 5 – Fight for social services.

This cluster was located on the top left side of the cluster map. The theme suggested that parents struggled with and sometimes had to fight for social services they required. Their negative experiences could be seen in such statements as: “I had to fight to get services from the social program” (#8), “I had to use my son’s diagnosis of autism to get help from the police in an abusive situation” (#9), and “I was starting with my three-year-old son to get him into a program and services. I tried to take one agency at a time so that I could digest all the information they gave to me. It’s so much” (#27). The fight for social services seemed to be a long battle for parents of children with disabilities as evidenced by such statements as “Parents have to fight for services and government supports. There has not been much change for decades” (#32). This category was labeled “Fight for Social Services.” The average bridging value of this cluster was a highest value (0.70) among the 6 clusters. The high value indicated that the statements were frequently sorted into different groupings. Parents’ rating of importance for this cluster was 3.61. This was ranked to be the second most important theme next to the “Funding Issues” category number 6.

Cluster 6 – Funding issues.

This cluster was located on the top right corner of the map. This category clearly reflected how parents experienced difficulties when funding was limited to help their children with disabilities. The statements presented the difficulties parents had in getting funding: “The government provides funding for help, but it is not enough to be effective” (#14), and “With FSCD it’s almost impossible to get funding and when we do get funding it is minimal” (#16). Parents also reported the issues related to funding limits: “The rate of pay is not enough to hire people to work at home. I have financial resources, but have difficulty finding help” (#12), and “With these children it takes a long time to form a bond that assists them to progress. The rate of pay from the government for staff in this field is not enough to keep them” (13). Parents indicated their challenges in getting support for their children, as evidenced by statements such as “We have to go through the constant battles from different government agencies to get the needed help for our children that can be financially, manpower, equipment, services, on and on” (#10). Another statement about a financial issue that also concerned parents was “AISH regulation limits the amount of money that parents can leave to or save for their children with disabilities” (#15). The statement reflected a policy that prevents parents from doing what they want for their adult children with disabilities, once the parents are no longer able to care for them. This category’s average rating of importance had the highest value, 4.07, of all categories in the map. The cluster bridging average index was very low, 0.04, suggesting it was a very tight cluster with a precise interpretation. This cluster was labeled “Funding Issues.”

Of all six themes from the parents’ negative perception of professional contacts concept map, the theme “Funding Issues” had the highest rating of importance value, 4.07, and the lowest bridging value, 0.04. This indicated that participants in the focus group perceived this category as the most important and distinct issue among the six categories. The ratings of importance of the other five themes were arranged from the higher values to the lower ones as follows: “Fight for social services” (3.61), “Inadequacy of school professionals” (3.49), “Professionals’ ignorance” (3.48), “Social service professionals’ lack of empathy” (3.39), and “Conflict with health professionals” (3.21). Four categories with bridging values above .35 were: “Professionals’ ignorance” (.40), “Social service professionals’ lack of empathy” (.53), “Inadequacy of school professionals” (.64), and “Fight for social services” (.70). These categories contained linking statements that were frequently sorted in different categories.

Reliability of the Concept Map Study

Trochim (1993b) states that even small samples of sorters can produce maps that fit almost as well as samples twice as large. To test whether it is also true of this study, four sets of sorted data received from the parents group and from the rehabilitation instructors group were initially analyzed separately. Then the sort data from both groups were combined and analyzed. The computer program performed a two-dimensional multidimensional scaling (MDS) for each group of sorted data. This MDS resulted in the production of point maps. The maps show the individual statements as points in two-dimensional (x, y) space. More similar statements, which were more frequently sorted into the same groups, were located closer to each other. Less similar statements, which were more frequently sorted into different groups, were located farther apart. This allowed statements to be grouped into clusters on the map. Also included were the computation of average ratings of importance, and average bridging values for each statement and cluster of statements. The bridging value indicates the degree to which the statement is related to statements that are close to it. A stress value for each of the concept maps was calculated. Table 6 presented the final stress values of the 6 maps that resulted from the two-dimensional solution of the MDS analysis. Stress is a statistical value reported for multidimensional scaling that reflects the goodness of fit of the map to the original dissimilarity matrix that served as input (Trochim, 1993b).

Table 6

Stress Values of 6 Concept Maps from 3 Different Groups of Sorters.

Number of sorters	Stress Value 19 (parents & rehabilitation staff)	Stress Value 7 (parents)	Stress Value 12 (rehabilitation staff)
Parents' Positive Perception of Professional Contacts Concept Map	0.240	0.261	0.246
Parents' Negative Perception of Professional Contacts Concept Map	0.199	0.236	0.217

All of the six stress values represented reasonably stable solutions. In a study of the reliability of concept mapping (Trochim, 1993b), the average stress value across 33 projects was .285 with a range from .155 to .352. The table suggests that stress values based on smaller sample sizes and different groups of sorters were well within the acceptable range and almost as low as the values from the combined larger sample. Furthermore, the stress values for the combined sorting groups were lower than those for either of the smaller groups. This suggested that there was no systematic difference between the sorters in the two groups. The sorted data that was grouped together from the parents and the rehabilitation instructors resulted in the lowest stress values of the concept maps. The two-dimensional solution of the MDS analysis resulted in a final stress value of .240 for the parents' positive perception of professional contacts concept map and a final stress value of .199 for the parents' negative perception of professional contacts concept map. These two lower stress values indicated a better fit. In addition, comparing the separated and combined stress values rules out the possibility that the parents and rehabilitation staff had consistently different sorting patterns, since this would result in higher stress values in the combined sorting analysis than in the two separate ones. Hence, the results of the sort data derived from the combined group of parents and rehabilitation instructors were used.

Phase Two – The Incidence Survey

Concept mapping is subject to the some of the same qualifications as qualitative research. It provides a breadth of understanding and parents' views about their experiences with professional contacts. The parents' brainstormed statements were grouped into themes, analyzed, organized, and interpreted. However, a limitation of this methodology is that the incidence of each statement is not determined for a representative sample of parents. Therefore, a survey was developed using the parents' brainstormed statements and concepts derived from the results of concept mapping analysis from phase one of the study. The survey was conducted to determine how frequently parents of individuals with disabilities endorsed the statements as relevant to their experiences with professional contacts. Participants were asked to complete demographic questions and then rate each statement of the survey questionnaires on a 6-point Likert response scale as 1=strongly disagree, 2=disagree, 3=neutral, 4=agree, 5=strongly agree, or 0=not applicable (Appendix J). The survey was distributed to a purposive sample of 133 parents of children with disabilities who attended programs at the Elves Special Needs Society in Edmonton. Only one parent from each family was asked to complete the survey. Forty-eight completed surveys (36.1%) were returned. Table 7 shows the survey participants' demographic information. The statements in the survey were re-organized into clusters according to the two concept maps derived from phase one of the study. The raw data from the survey was summarized as frequencies, percentage, means, weight average means, and standard deviations to determine how participants endorsed statements. The results were presented in Table 8 and Table 9.

The survey participants' characteristics.

Forty-eight parents of individuals with disabilities participated in the survey. Eighty-three percent of the participants were female, and 17% were male. Sixty-nine percent of the parents were married, 29% were single parents, and 2% did not indicate marital status. Twenty-three percent of the parents ranged in age from 31 to 40 years, 54% ranged from 41 to 50 years, 21% were more than 50 years old, and 2% of the parents did not list their ages. Eighty-five percent of participants lived in a city, 13 % lived in a rural area, and 2% did not respond to this question. Forty-four percent of parents had children with disabilities whose ages ranged from 2.5 to 6 years, 10% had children whose ages ranged from 12.1

to 18 years, and 31% had adult children more than 18 years old. The majority of participants (69%) were biological parents, 8% were adoptive parents, 19% were foster parents, and 4% were legal guardians. These parents had children with a wide range of disabilities that included developmental delays (33%), cerebral palsy (15%), autism (8%), fetal alcohol spectrum disorder (8%), global developmental delay (4%), language delay (4%), and spastic quadriplegia (4%). When added together, other disabilities (2.1% each), were reported among a total of 23% of the children. These were children with Angelman syndrome; blindness and developmental delay; blindness, deafness, and developmental delay; brain injury; chromosome deletion; dystonia; Leigh's disease; intellectual disability; Rett syndrome; sensory processing disorder, and tuberous sclerosis. Table 7 presents characteristics of the survey participants.

Table 7

Demographic Characteristics of the Survey Participants (n = 48)

Variable	Frequency	Percent
Female	40	83.3
Male	8	16.7
Married	33	68.8
Single parent	14	29.2
Missing	1	2.1
Age 31-40	11	22.9
41-50	26	54
50+	10	20.8
Missing	1	2.1
Live in City	41	85.4
Rural	6	12.5
Missing	1	2.1
Child’s age 2.5 - 6 yrs.	21	43.8
6.1-12	5	10.4
12.1-18	6	12.5
18+	15	31.3
Missing	1	2.1
Relationship: Biological parent	33	68.8
Adoptive parent	4	8.3
Foster parent	9	18.8
Legal guardian	2	4.2
Type of disability:		
Angelman syndrome	1	2.1
Autism	4	8.3
Blind & developmental delay	1	2.1
Blind & Deaf & Delay	1	2.1
Brain injury	1	2.1
Chromosome deletion	1	2.1
Cerebral palsy	7	14.6
Developmental delays	16	33.4
Dystonia	1	2.1
FASD	4	8.3
Global developmental delay	2	4.2
Language delay	2	4.2
Leigh’s disease	1	2.1
Mentally challenged	1	2.1
Rett syndrome	1	2.1
Sensory processing disorder	1	2.1
Spastic quadriplegia	2	4.2
Tuberous sclerosis	1	2.1
Total	48	100%

Incidence Survey Results – Parents' Positive Perception of Professional Contacts

The statements in the survey that derived from the parents' positive perception of professional contacts concept map were organized by clusters. The raw data was summarized as means, standard deviations, percentage of each statement by cluster, and cluster means. The results are presented by clusters in Table 8. A total of 39 statements of parents' perception of professional contacts that made them feel secure in their relationship with their children in the incidence survey, 16 of them had a statement average of 4 and above, and 16 more statements had a statement average of 3.4 and above (agree/strongly agree). The results indicated high ratings of agreement to 32 positive statements in the survey. Only seven positive statements received a variation of responses and had an average statement mean of 3.3 or below, but not less than 2.5. The results on these statements also indicated that more than 60 percent of participants perceived that those experiences were not applicable to them. What follows are detailed findings from each category and its statements, starting with a cluster that had a highest average mean value.

Table 8

Frequencies, Percentages, Means, Standard Deviations, and Weight Average Means of Each Category for Parents' Positive Perception of Professional Contacts Incidence Survey

STATEMENTS	1 S. Dis-agree		2 Dis-agree		3 Neutral		4 Agree		5 S Agree		0 N/A		<u>M</u>	<u>SD</u>
Cluster #1 **<u>Supportive services from health professionals</u>**	f	%	f	%	f	%	f	%	f	%	f	%		
1. There have been many health professionals my child's life, who have been empathetic and done what we asked them to.	-	-	4	8.3	4	8.3	27	56.3	12	25.0	1	2.1	4.0	.83
48. A therapist went on to contact other people to help complete my child's assessment.	1	2.1	1	2.1	2	4.2	14	29.2	8	16.7	22	45.8	4.0	.96
3. Therapists provided knowledge that we needed. We are able to use it in a way that my child could understand.	2	4.2	3	6.3	3	6.3	21	43.8	11	22.9	8	16.7	3.9	1.10
18. Therapists provide me with skills to assist my child at home. Through this my child makes more gains than only seeing them a few times a month.	2	4.2	7	14.6	6	12.5	9	18.8	12	25.0	12	25.0	3.6	1.30
26. Many professionals really go the extra mile to do what we asked them to do.	3	6.3	3	6.3	13	27.1	20	41.7	9	18.8	-	-	3.6	1.10
10. Some doctors are willing to see my child more frequently to maintain adequate care because of her/his needs.	-	-	6	12.5	6	12.5	16	33.3	17	35.4	3	6.3	4.0	1.00
40. The hospital referred our two-and-a-half- year-old child to a special needs program. I had someone to turn to.	-	-	-	-	7	14.6	5	10.4	9	18.8	27	56.3	4.1	0.90
11. My pediatrician continues to see our child well into his/her adult years.	1	2.1	2	4.2	5	10.4	6	12.5	12	25.0	22	45.8	4.0	1.20
57. A hospital has been helpful in giving supplies, wheelchairs, orthotics for shoes and prosthetics	2	4.2	4	8.3	3	6.3	5	10.4	7	14.6	27	56.3	3.5	1.40
WEIGHT AVERAGE MEAN = 3.85														

STATEMENTS	1 S. Dis-Agree		2 Dis-agree		3 Neutral		4 Agree		5 S Agree		0 N/A		M	SD
	f	%	f	%	f	%	f	%	f	%	f	%		
Cluster #2 **Psychological support from health professionals**														
44. The multi-disciplinary team in the hospital told me that I did not do anything wrong during pregnancy to cause my child to have disabilities. This helped me to come out of my depression.	2	4.2	2	4.2	3	6.3	6	12.5	5	10.4	30	62.5	3.6	1.3
19. A neurologist reassured me that my child's seizures were not caused by anything that I was doing.	1	2.1	-	-	6	12.5	4	8.3	11	22.9	26	54.2	4.1	1.1
58. Knowing the diagnosis made me understand the odd behaviors of my child.	-	-	2	4.2	5	10.4	11	22.9	19	39.6	11	22.9	4.3	0.9
7. A therapist called me to offer help in case I needed it. She/he went beyond her/his duties to help me.	4	8.3	4	8.3	1	22.9	15	31.3	8	16.7	6	12.5	3.5	1.2
51. My pediatrician said that she/he will do what my child needs regardless of what I have and she/he will take my problems seriously.	2	4.2	3	6.3	7	14.6	7	14.6	14	29.2	5	31.3	3.9	1.3
53. A second opinion from a pediatrician supported me for not having my child go through unnecessary testing.	2	4.2	1	2.1	5	10.4	4	8.3	3	6.3	33	68.8	3.3	1.3
61. My pediatrician listened to me patiently. I really appreciate him/her.	2	4.2	1	2.1	1	2.1	10	20.8	30	62.5	4	8.3	4.5	1.0
30. When my child was connected with many wires at the hospital, a nurse gave him/her good care. This made my child and I feel very happy.	1	2.1	2	4.2	3	6.3	5	10.4	15	31.3	22	45.8	4.2	1.2
WEIGHT AVERAGE MEAN = 3.97														

Table 8 (continued)

STATEMENTS	1 S. Dis-Agree		2 Dis-Agree		3 Neutral		4 Agree		5 S Agree		0 N/A		M	SD
	f	%	f	%	f	%	f	%	f	%	f	%		
Cluster #3 **Supportive care-workers**														
8. Care-workers work one-on-one with my child and put their whole hearts into making sure he/she learns.	-	-	2	4.2	5	10.4	16	33.3	21	43.8	4	8.3	4.3	0.9
15. Care-workers have the means to learn the best way how to help my child.	1	2.1	4	8.3	11	22.9	22	45.8	9	18.8	1	2.1	3.7	1.0
63. A care-worker has developed a strong bond with my child and chose to transition with him/her to the school setting.	1	2.1	1	2.1	3	6.3	5	10.4	8	16.7	30	62.5	4.0	1.9
41. My child's care-worker has gone above and beyond by helping to advocate for more funding.	3	6.3	3	6.3	6	12.5	10	20.8	10	20.8	16	33.3	3.7	1.3
WEIGHT AVERAGE MEAN = 3.91														

Table 8 (continued)

STATEMENTS	1 S. Dis-Agree		2 Dis-Agree		3 Neutral		4 Agree		5 S Agree		0 N/A		M	SD
Cluster #4 **<u>Social services help home-life balance</u>**	f	%	f	%	f	%	f	%	f	%	f	%		
67. A staff person provided me with the skills required to help my child myself.	2	4.2	3	6.3	8	16.7	10	20.8	15	31.3	10	20.8	3.9	1.2
32. A staff person gave me hope by showing me how to focus on the positive gains my child was making. I have more good days with my child.	1	2.1	2	4.2	9	18.8	16	33.3	9	18.8	11	22.9	3.8	1.0
71. They ask me regularly if I am fine. They really care about me.	4	8.3	3	6.3	12	25.0	13	27.1	10	20.8	6	12.5	3.5	1.2
43. She/he taught my child at home. This helped lessen my tension and gave me strength when I was exhausted.	4	8.3	1	2.1	2	4.2	3	6.3	3	6.3	35	72.9	3.0	1.6
23. Care-workers prompt me to do other activities besides just caring for my child. They helped me to lead my life in a normal way.	7	14.6	5	10.4	13	27.1	7	14.6	5	10.4	11	22.9	3.0	1.3
39. Funding by FSCD have helped to make a home program and supportive services possible.	2	4.2	2	4.2	7	14.6	10	20.8	12	25.0	15	31.3	3.9	1.2
21. A FSCD staff asked me “why we [FSCD staff] stressed you out?” At least she/he tried to identify what can keep me from having too much stress, when I am in contact with FSCD.	5	10.4	3	6.3	8	16.7	1	2.1	2	4.2	29	60.4	2.6	1.3
47. Social workers were very respectful and provided a lunch program for my child.	2	4.2	-	-	6	12.5	2	4.2	3	6.3	35	72.9	3.3	1.6
WEIGHT AVERAGE MEAN = 3.46														
Cluster #5 **<u>Supportive School Professionals</u>**														
2. Teachers have supported and have advocated services needed by both my child and me.	-	-	3	6.3	2	4.2	20	41.7	23	47.9	-	-	4.3	0.8

Table 8 (continued)

STATEMENTS	1 S. Dis-Agree		2 Dis-Agree		3 Neutral		4 Agree		5 S Agree		0 N/A		M	SD
Cluster #5 **Supportive School Professionals** (continued)	f	%	f	%	f	%	f	%	f	%	f	%		
72. Teachers prompted me to access services I was unaware of.	1	2.1	5	10.4	7	10.4	15	31.3	11	22.9	9	18.8	3.8	1.1
14. Therapy for children with disabilities at school with a consistent routine has helped my child gain different skills in activities of daily living.	-	-	3	6.3	6	12.5	18	37.5	17	35.4	4	8.3	4.1	0.9
34. A social worker at my child's school has helped us to access services for any needs my child has had. She/he puts us in touch with many organizations.	2	4.2	3	6.3	6	12.5	7	35.4	9	18.8	11	22.9	3.8	1.1
68. Social worker acts as an intermediary between a family and staff members to see positive change.	1	2.1	-	-	9	18.8	15	31.3	10	20.8	13	27.1	3.9	0.9
28. Because of a dedicated professional my child's transition to school has been less stressful.	1	2.1	-	-	7	14.6	14	29.2	15	31.3	11	22.9	4.1	0.9
9. I have been very impressed by some teachers who stretch their creativity to reach my child with different teaching methods.	1	2.1	1	2.1	2	4.2	18	37.5	25	52.1	1	2.1	4.4	0.9
24. A program supervisor at school is going to try to implement the home video about our family situation as a teaching tool so that staff can be more empathetic to what families are going through.	3	6.3	4	8.3	3	6.3	4	8.3	1	2.1	33	68.8	2.7	1.3
70. Teachers praise your effort as a parent to help you remember that you do good jobs.	2	4.2	1	2.1	12	25.0	12	25.0	18	37.5	3	6.3	4.0	1.1
22. Social workers at the school were helpful with money issues (for example, by providing gift cards for food). This gave me more positive energy when I had financial difficulty.	6	12.5	1	2.1	3	6.3	3	6.3	6	12.5	29	60.4	3.1	1.7
WEIGHT AVERAGE MEAN = 3.96														

Cluster number 2, “Psychological support from health professionals,” had the highest average mean of all the categories, with a mean of 3.97. There were eight statements in this category. Every statement in this category had a mean greater than 3.0, ranging from 3.3 to 4.5 (agree/strongly agree). The statements with the highest ratings of agreement and highest number of parents endorsing this theme were (#61) “My pediatrician listened to me patiently. I really appreciate him/her” (83% of parents agreed with the statement and it had a mean of 4.5), and (#58) “Knowing the diagnosis made me understand the odd behaviors of my child,” (63% of the participants reported and it had a mean of 4.3). These were followed by statements (#30) “When my child was connected with many wires at the hospital, a nurse gave him/her good care. This made my child and I feel very happy” (4.2), and (#19) “A neurologist reassured me that my child’s seizures were not caused by anything that I was doing” (4.1). Forty-two percent and 31% of parents agreed with these statements respectively. The ratings of agreement for the rest of other statements had means below 4. These statements were: (#51) “My pediatrician said that she/he will do what my child needs regardless of what I have and she/he will take my problems seriously” (3.9), (#44) “The multidisciplinary team in the hospital told me that I did not do anything wrong during pregnancy to cause my child to have disabilities. This helped me to come out of my depression” (3.6), and (#7) “A therapist called me to offer help in case I needed it. She/he went beyond her/his duties to help me” (3.5). Statement (# 53), “A second opinion from a pediatrician supported me for not having my child go through unnecessary testing” had a mean of 3.3. This was the only statement in this cluster that indicated a split in responses: 15% and 10% of parents endorsed agreement and neutral respectively. However, a high number of participants (69%) perceived the statement as not applicable to their experience.

Cluster number 5, “Supportive School Professionals,” had the weight average mean of 3.96, which was as high as the mean of cluster number 2. Ten statements were contained in this theme. High ratings of agreement were found on most of the statements in this category. Nevertheless, there were two statements that indicated a variation in the agreement of parents and had high numbers of parents perceiving them as non-applicable to their experience. The two statements were (#24) “A program supervisor at school is going to try to implement the home video about our family situation as a teaching tool so that staff can be more empathetic to what families are going through,” and (#22) “Social workers at the school were helpful with money issues (for example, by providing gift cards for food). This gave me more positive energy when I had financial difficulty.” These statements had a mean of 2.7 and 3.1 respectively. Also, a high number of parents, 69% and 60% respectively, found the statements were not applicable to them. High ratings of agreement were found on eight statements in this category. The highest average agreement was found for the statement number 9, “I have been very impressed by some teachers who stretch their creativity to reach my child with different teaching methods”: 89.6% of parents endorsed the statement and it had a mean of 4.4. This was followed by statement number 2, which had a mean value of 4.3 and 89.6% parental endorsement: “Teachers have supported and have advocated services needed by both my child and me.” Statements number 14, number 28, and number 70 had high ratings of agreement with means of 4 or 4.1. Seventy-three percent of parents endorsed the statement “Therapy for children with disabilities at school with a consistent routine has helped my child gain different skills in activities of daily living.” Sixty-one percent of parents agreed with the statement “Because of a dedicated professional, my child’s transition to school has been less stressful,” and 63% agreed that “Teachers praise your effort as a parent to help you remember that you do good jobs.” The following statements also had a high rating of agreement with means of 3.9 or 3.8, and were endorsed by more than 50% of the participants: (#68) “Social worker acts as an intermediary between a family and staff members to see positive change,” (#34) “A social worker at my child’s school has helped us to access services for any needs my child has had. She/he puts us in touch with many organizations,” and (#72) “Teachers prompted me to access services I was unaware of.”

Cluster number 3, “Supportive care-workers,” contained four statements and had a high mean parental endorsement rating of 3.91. This category was ranked with the third highest average mean of the five clusters. Each of the four statements contained in this category had a high statements mean ranging from 3.7 to 4.3. The highest ratings of agreement and highest number of parents endorsing (77%) was found for the statement number 8, “Care-workers work one-on-one with my child and put their whole hearts into making sure he/she learns” (4.3). The next-highest ratings of agreement and parental endorsement, with 65% of respondents, was statement number 15, “Care-workers have the means to learn the best way how to help my child” (3.7). Forty-two percent of parents agreed with statement number 41, “My child’s care-worker has gone above and beyond by helping to advocate for more funding” (3.7). A low number of respondents (27%) endorsed statement number 63, “A care-worker has developed a strong bond with my child and chose to transition with him/her to the school setting,” with a mean of 4. A high number of parents (63%) perceived that this statement did not apply to their experience.

Cluster number 1, “Supportive services from health professionals,” contained 9 statements and had an average mean of 3.85. All the statements in this cluster had a high mean value range from 3.5 to 4.1. There were several statements on which more than 50% of parents agreed. Eighty-one percent of parents agreed (#1) that “there have been many health professionals in my child’s life, who have been empathetic and done what we asked them to,” followed by 69% who endorsed (#10) “Some doctors are willing to see my child more frequently to maintain adequate care because of her/his needs,” 67% who agreed with (#18) “Therapists provided knowledge that we needed. We are able to use it in a way that my child could understand,” and 61% agreed with the statement (#26) that “many professionals really go the extra mile to do what we asked them to do.” An equal number of parents, 46%, both agreed and disagreed with statement number 48, “A therapist went on to contact other people to help complete my child’s assessment.” Forty-four percent of parents agreed with statement number 18, “Therapists provide me with skills to assist my child at home. Through this my child makes more gains than only seeing them a few times a month.” High numbers of parents said that the following statements did not apply to them: (#57) “A hospital has been helpful in giving supplies, wheelchairs, orthotics for shoes and prosthetics” (56%); (#40) “The hospital referred my two-and-a-half-year-old child to a special needs program. I had someone to turn to” (56%), and (#11) “My pediatrician continues to see our child well into his/her adult years” (46%). The numbers of respondents agreeing with the statements were 25%, 29%, and 38% respectively.

Cluster number 4, “Social services help with home-life balance,” had the least weight average mean (3.46) among the five categories. This category contained eight statements. The following four statements generated a considerable degree of variation, and a high number of parents reported that at least three of the statements did not apply to them**:**(#43) “She/he taught my child at home. This helped lessen my tension and gave me strength when I was exhausted” (3.0) (73% found this did not apply to their experience.); (#21) “A FSCD staff asked me ‘why we [FSCD staff] stressed you out?’ At least she/he tried to identify what can keep me from having too much stress, when I am in contact with FSCD” (2.6). (60% found this did not apply to their experience); (#47) “Social workers were very respectful and provided a lunch program for my child” (3.3) (73% found this did not apply to them). A variation in agreement was reflected clearly in the responses to statement number 23, “Care-workers prompt me to do other activities besides just caring for my child. They helped me to lead my life in a normal way” (3.0). There were 25% of participants who reported agreement with this statement, another 25% disagreed, 27% were neutral, and 23% not applicable to their experience.

High ratings of agreement were found on four statements. Fifty-two percent of parents endorsed statements number 67, “A staff person provided me with the skills required to help my child myself,” and number 32 “A staff person gave me hope by showing me how to focus on the positive gains my child was making. I have more good days with my child.” These statements had a mean of 3.9 and 3.8 respectively. Forty-six percent of participants agreed with the statement “Funding by FSCD have helped to make a home program and supportive services possible,” which had a mean of 3.9. Statement number 71 “They ask me regularly if I am fine. They really care about me,” 48% of parents endorsed the statement and the mean was 3.5.

Incidence Survey Results – Parents’ Negative Perception of Professional Contacts

The statements in the survey that derived from the parents’ negative perception of professional contacts concept map were organized into clusters. The raw data was summarized as means, standard deviations, percentage of each statement by cluster, and cluster means. Table 9 contains the listing results, presented by clusters. From a total of 33 negative statements in the incidence survey, 16 had an item average of over 3.5, reflecting parents’ substantial agreement with these statements. Seven statements averaged a statements’ mean of less than 2.3, indicating that many participants disagreed with them. Seven statements had an average mean of 3.0 or close to 3.0. The results presented a variation of parents’ perceptions of those experiences with professional contacts. In cluster number 4, 92% and 94% of parents perceived statements number 16 and number 29 respectively as not applicable to their experiences. These statements were: “Social services wanted us to give back our adopted child when we found out later that she/he had cerebral palsy. We were pestered by them for quite awhile for refusing to give her/him back” (2.5), and “A social program at a women’s shelter refused services due to my child’s diagnosis of autism” (2.3). A total of 88% of participants said that the following statement, number 56 in cluster 5, did not apply to them: “I had to use my child’s diagnosis of autism to get help from the police in an abusive situation.”

Table 9

Frequencies, Percentages, Means, Standard Deviations, and Weight Average Means of Each Category for Parents' Negative Perception of Professional Contacts Incidence Survey

STATEMENTS	1 S. Dis-Agree		2 Dis-Agree		3 Neutral		4 Agree		5 Strongly Agree		0 N/A		M	SD
	f	%	f	%	f	%	f	%	f	%	f	%		
Cluster #1 **Inadequacy of school professionals**														
64. I felt pre-school assessment services could have warned me better about the outcome.	5	10.4	3	6.3	10	20.8	5	10.4	4	8.3	21	43.8	3.0	1.3
5. Parents are often excluded from important discussions and decision-making in school.	14	29.2	16	33.3	8	16.7	6	12.5	2	4.2	2	4.2	2.3	1.1
37. A school supervisor told me not to expect my child to get any better, or expect progress so I left that school.	10	20.8	5	10.4	3	6.3	2	4.2	3	6.3	25	52.1	2.3	1.5
6. Teachers are not willing to use strategies in school that were developed and already work at home.	18	37.5	16	33.3	8	16.7	3	6.3	2	4.2	1	2.1	2.0	1.1
27. Teachers are not willing to take into account the parents' personal experience with the child.	21	43.8	12	25.0	7	14.6	4	8.3	3	6.3	1	2.1	2.1	1.2
25. The constant change of personnel at school causes frustration because we have to deal one day with one person and another day with another person.	4	8.3	6	12.5	10	20.8	7	14.6	3	6.3	18	37.5	3.0	1.2
36. There is a lack of tolerance and understanding about children with disabilities in society.	2	4.2	3	6.3	4	8.3	13	27.1	25	52.1	1	2.1	4.2	1.1
WEIGHT AVERAGE MEAN = 2.68														

Table 9 (continued)

STATEMENTS	1 S. Dis-Agree		2 Dis-Agree		3 Neutral		4 Agree		5 S. Agree		0 N/A		M	SD
Cluster #2 **Conflict with health professionals**	f	%	f	%	f	%	f	%	f	%	f	%		
35. I identified the fact that there was a problem with my child, but the doctor told me there was nothing wrong, that this was normal.	8	16.7	6	12.5	5	10.4	7	14.6	6	12.5	16	33.3	2.9	1.5
20. Multidisciplinary team at a hospital persuaded the parents to use tube feeding for their children over mouth feeding.	7	14.6	1	2.1	3	6.3	4	8.3	3	6.3	30	62.5	2.7	1.6
4. A health professional told us to give our child up because he/she also had a child with disability and his/her personal relationship broke up.	17	35.4	5	10.4	2	4.2	1	2.1	1	2.1	22	45.8	1.6	1.1
62. A doctor mentioned that my child would put me in difficult situations.	8	16.7	2	4.2	8	16.7	5	10.4	6	12.5	19	39.6	3.0	1.5
WEIGHT AVERAGE MEAN = 2.57														
Cluster #3 **Professionals' Ignorance**														
45. It is rude for professionals to say to parents to put their children aside or give up on them. They should be encouraging parents to help their children.	3	6.3	-	-	3	6.3	5	10.4	29	60.4	8	16.7	4.4	1.2
13. Some professionals have a lot of knowledge but lack experience.	1	2.1	4	8.3	15	31.3	17	35.4	10	20.8	1	2.1	3.7	1.0
60. Some professionals are rude, condescending.	4	8.3	4	8.3	9	18.8	11	22.9	17	35.4	3	6.3	3.7	1.3
49. Some professionals do not have the relational skills necessary to deal with parents and children with disabilities.	1	2.1	4	8.3	9	18.8	8	16.7	23	47.9	3	6.3	4.1	1.1
12. I feel disappointed when professionals promise me services that they cannot deliver.	2	4.2	6	12.5	3	6.3	11	22.9	14	29.2	12	25.0	3.8	1.3
66. Professionals are not forthcoming about all services that are available.	5	10.4	4	8.3	6	12.5	11	22.9	18	37.5	4	8.3	3.8	1.4
WEIGHT AVERAGE MEAN = 3.89														

Table 9 (continued)

STATEMENTS	1 S. Dis Agree		2 Dis-Agree		3 Neutral		4 Agree		5 S. Agree		0 N/A		M	SD
	f	%	f	%	f	%	f	%	f	%	f	%		
***Cluster #4* <u>Social service professionals' lack of empathy</u>**														
16. Social services wanted us to give back our adopted child when we found out later that she/he had cerebral palsy. We were pestered by them for quite awhile for refusing to give her/him back.	1	2.1	-	-	3	6.3	-	-	-	-	44	91.7	2.5	1.0
55. A mother once said to me "this is my first visit with FSCD which a staff member did not make me cry."	3	6.3	1	2.1	9	18.8	3	6.3	2	4.2	30	62.5	3.0	1.2
29. A social program at a women's shelter refused services due to my child's diagnosis of autism.	1	2.1	1	2.1	-	-	1	2.1	-	-	45	93.8	2.3	1.5
42. A service worker told me if I could not control and calm my child I would not get my cheque on that day.	8	16.7	1	2.1	2	4.2	2	4.2	-	-	35	72.9	1.9	1.2
46. A social worker told me to downplay my child's function in order to get more funding.	11	22.9	3	6.3	4	8.3	3	6.3	2	4.2	25	52.1	2.2	1.4
69. Professionals protect their territory and their funding, particularly in a school system.	2	4.2	4	8.3	3	27.1	8	16.7	2	25.0	9	18.8	3.6	1.2
65. Lack of accountability on how professionals spend the funding they receive.	4	8.3	2	4.2	3	27.1	9	18.8	2	25.0	8	16.7	3.6	1.3
WEIGHT AVERAGE MEAN = 3.07														
***Cluster #5* <u>Fight for social services</u>**														
38. Parents have to fight for services and government supports. There has not been much change for decades.	1	2.1	5	10.4	4	8.3	5	10.4	29	60.4	4	8.3	4.3	1.2
56. I had to use my child's diagnosis of autism to get help from the police in an abusive situation.	1	2.1	-	-	1	2.1	3	6.3	1	2.1	42	87.5	3.5	1.4

Table 9 (continued)

STATEMENTS	1 S. Dis-Agree		2 Dis-Agree		3 Neutral		4 Agree		5 S. Agree		0 N/A		M	SD
Cluster #5 **Fight for social services** (continued)	f	%	f	%	f	%	f	%	f	%	f	%		
33. I was starting with my three-year-old child to get him/her into a program and services. I tried to take one agency at a time so that I could digest all the information they gave me. It's so much.	1	2.1	1	2.1	2	4.2	17	35.4	7	14.6	20	41.7	4.0	0.9
WEIGHT AVERAGE MEAN = 4.12														
Cluster #6 **Funding issues**														
52. We have to go through the constant battles from different government agencies to get the needed help for our children that can be financially, manpower, equipment, services, on and on.	2	4.2	2	4.2	4	8.3	6	12.5	22	45.8	12	25.0	4.2	1.2
31. With these children it takes a long time to form a bond that assists them to progress. The rate of pay from the government for staff in this field is not enough to keep them.	4	8.3	-	-	5	10.4	6	12.5	27	56.3	6	12.5	4.2	1.3
54. The rate of pay is not enough to hire people to work at home. I have financial resources, but have difficulty finding help.	1	2.1	1	2.1	7	14.6	4	8.3	19	39.6	16	33.3	4.2	1.1
59. The government provides funding for help, but it is not enough to be effective.	-	-	3	6.3	10	20.8	10	20.8	20	41.7	5	10.4	4.1	1.0
17. With FSCD, it's almost impossible to get funding and when we do get funding it is minimal.	4	8.3	5	10.4	13	27.1	7	14.6	6	12.5	13	27.1	3.2	1.2
50. AISH regulations limit the amount of money that parents can leave to or save for their children with disabilities.	5	10.4	-	-	8	16.7	5	10.4	13	27.1	17	35.4	3.7	1.5
WEIGHT AVERAGE MEAN = 3.95														

Findings for each category and its statements are described in detail starting from categories with higher weight average mean values. Compared to the other five clusters, cluster number 3, "Professionals' Ignorance," had the highest number of parents agreeing with every statement in the category, with a high average agreement mean of 3.89. Every statement in the category had a mean greater than 3.5 (agree/strongly agree). The statement with the highest rating of agreement and also a high number of parents who endorsed the theme was number 45. Seventy-one percent of parents agreed that "It is rude for professionals to say to parents to put their children aside or give up on them. They should be encouraging parents to help their children" (4.4). The rest of the statements in this category also had high ratings of agreement. Sixty-five percent of parents reported that "Some professionals do not have the relational skills necessary to deal with parents and children with disabilities" (4.1), followed by 60% who agreed that "Professionals are not forthcoming about all services that are available" (3.8), 52% who reported that "I feel disappointed when professionals promise me services that they cannot deliver" (3.8), 58% who felt "Some professionals are rude, condescending" (3.7), and 56% who perceived that "Some professionals have a lot of knowledge but lack experience" (3.7).

Cluster number 5, "Fight for Social Services," contained only three statements and had a high mean of 4. It was significant that 71% of respondents reported that "Parents have to fight for services and government supports. There has not been much change for decades" with a mean of 4.3. Fifty percent of parents agreed that "I was starting with my three-year-old child to get him/her into a program and services. I tried to take one agency at a time so that I could digest all the information they gave me. It’s so much,” a statement with a mean of 4. Eighty-eight percent of parents said that statement number 56 did not apply to their experience: “I had to use my child’s diagnosis of autism to get help from the police in an abusive situation.” However, 8% of parents agreed with the statement, which had a mean of 3.5.

Cluster number 6, “Funding Issues,” contained six statements and had a high mean of 3.95. Four statements had high ratings of agreement with a mean of more than 4, and two statements had a mean of more than 3. Statement number 31 had the highest number of parents agreeing, and a high mean of 4.2. Sixty-nine percent of parents perceived that “With these children it takes a long time to form a bond that assists them to progress. The rate of pay from the government for staff in this field is not enough to keep them.” Nearly the same number, 63 percent, agreed that “The government provides funding for help but it is not enough to be effective” (4.1); 58% endorsed statement number 52, “We have to go through the constant battles with different government agencies to get the needed help for our children that can be financially, manpower, equipment, services, on and on” (4.2). Forty-eight percent agreed with statement number 54, “The rate of pay is not enough to hire people to work at home. I have financial resources, but have difficulty finding help” (4.2); and 38% endorsed statement number 50, “AISH regulations limit the amount of money that parents can leave to or save for their children with disabilities” (3.7). Statement number 17, “With FSCD, it’s almost impossible to get funding and when we do get funding it is minimal,” had a mean of 3.2. However, a high degree of variation was apparent among responses for this statement: 19% disagreed, 27% of perceived the statement as neutral, 27% agreed, and 27% said it did not apply to their experience.

Cluster number 2, "Conflict with Health Professionals," contained four statements and had the lowest cluster average mean of 2.6. The results of three statements in this category reflected a significant variation of responses. These statements were: (#35), "I identified the fact that there was a problem with my child, but the doctor told me there was nothing wrong, that this was normal" (2.9); (#20), "multidisciplinary team at a hospital persuaded the parents to use tube feeding for their children over mouth feeding" (2.7); and (#62), "a doctor mentioned that my child would put me into difficult situations" (3.0). Only statement number 4 in this category had a clear rating of disagreement with a mean of 1.6. Forty-six percent of participants disagreed with the statement that "A health professional told us to give our child up because he/she also had a child with disability and his/her personal relationship broke up."

Cluster number 1, "Inadequacy of School Professionals," contained seven statements and had a mean of 2.7. The results in this category varied substantially. There were high levels of disagreement and a mean lower than 2.5 with four statements. The statements were: (#6), "Teachers are not willing to use strategies in school that were developed and already work at home" (71%); (#27), "Teachers are not willing to take into account the parents' personal experience with the child" (69%); (#5), "Parents are often excluded from important discussions and decision-making in school" (63%); and (#37), "A school supervisor told me not to expect my child to get any better, or expect progress, so I left that school" (31%). Only one statement, 36, had a high rating of agreement, with a mean of 4.2: "There is a lack of tolerance and understanding about children with disabilities in society" (79%). A variation was seen among responses to statements 64 and 25; both had a mean of 3. The statements were: "I felt pre-school assessment services could have warned me better about the outcome," and "The constant change of personnel at school causes frustration because we have to deal one day with one person and another day with another person."

Cluster number 4, "Social Service Professionals' Lack of Empathy," contained seven statements and had a mean of 3. A considerable degree of variation was apparent among responses to the statements in this category. It is also important to note that more than 50% of participants found that five statements in this theme did not apply to their experiences. Most of the parents found that statements 29 and 16 did not apply to their experiences: (#29), "A social program at a woman's shelter refused services due to my child's diagnosis of autism" (94%); and (#16), "Social services wanted us to give back our adopted child when we found out later that she/he had cerebral palsy. We were pestered by them for quite awhile for refusing to give her/him back" (92%). Two statements had a mean of less than 2.5 and were negatively endorsed by parents. Nineteen percent of participants disagreed with statement 42, "A service worker told me if I could not control and calm my child, I would not get my cheque on that day," but 73% of parents found this did not apply to their experience. Twenty-nine percent of respondents disagreed with statement number 46, "A social worker told me to downplay my child’s function in order to get more funding,” while 52% reported that the statement did not apply to their experience. Parents reported substantial agreement with statements 69 and 65; both had a mean of 3.6. These statements were, “Professionals protect their territory and their funding, particularly in a school system” (42%); and “Lack of accountability on how professionals spending the funding they receive” (44%). Statement number 55, “A mother once said to me “this is my first visit with FSCD which a staff member did not make me cry,” had a mean of 3. Nineteen percent of respondents perceived the statement as neutral, and 63% said it did not apply to their experience.

Summary of the Results

Forty-eight parents of individuals with disabilities who attend the Elves Special Needs Society Programs completed the survey. The survey included basic demographic questions for parents and 72 statements derived from the two concept maps developed in the study’s first phase. Results of the five themes derived from the parents’ positive perception of professional contacts concept map were organized by the mean numbers of parents who endorsed agreement for the various categories from the highest average mean to the lowest as follows: “psychological support from health professionals” (3.97), “supportive school professionals” (3.96), “supportive care-workers” (3.91), “supportive service from health professionals” (3.85), and “social services help with home-life balance” (3.46). Responses to the positive statements in the survey varied only slightly. There was a significant amount of agreement with most of the parents’ positive perceptions of professional contacts statements that enhanced their roles to caring for a child with disabilities, as shown in Table 10. Thirty-two statements had high ratings of agreement. Six statements had a split opinion, either between neutral with agreement (#53, # 47), neutral with disagreement (#21), or agreement with disagreement (#22, #43, #24). Also a high number of parents, more than 60%, said that the statements did not apply to their experiences. Statement number 23 received variable responses. There were no apparent differences in responses based on demographic variables. Most statements received high levels of agreement. Table 10 and Table 11 present the descending statements’ means and the percentage of parents who endorsed statements in the survey.

Table 10

Descending Statement Means and Percentages of Parent-Endorsed Positive Statements from the Survey

Rank	**Statements**	**% Parent-Endorsed Statements ***				
		Mean	A/SA	NEU	SD/D	N/A
1.	My pediatrician listened to me patiently. I really appreciate him/her (#61)	4.48	83.3	20.8	6.3	8.3
2.	I have been very impressed by some teachers who stretch their creativity to reach my child with different teaching methods. (#9)	4.38	89.6	4.2	4.2	2.1
3.	Teachers have supported and have advocated services needed by both my child and me. (#2)	4.31	89.6	4.2	6.3	0.0
4.	Care-workers work one-on-one with my child and put their whole hearts into making sure he/she learns.(#8)	4.27	77.1	10.4	4.2	8.3
5.	Knowing the diagnosis made me understand the odd behaviors of my child. (#58)	4.27	62.5	10.4	4.2	22.9
6.	When my child was connected with many wires at the hospital, a nurse gave him/her good care. This made my child and I feel very happy. (#30)	4.19	41.7	6.3	6.3	45.8
7.	Because of a dedicated professional my child's transition to school has been less stressful. (#28)	4.14	60.5	14.6	2.1	22.9
8.	Therapy for children with disabilities at school with a consistent routine has helped my child gain different skills in activities of daily living. (#14)	4.11	72.9	12.5	6.3	8.3
9.	The hospital referred my two-and-a-half-year-old child to a special needs program. I had someone to turn to. (#40)	4.10	29.2	14.6	0.0	56.3
10.	A neurologist reassured me that my child's seizures were not caused by anything that I was doing. (#19)	4.09	31.2	12.5	2.1	54.2
11.	A therapist went on to contact other people to help complete my child's assessment. (#48)	4.04	45.9	4.2	4.2	45.8

Note. SA=Strongly agree, A=Agree, NEU=Neutral, SD=Strongly disagree, D=Disagree, N/A= Not applicable

Table 10 (continued)

Rank	**Statements**	**% Parent-Endorsed Statements ***				
		Mean	SA/A	NEU	SD/D	N/A
12.	A care-worker has developed a strong bond with my child and chose to transition with him/her to the school setting. (#63)	4.0	27.1	6.3	4.2	62.5
13.	My pediatrician continues to see our child well into his/her adult years. (#11)	4.0	37.5	10.4	6.3	45.8
14.	There have been many health professionals in my child's life, who have been empathetic and done what we asked them to.(#1)	4.0	81.3	8.3	8.3	2.1
15.	Some doctors are willing to see my child more frequently to maintain adequate care because of his/her needs. (#10)	3.98	68.7	12.5	12.5	6.3
16.	Teachers praise your effort as a parent to help you remember that you do good job.(#70)	3.96	62.5	25.0	6.2	6.3
17.	Social worker acts as an intermediary between a family and staff members to see positive change.(#68)	3.94	52.1	18.8	2.1	27.1
18.	Therapists provided knowledge that we needed. We are able to use it in a way that my child could understand.(#3)	3.90	66.7	6.3	10.5	16.7
19.	A staff person provided me with the skills required to help my child myself. (#67)	3.87	52.1	16.7	10.5	20.8
20.	My pediatrician said that she/he will do what my child needs regardless of what I have and she/he will take my problems seriously. (#51)	3.85	43.8	14.6	10.5	31.3
21.	Funding by FSCD have helped to make a home program and supportive services possible. (#39)	3.85	45.8	14.6	8.4	31.3
22.	A staff person gave me hope by showing me how to focus on the positive gains my child was making. I have more good days with my child. (#32)	3.81	52.1	18.8	6.3	22.9
23.	Teachers prompted me to access services I was unaware of. (#72)	3.77	54.2	14.6	12.5	18.8

Note. SA=Strongly agree, A=Agree, NEU=Neutral, SD=Strongly disagree, D=Disagree, N/A= Not applicable

Table 10 (continued)

Rank	**Statements**	**% Parent-Endorsed Statements ***				
		Mean	SA/A	NEU	SD/D	N/A
24.	A social worker at my child's school has helped us to access services for any needs my child has had. She/he puts us in touch with many organizations. (#34)	3.76	54.2	12.5	10.5	22.9
25.	Care-workers have the means to learn the best way how to help my child. (#15)	3.72	64.6	22.9	10.4	2.1
26.	My child's care-worker has gone above and beyond by helping to advocate for more funding. (#41)	3.66	41.6	12.5	12.6	33.3
27.	Therapists provide me with skills to assist my child at home. Through this my child makes more gains than only seeing them few times a month. (#18)	3.61	43.8	12.5	18.8	25.0
28.	Many professionals really go the extra mile to do what we asked them to do. (#26)	3.60	60.5	27.1	12.6	0.0
29.	The multi-disciplinary team in the hospital told me that I did not do anything wrong during pregnancy to cause my child to have disabilities. This helped me to come out of my depression. (#44)	3.56	22.9	6.3	8.4	62.5
30.	They ask me regularly if I am fine. They really care about me. (#71)	3.52	47.9	25.0	14.6	12.5
31.	A hospital has been helpful in giving supplies, wheelchairs, orthotics for shoes and prosthetics. (#57)	3.52	25.0	6.3	12.5	56.3
32.	A therapist called me to offer help in case I needed it. She/he went beyond her/his duties to help me. (#7)	3.45	48.0	22.9	16.6	12.5
	High percentages of not applicable statements and split in responses					
1.	A second opinion from a pediatrician supported me for not having my child go through unnecessary testing. (#53)	3.33	14.6	10.4	6.3	68.8
2.	Social workers were very respectful and provided a lunch program for my child. (#47)	3.31	10.5	12.5	4.2	72.9

Table 10 (continued)

Rank	**Statements**	**% Parent-Endorsed Statements ***				
		Mean	SA/A	NEU	SD/D	N/A
3.	Social workers at the school were helpful with money issues (for example, by providing gift cards for food). This gave me more positive energy when I had financial difficulty. (#22)	3.11	18.8	6.3	14.6	60.4
4.	She/he taught my child at home. This helped lessen my tension and gave me strength when I was exhausted. (#43)	3.00	12.6	4.2	10.4	72.9
5.	A program supervisor at school is going to try to implement the home video about our family situation as a teaching tool so that staff can be more empathetic to what families are going through. (#24)	2.73	10.4	6.3	14.6	68.8
6.	A FSCD staff asked me “why we [FSCD staff] stressed you out?” At least she/he tried to identify what can keep me from having too much stress, when I am in contact with FSCD. (#21)	2.58	6.3	16.7	16.7	60.4
	Variation in responses statement					
1.	Care-workers prompt me to do other activities besides just caring for my child. They helped me to lead my life in a normal way. (#23)	2.95	25.0	27.1	25.0	22.9

Note. SA=Strongly agree, A=Agree, NEU=Neutral, SD=Strongly disagree, D=Disagree, N/A= Not applicable

Table 11

Descending Statements Means and Percentages of Parent-Endorsed Negative Statements from the Survey

Rank	**Statements**	**% Parent-Endorsed Statements ***				
		Mean	SA/A	NEU	SD/D	N/A
1.	It is rude for professionals to say to parents to put their children aside or give up on them. They should be encouraging parents to help their children. (#45)	4.43	70.8	6.3	6.3	16.7
2.	Parents have to fight for services and government supports. There has not been much change for decades. (#38)	4.27	70.8	8.3	12.5	8.3
3.	With these children it takes a long time to form a bond that assists them to progress. The rate of pay from the government for staff in this field is not enough to keep them. (#31)	4.24	68.8	10.4	8.3	12.5
4.	We have to go through the constant battles from different government agencies to get the needed help for our children that can be financially, manpower, equipment, services, on and on. (#52)	4.22	58.3	8.3	8.4	25.0
5.	The rate of pay is not enough to hire people to work at home. I have financial resources, but have difficulty finding help. (#54)	4.22	47.9	14.6	4.2	33.3
6.	There is a lack of tolerance and understanding about children with disabilities in society. (#36)	4.19	79.2	8.3	10.5	2.1
7.	The government provides funding for help, but it is not enough to be effective. (#59)	4.09	62.5	20.8	6.3	10.4
8.	Some professionals do not have the relational skills necessary to deal with parents and children with disabilities. (#49)	4.07	64.6	18.8	10.4	6.3
9.	I was starting with my three-year-old child to get him/her into a program and services. I tried to take one agency at a time so that I could digest all the information they gave me. It’s so much. (#33)	4.00	50.0	4.2	4.2	41.7
10.	I feel disappointed when professionals promise me services that they cannot deliver. (#12)	3.81	52.1	6.3	16.7	25.0

Note. SA=Strongly agree, A=Agree, NEU=Neutral, SD=Strongly disagree, D=Disagree, N/A= Not applicable

Table 11 (continued)

Rank	**Statements**	**% Parent-Endorsed Statements ***				
		Mean	SA/A	NEU	SD/D	N/A
11.	Professionals are not forthcoming about all services that are available. (#66)	3.75	60.4	12.5	18.7	8.3
12.	Some professionals are rude, condescending. (#60)	3.73	58.3	6.3	16.7	25.0
13.	AISH regulations limit the amount of money that parents can leave to or save for their children with disabilities. (#50)	3.68	37.5	16.7	10.4	35.4
14.	Some professionals have a lot of knowledge but lack experience. (#13)	3.66	56.2	31.3	10.4	2.1
15.	Professionals protect their territory and their funding, particularly in a school system. (#69)	3.62	41.7	27.1	12.5	18.8
16.	Lack of accountability on how professionals spend the funding they receive. (#65)	3.58	43.8	27.1	12.5	16.7
	Split and Variation statements					
1.	With FSCD, it's almost impossible to get funding and when we do get funding it is minimal. (#17)	3.17	27.1	27.1	18.7	27.1
2.	I felt pre-school assessment services could have warned me better about the outcome. (#64)	3.00	18.7	20.8	16.7	43.8
3.	A mother once said to me "this is my first visit with FSCD which a staff member did not make me cry." (#55)	3.00	10.5	18.8	8.4	62.5
4.	The constant change of personnel at school causes frustration because we have to deal one day with one person and another day with another person. (#25)	2.97	20.9	20.8	20.8	37.5
5.	A doctor mentioned that my child would put me in difficult situations. (#62)	2.97	22.9	16.7	20.9	39.6
6.	I identified the fact that there was a problem with my child, but the doctor told me there was nothing wrong, that this was normal. (#35)	2.91	27.1	10.4	29.2	33.3
7.	Multidisciplinary team at a hospital persuaded the parents to use tube feeding for their children over mouth feeding. (#20)	2.72	14.6	6.3	16.7	62.5

Note. SA=Strongly agree, A=Agree, NEU=Neutral, SD=Strongly disagree, D=Disagree, N/A= Not applicable

Table 11 (continued)

Rank	**Statements**	**% Parent-Endorsed Statements ***				
		Mean	SA/A	NEU	SD/D	N/A
	Non-applicable statements					
1.	I had to use my child's diagnosis of autism to get help from the police in an abusive situation. (#56)	3.50	8.4	2.1	2.1	87.5
2.	Social services wanted us to give back our adopted child when we found out later that she/he had cerebral palsy. We were pestered by them for quite awhile for refusing to give her/him back. (#16)	2.50	0.0	6.3	2.1	91.7
3.	A social program at a women's shelter refused services due to my child's diagnosis of autism. (#29)	2.33	2.1	0.0	4.2	93.8
	Parents- endorsed disagreement statements					
1.	A school supervisor told me not to expect my child to get any better, or expect progress so I left that school. (#37)	2.26	10.5	6.3	31.2	52.1
2.	Parents are often excluded from important discussions and decision-making in school. (#5)	2.26	16.7	16.7	62.5	4.2
3.	A social worker told me to downplay my child's function in order to get more funding. (#46)	2.22	10.5	8.3	29.2	52.1
4.	Teachers are not willing to take into account the parents' personal experience with the child. (#27)	2.06	14.6	14.6	68.8	2.1
5.	Teachers are not willing to use strategies in school that were developed and already work at home. (#6)	2.04	10.5	16.7	70.8	2.1
6.	A service worker told me if I could not control and calm my child I would not get my cheque on that day.(#42)	1.85	4.2	4.2	18.8	72.9
7.	A health professional told us to give our child up because he/she also had a child with disability and his/her personal relationship broke up.(#4)	1.62	4.2	4.2	45.8	45.8

Note. SA=Strongly agree, A=Agree, NEU=Neutral, SD=Strongly disagree, D=Disagree, N/A= Not applicable

The results of the 6 themes derived from the parents' negative statements about professional contacts concept map were organized based upon the survey cluster means of the participants' agreement from the most to the least as follows: "fight for social services" (4.12), "funding issues" (3.95), "professionals' ignorance" (3.89), "social service professionals' lack of empathy" (3.07), "inadequacy of school professionals" (2.68), and "conflict with health professionals" (2.57). Table 11 presents 33 statements ordered from those that received the highest agreement ratings to those that received the lowest. Sixteen statements had means above 3.5 and a high number of parents agreed with these statements. Seven statements had means lower than 2.5 and a high percentage of parents disagreed with them. There were three statements that more than 80% of the parents said did not apply to their experience. Seven statements received split or variable opinions from the participants. There were no systematic differences presented in the statement data results associated with any of the demographic variables.

Validation of the Conceptual Themes

The qualitative method used in this study enhanced the study's validity in several ways. The parents of individuals with disabilities described issues based on their own experience of professional contacts. The issues were not determined a priori. These parents had provided care and had a close relationship with their children with disabilities for years, in some cases well into their son's or daughter's adult years. They were asked to describe what they perceived as positive or negative professional contacts based on their own experience. The validity of the master lists obtained in the focus group was achieved through saturation of information, until there were no additional original responses made. The participants reviewed the statements they generated. During and at the end of the focus group process, they edited and made suggestions to clarify and simplify the statements. Finally, they were asked to examine the final lists for any redundant or unclear statements. Content validity and validity of the editing process were established as a result of the manner in which the statements were generated and edited by participants. Finally, participants sorted the data and organized them into themes. Then the sorted data were statistically analyzed to produce a range of cluster or categorical solutions. The researcher's role was limited to determining an optimal number of clusters in the solution. This minimized the potential bias introduced by the researcher. Jackson and Trochim (2002) state that concept mapping is appropriate when a researcher does not want to impose his or her preconceptions on a research study. The process ensured that the research results, statements, and concept themes accurately represent the experiences that parents of persons with disabilities have with professional contacts.

CHAPTER V

Summary and Discussion

This chapter provides a summary and a discussion of the research findings. These results are compared with previous research on professional supports for parents of children with disabilities. The chapter also discusses the study's limitations, practical implications, and directions for future research.

Summary of Findings and Discussion

This study's focus was to identify and describe parents' perceptions of professional practices that enhanced or undermined their roles as parents and their relationships with their children with disabilities. Concepts revealed from the data indicated several forms of professionals' practices that met or did not meet the parents' needs, and thus promoted or hindered their ability to adapt to caring for a child with disabilities. In the focus group, 8 participants generated 72 statements that identified their positive and negative experiences with professional contacts. Thirty-nine statements described positive experiences with professional contacts, and 33 statements described negative experiences. The concept mapping system was used to analyze data. It revealed 5 major clusters of professionals' contacts that parents perceived as promoting their adaptation. These clusters were: 1) supportive service from health professionals, 2) psychological support from health professionals, 3) supportive care-workers, 4) social services help with home-life balance, and 5) supportive school professionals. Each of these clusters had the average rating of importance value ranging from 3.5 to 4, indicating that participants considered them to be important to very important. Within each of these main categories participants perceived several forms of professional practice as enhancing their parental roles and their relationships with their children with disabilities. These positive practices were: a) providing new skills, b) demonstrating empathy and commitment, c) processing competence and skill, d) demonstrating effectiveness in handling instrumental and funding supports, e) using good communication skills, and f) providing knowledgeable advice about supportive resources.

Six main themes of professional practices that parents perceived as undermining their parental roles and their relationships with their children with disabilities were revealed as: 1) inadequacy of school professionals, 2) conflict with health professionals, 3) professionals' ignorance, 4) social service professionals' lack of empathy, 5) fight for social services, and 6) funding issues. The average of importance rating value of items in each cluster ranged from 3.2 to 4, indicating that the participants considered these to be important to very important. This six themes can be addressed by improvement in four areas: a) better communication, b) greater collaboration with parents, c) clearer accountability for funding and servicing, and d) better understanding of the families' situations. The study revealed that healthcare professionals, school professionals, social service professionals, and care-workers, whom parents often had contacted, were all important sources of professional support.

Following the focus group study, an incidence survey was conducted to determine how the finding from phase one can be applied to a larger group of parents of children with disabilities. A survey based on the participants' statements was distributed to purposively selected parents whose young or adult children with disabilities attended a pre-school, school, or adult day program at the Elves Special Needs Society in Edmonton (N=133), Alberta, Canada. The response rate was 36.1% (n=48). The sample characteristics were sufficiently varied so that the study would include a wide range of parents of children with disabilities. The survey results clearly indicated that a majority of participants agreed with most of the findings in the focus group study. However, there was also some variation in the survey respondents' agreement with some of the statements. The survey results of the two maps were summarized and discussed separately below.

The survey based on statements from the positive concept map showed that all five clusters had high average mean importance weights ranging from 3.5 to 4. These results indicated that most participants had predominately positive experiences with their professional contacts. They perceived that these professional contact experiences enhanced their parenting roles. The five categories were:

1. *Psychological support from health professionals.* This cluster (number 2) had the highest average mean weight of 3.97. The statements in this cluster revealed that parents valued healthcare professionals who were committed to providing services to families, took families' problems seriously, felt empathetic to families' situation, and used effective communication skills. It was clear that professionals tried to help parents to remain positive and be able to cope well with their situations. This finding is consistent with previous

studies. Egilson (2010) interviewed 17 parents of children with disabilities on their perspectives of therapy services for their children. The parents described individual characteristics of professionals, which meant much more to them than a professional title or degree. They emphasized the importance of the therapists' initiative, insight, reliability, and communication skills. Kenny and McGilloway (2007) explained that it is necessary to have appropriate and effective support services to help parents cope with their situations and feelings because their attitudes and feelings affect their behavior toward their children with disabilities. A statement in this cluster that had the highest ratings of agreement by the parents was, "My pediatrician listened to me patiently. I really appreciate him." Parents appreciated professionals who used good communication and active listening skills in communicating with them. Parents considered this kind of caring practice to have a positive influence on their psychological well being. Watson, Kieckhefer, and Olshansky (2006) explored the experience of parents of children with developmental delays and professional providers communication in the context of early intervention. They found that both parents and providers put great energy into making their relationships work. The parents in the Watson, Kieckhefer, and Olshanksy study valued relationships that are personal and informal more than those that are distant and professional.

2. *Supportive school professionals.* This cluster (number 5) had a high average mean weight of 3.96. Parents reported contacts with teachers, social workers, and therapists. The statements in this cluster indicated that parents recognized

school professionals who were competent, skillful, empathetic, committed to their work with the families, effective communicators, and knowledgeable of supportive resources. The two statements in this cluster that had the highest ratings of agreement from parents were, “I have been very impressed by some teachers who stretch their creativity to reach my child with different teaching methods,” and “Teachers have supported and have advocated services needed by both me and my child.” Other forms of professional practice, such as encouraging parents by reminding them that they were doing a good job and helping them access services and receive supports they needed, were also indicated to be important. These statements show that school professionals provide supports that meet the needs of the parents and their children. Parents felt that they had access to accountable school professional services. Ingber and Dromi (2010) explored parents’ viewpoints on the actual and desired family-centered practice in early intervention centers for children with hearing loss in Israel. The majority of 120 mothers of children with hearing loss in this study indicated that professionals’ willingness to collaborate with parents is viewed as encouraging and empowering them in the process of early intervention. Davis and Gavidia-Payne (2009) studied 64 parents of children with a developmental delay or disability from 14 early childhood intervention centers in Melbourne, Australia. Their study results clearly indicated that parental perceptions and experiences with family-centered professional support are among the strongest predictors of family quality of life. Family-centered professional supports described in their study included: (a) enabling and partnership, (b) providing general information, (c) offering coordinated and comprehensive care, and (d) giving respectful and supportive care. Shelden, Angell, Stoner, and Roseland (2010) investigated the relationship between school principals and the mothers of children with disabilities, specifically factors that influence the mothers' level of trust in the principals. Parents indicated that they trust principals who are perceived as approachable, warm, respectful, and caring for children or the parents themselves.

3. *Supportive care-workers.* This cluster (number 3) had a high average weight mean of 3.91. It pertained to direct care-workers whom parents viewed as one of the important groups of professionals with whom they had contact. Participants reported their positive experiences with care-workers, who they considered to be competent and committed to working with individuals with disabilities. The statement with the highest rating of agreement in this cluster was, "Care-workers work one-on-one with my child and put their whole hearts into making sure he/she learns." Parents showed appreciation of care-workers who had the means to learn the best way to help the child, and were able to develop a bond with the child. Care-workers spend long periods with individuals with disabilities, relieving parents of some of this responsibility. Reliable care workers who have good relationships with children with disabilities can alleviate some of the stress and demands on parents. Tadema and Vlaskamp (2010) explored the perceived burden and support among 133 parents of children with profound intellectual and multiple disabilities in the Netherlands. Respite care and home support services were found to be highly

valued and very effective in alleviating parents' perceived burdens. This is in accordance with the finding by Redmond and Richardson (2003), who interviewed 17 mothers of young children with severe disabilities. They concluded that mothers greatly appreciated home-based respite care. Short-term home-based respite helps mothers to have brief breaks that allow them to rest or engage in other activities they need to do.

4. *Supportive services from health professionals.* This cluster (number 1) also had a high average mean weight of 3.85. Healthcare professionals whom parents mentioned having contacted with were doctors, pediatricians, neurologists, therapists, and nurses. The statement in this cluster that had the highest average positive agreement was, "there have been many health professionals in my child's life, who have been empathetic and done what we asked them to." Parents felt less stress knowing that there were always some professionals to whom they could turn. Other health professionals' practices that parents valued were the willingness to provide care adequate to fit the child's needs, and teaching new skills to parents to use to help their children at home. Olsson and Hwang (2003) used a mailed survey to 226 families with children with disabilities in southwest Sweden. They found that perceived availability of support, actual access to support, and satisfaction with the support received are important for parental well-being, because all led parents to perceive that they have control over services and their life situations. In a Canadian study by Darrah, Evans, and Adkins (2002) 86 parents of adolescents or young adults with cerebral palsy were interviewed regarding

their satisfaction with professional services. These parents reported that caring and supportive professionals have a positive influence on their experience. They appreciated small acts of caring and listening by their child's teachers and health professionals.

5. *Social services help with home-life balance.* Cluster number 4 had an average mean weight of 3.46. The two statements in this cluster with which participants most strongly agreed were, "A staff person provided me with skills to help my child myself," and "A staff person gave me hope by showing me how to focus on the positive gains my child was making. I have more good days with my child." Acquired new skills helped parents to understand and deal appropriately with children with special needs. Also, focusing on small improvements in their children helped parents maintain positive feelings and attitudes. Results indicated that parents perceived that it was useful to learn new skills to help their children progress, and also to receive psychological supports from professionals. Claire and Gill (2010) interviewed 7 parents of pre-school children with disabilities to gain an understanding of their experiences with professional services. Parents emphasized their satisfaction with professionals who have competent technical and interpersonal skills. Bailey, Parette, Stoner, Angell, and Carroll (2006) interviewed 6 parents of children with disabilities who use Augmentative and Alternative Communication devices (AAC). They investigated the participants' perceptions of how AAC devices are managed and used at home and in high school settings for youth with moderate or severe disabilities. The parents

> indicated that effective professional teams make efforts to understand the family, and provide opportunities for the family to contribute to the team. The researchers argued that valuing parents' viewpoints and encouraging them in the teaming process facilitates trust and increases parental involvement.

These survey results demonstrate that high numbers of participants agreed with 32 out of 39 positive statements regarding professional contacts. There were 6 statements which higher numbers of participants said did not relate to their experiences, and one statement that received variable responses. Overall, most of the participants agreed with the statements included in the positive concept map about experiences with professionals. However, small percentages of participants indicated their disagreement. This could be interpreted in many ways. It was likely that some experiences were specific to only a few parents. Unfortunately, some parents may have had experiences with incompetent or unhelpful professionals. Other parents may have had unrealistically high expectations of professionals that could not be met. Nevertheless, parents' experiences with professionals' practices appeared to be very important in supporting their parental roles and their relationships with their children with disabilities. Some experiences appeared to remain with them for a very long time and shape their perceptions of formal support services. The percentage of participants expressing dissatisfaction was small, and due to the small number of participants in the study, further investigation is needed. A study with a larger sample size might provide a better picture of these issues.

Summarized below are the survey results from the 6 clusters of the negative concept describing professionals' practices that parents perceived as demanding or undermining their efforts to care for their children with disabilities:

1. *Fight for social services.* Cluster number 5 on the map had the highest average mean weight of 4.12. This theme reflected difficulties that parents went through in requesting and receiving supports from social services. Participants agreed with the statement, "I was starting with my three-year-old child to get him/her into program and services. I tried to take one agency at a time so that I could digest all the information they gave me. It's so much." Parents also voiced the issue of long-term conflict with service providers and social service support system representatives. The statement in this category with which participants most strongly agreed, "Parents have to fight for services and government supports. There has not been much change for decades." The conflicting finding around services is consistent with previous studies. Fisher (2009) conducted a comprehensive literature review of parent-professional conflict about special education services in United States. The study revealed that a lack of resources and an absence of effective communication are found to increase tension and conflict between parents and professionals. Similarly, Olsson and Hwang (2003) described several parents who feel that they struggle to get appropriate support for their children. They believed that their time was wasted on finding out about services and that many services were not living up to their promise. Acknowledging these shortcomings, policy makers and professionals need to improve service delivery to achieve an

effective approach. The complexity and difficulty of getting services needs to be eliminated or at least reduced substantially, and the use of effective communication by professionals should be promoted.

2. *Funding issues.* Cluster number 6 had a high average mean weight of 3.95. Parents expressed their frustration related to inadequate funding that led to difficulty in finding qualified, long-term service providers to support individuals with disabilities. More than 60% of participants agreed with statements such as, “With these children it takes a long time to form a bond that assists them to progress. The rate of pay from the government for staff in this field is not enough to keep them” and “The government provides funding for help, but it is not enough to be effective.” Stone (2001) points out that it is essential for care-workers to provide quality of care to vulnerable people. However, care-workers are among the lower wages earners. Given the lack of financial incentives, and demanding working conditions, it is difficult to retain and recruit effective care-workers for families. Stone concluded that policy makers, researchers, and the general public pay little attention to issues related to long-term-care workers. When the needs of a child with disabilities are not met, the parents feel guilt and stress. In addition, families may face financial hardship because of the additional costs of caring for their children with disabilities and decreased opportunities for both parents to take on paid work (Herman & Thompson, 1995). Fifty-eight percent of parents also reported that they experienced constant battles with different government agencies to obtain necessary help for their children. Darrah et al. (2002) reported parents’

feelings of frustration with professionals, who often do not share information about available services spontaneously, but restrict themselves to answering only the specific questions that parents ask. These conflicting and poor relationships between professionals and parents lead the two groups to distance themselves from each other.

3. *Professionals' ignorance.* Cluster number 3 had a high average mean of weight, 3.89. The statement with which most participants agreed was, "It is rude for professionals to say to parents to put their children aside or give up on them. They should be encouraging parents to help their children." This statement clearly reflected the extent to which the professionals did not understand the parents' situation and feelings. Parents seek information and support from health professionals in order to understand their children's needs and what they can do for them. Insensitive communication by professionals could also cause parents to experience psychological stress. Parents may experience ambivalent feelings regarding care for their children. They love their children and want to be good parents and caregivers. At the same time, they may feel overwhelmed by the demands of caring for their children. When they ask for help and are told "you can give up and abandon your child if you can't handle it," they feel hurt and angry because they want help to be good parents. They do not want to give up on their child; receiving such advice makes them feel that they are not being heard.

Harnett and Tierney (2009) conducted a study in Ireland, involving 22 focus groups and a questionnaire survey of 1,588 professionals and 584 parents of children with disabilities. The study was undertaken to find out if professionals give parents realistic and hopeful messages about their children. In this study, many parents reported that they do not hear hopeful messages. They are often left feeling that their children are seen only in the context of their disabilities and not as valued individuals. The researchers comment that professionals can give realistic and hopeful messages to parents by telling them about available supports and emphasizing the value and importance of every child. In study by Beresford (1996) conducted in-depth interviews with, 20 parents of children with severe disabilities. The researcher argued that having contact with a high number of professionals is not only time consuming, but is also frequently associated with frustration, disappointment, and anger on the part of parents of children with disabilities.

4. *Social service professionals' lack of empathy.* Cluster number 4 had a cluster mean of 3.07. Two statements in this category had higher numbers of agreement from parents. These statements were, "Lack of accountability on how professionals spend the funding they receive," and "Professionals protect their territory and their funding, particularly in a school system." These statements reflected the perception that parents felt that professional displayed a lack of accountability in the area of funding management. Clarifying the funding procedures and establishing more collaboration with parents might lead to the parents having greater trust in the way professionals manage funding. Bianco, Garrison-Wade, Tobin, and Lehmann (2009) interviewed 9 parents about their perceptions of their roles in the lives of their children with

disabilities during the post-high-school years. In this study, parents described their need to establish collaborative relationships with service agencies. Many parents felt that their relationships with agencies and service providers were not always collaborative and that their attempts to collaborate were unwelcome. They viewed successful collaborations as trusting relationships that could fill the existing service gaps and help their children to meet their needs. Hodge and Runswick-Cole (2008) stated that conflict between professionals and parents on resource allocation is inevitable when parents want what they think is right for their child and professionals are limited by a policy context. The understanding of the underlying needs of families of children with disabilities and the concept of working “with” parents as partners instead of “for” them may lead to a better understanding and collaboration between the service providers and the parents.

5. *Inadequacy of school professionals.* Cluster number 1 had a cluster average mean of 2.7. One statement in this cluster on which a high number of parents agreed was, “There is a lack of tolerance and understanding about children with disabilities in society.” This statement suggested that it cannot be assumed that every professional has an accurate or helpful understanding of disability issues. Kenny and McGilloway (2007) similarly reported that many parents of children with learning disabilities in their study expressed frustration and disappointment at the general lack of public tolerance and understanding of people with intellectual disabilities. The participants also indicated that some professionals lacked an appreciation of the value of parents’ contributions as

collaborators. Wiart, Ray, Darrah, and Magill-Evans (2010) explored 39 parents of children with cerebral palsy on their experiences with occupational therapists and physiotherapists. They focused in the areas of setting on functional and collaborative goals for the children at school. Parents commented that they appreciate the accountability of their child's Individual Program Plan (IPP) but feel that they do not have adequate input into setting goals at their children's schools. Hence, family priorities do not come into play when these important goals are established. Sandberg and Ottosson (2010) interviewed 20 parents, pre-school teachers, and other professionals about their experiences of cooperation regarding children in need of special support. Parents said that professionals and teachers did not always follow through on joint decisions, nor did they always provide vital information regarding special aids and rights. Several parents mentioned that a lack of information and communication between school professionals is a major cause of frustration. It became apparent that cooperation between parents and school professionals is critical because it can benefit the child's positive development and the parents' well-being.

6. *Conflict with health professionals.* Cluster number 2 had a low cluster average mean weight of 2.6. Interestingly, there were variations in agreement on three out of four reported statements in this cluster. The statements were: "A doctor mentioned that my child would put me into difficult situations," "I identified the fact that there was a problem with my child but the doctor told me there was nothing wrong …that was normal," and "Multidisciplinary team at a

hospital persuaded the parents to use tube feeding for their children over mouth feeding." This variation could be interpreted to mean that different parents have differing views of the same experiences, or that only a minority of the families would receive recommendations for tube-feeding -- that this, for example, would not have been every family's experience. Writing about problems that individuals with learning disabilities experienced in hospital settings, Hebron (2009) described parents feeling that their opinions and assessments about their children are ignored by health care professionals. Parents struggle to have health professionals accept them as effective partners in care, and their complaints are often not heard. Redmond and Richardson (2003) found that mothers of children with severe/profound intellectual disabilities had a clear willingness and commitment to care for their children in the family home. However, these mothers frequently referred to the services offered to them as unreliable, poorly coordinated, and difficult to access. From a comprehensive literature review, Fisher (2009) found that one of the major sources of conflict between professionals and parents was the failure to use effective communication and collaboration skills.

There were 33 negative statements in the survey. Participants agreed with 16 of these, with means greater than 3.5 (agree/strongly agree). Participants endorsed that 3 of the statements did not apply to their experiences. A higher percentage of parents disagreed with 7 statements. Another 7 statements received highly variable opinions. It was important to keep in mind that some experiences might be very specific and important to some parents that they had remained with them. Negative experiences with professionals can lead parents to lose trust with the professionals, resulting in stress and conflict between the two groups. Consequently, supportive services could be useless or even harmful in some instances.

Overall, there was little variation in the responses to some survey statements. While the sample appeared to have adequate demographic characteristics, the numbers were not sufficient to arrive at a judgment about the presence or absence of subgroup differences. To apply the results of the incidence survey of parents of children with disabilities to a larger population must be evaluated cautiously. Parents of individuals with disabilities engaged in adaptive forms of coping. Their children’s unique needs led them to seek supports from many formal professionals. To achieve the goal of accountability in supportive services for families of children with disabilities, necessary services should be available in the community without requiring families to fight for them. Importantly, professionals should be able to competently deliver services that fit the families’ needs. Parents were affected concurrently, in multiple ways, by professionals’ supportive practices. As an example, a parent said that “Therapists provided knowledge that we needed. We are able to use it in a way that my child could understand.” This statement suggested that professionals helped parents in many ways, just as Honey and Halse (2006) suggest, including helping parents to understand more about their child’s development, attain new skills to help their child, empathize with the child, cultivate helpful meanings and attitudes about their child, and decrease their own fear and anxiety. This study’s findings were consistent with theoretical components of the Double ABCX theory and the FAAR model. The availability of resources, access to professionals' supports, and satisfaction with the supports received all affected how parents adapted or adjusted in time of stress. Saloviita et al. (2003) point out that when it comes to predicting parental stress, the way that parents define their situation (c C factor) and the various resources available to them (b B factor) are more important than the child's actual condition. As indicated by concurrence earlier in this chapter, the study results were consistent with existing literature on the issues of parents of individuals with disabilities and professionals' support.

Limitations of the Study

This study's findings are limited due to the small sample size, and only one source of data. Participants were parents of individuals with disabilities who attended pre-school, school, and adult day programs at the Elves Special Needs Society in Edmonton, Alberta. Because the setting is in an urban area, most of the participants (85%) lived in the urban environment and only 13% of participants lived in rural areas. The small sample size made it impossible to identify differences among groups of participants with various demographic characteristics. Thus, the results should be cautiously interpreted and should not be generalized to all parents of individuals with disabilities in the province. Another limitation is that some participants' reported experiences may have been influenced by other parents in the focus group, and some parents might not have fully disclosed all aspects of their opinions and experiences in the group. They may have considered some of their positive or negative experiences with professional contacts to be too sensitive or private to discuss in the group.

Implications for Professional Practice

Parents of children with disabilities typically come into contact with many professionals and expect to receive the appropriate supports and services to meet their children's unique needs. This research has identified supports and challenges that the parents faced with professionals' practices. This study began from the ground up; that is, potentially supportive and challenging interactions were identified from the perspective of the parents and not suggested by the researcher. Descriptive concepts that characterize the parents' perceptions resulted from the concept mapping analysis. These findings can supply service providers and researchers in Alberta with information for continued discussion, to improve provincial supportive services, or to develop training programs for service provider professions.

The findings of this research and the results in the existing literature are very similar. Components of supportive professional practice found in the study should be implemented and promoted. The important components of professional practices that should be emphasized and promoted among service providers based on the five positive clusters were:

a.) *Provision of skills.* Parents appreciated professionals who provided skills that they could use to help their children.

b.) *Empathy and Commitment.* Parents valued professionals who felt empathy, understood their situation, and committed to providing appropriate services to fit the families' needs.

c.) *Competence and skill.* Parents trusted professionals who were competent and skillful in their work. Parents expected to see the effectiveness and results of the services that their children received.

d.) *Instrumental and funding supports*. Professionals handling instrumental or funding supports effectively were perceived as helpful to children with disabilities. Parents trusted these individuals.

e.) *Good communication skills.* Parents reported that they remember how much it meant for them to have professionals listen to their issues, clarify their doubts, or acknowledge their difficulties. Professionals with encouraging and caring attitudes influenced parents to maintain positive feelings and attitudes about their parenting roles and, concurrently, their children's well-being.

f.) *Knowledge of supportive resources.* Professionals helped parents to obtain useful information and access supportive resources to meet their children's needs or made service referrals to families.

Important components of professionals' practices that parents perceived as undermining their parental roles emerged from the 6 negative clusters were:

a.) *Bad communication.* Many of the statements indicate that parents felt frustrated and anxious when professionals communicated negatively about children with disabilities.

b.) *Lack of collaboration.* Parents reported that professionals were not willing to consider their opinions or experiences.

c.) *Lack of accountability on funding and servicing issues.* Parents perceived a lack of accountability of how professionals manage funding and material supports. Parents reported that they had to fight to get the funding and support they required.

d.) *Incompetence and lack of understanding.* Parents indicated many forms of professional practices that they perceived as incompetent, including lack of understanding of their situation, lack of empathy, or lack of tolerance for individuals with disabilities.

Clearly, this research suggests that interactions between professionals and parents are complex. They cannot simply be characterized as good or bad. They are often good and bad. They will never be perfect, but there is always a need to work toward something better. Professionals should not merely give up and assume that they do more harm than good or that parents are unreasonable and will never be satisfied. Professionals need to recognize that they play an important role in supporting parents, and that sometimes their attempts at support are not merely ineffective but actually harmful.

Findings from this study indicate that many positive things are happening. Parents describe positive experiences with professionals they have contacted including healthcare professionals, school professionals, care-workers, and social service professionals. They recognize professionals' practice of caring support, competence, good communication, partnership with parents, and commitment to their work. These characteristics, which certainly benefit parents in caring for their children with disabilities, should be promoted and recognized among professionals and society at large.

However, there is room for improvement. Parents described negative experiences with professionals whom they perceive as unwilling to collaborate, not accountable on funding and service issues, incompetent, and lacking in communication skills and empathy. The findings suggest that some professionals need to be educated and supervised to develop a better understanding of families' situations, and an ability to see parents as unique individuals who are linked to their children with unique needs. Professionals should be trained to understand parents' underlying interest and needs rather than viewing these as mere demands (Fisher, 2009). Negative experiences with professional contacts may cause parents undue stress and lead them to distance themselves from the professionals. Services can be improved, but for that to happen, training for professionals needs to be implemented in the areas of disabilities care issues, communication and psychological support skills, collaboration and relationship development, and management of funding and material supports.

It is important for supportive professionals to be aware of which of their practices affect parents, and avoid repeating ineffective practices. The need for supportive interventions from professionals is heightened by the critical role that parents play in caring for their children with disabilities in the community and the shift to a family-centered approach and accountability of results. Competent professionals will be able to alleviate some of the burden and help parents be more effective.

The generally positive but mixed results reported in this study have implications for the application of the Double ABCX and Family Adjustment and Adaptation models. These findings make it apparent that professionals' intentions to provide support and service agencies missions to provide support do not in themselves ensure that interactions with families will be experienced as supportive. In some cases, interactions and services actually increased perceived stress in families. Therefore, in applying these models to service delivery systems, it is essential that the actual impact on families be determined, rather than simply assuming all interactions and services will have beneficial effects.

Future Research Directions

Findings from this study have important implications for future research. Additional research is required to validate the results and explore their reliability. The sample for this study came from parents whose children with disabilities attended one non-profit organization in a large urban area. It is suggested that future research be conducted on a larger sample size of parents of children with disabilities, and from many different settings, such as schools, hospitals, and social service organizations in urban and rural areas. To be able to generalize the findings, the study can be conducted with a provincial or even national sample. Data from a larger sample size may identify differences among parents with various demographic characteristics. It would also be interesting and useful to conduct a study and generate concept maps of professionals' perception of parents’ contacts. Through this we would understand the whole picture of the positive and negative perceptions from both sides of the relationship. Further research ideas can also be developed on how to better address some of the difficult areas. For example, actually ask focus groups of parents and professionals how they would handle some of the interactions that are identified as problems. Understanding the parents’ and professionals’ experiences would provide a sound empirical basis, making it easier to enhance the improvement or development of families’ intervention practice and policy. In addition, the survey can be a useful tool for evaluating professionals’ performance, and to examine the progress of and find ways to further improve professional practices.

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APPENDIX A

UNIVERSITY OF ALBERTA

Invitation letter to participate in a focus group interview

Dear parent,

We would like to invite you to take part in a study on **"Parents' perceptions of professional contacts during their adaptation to caring for a child with disabilities."** This study is being conducted at the University of Alberta in an effort to identify and describe which professional practices enhance or hinder parents' adaptation or role in caring for a child with disabilities. Part of this study will include a focus interview with a group of concerned parents such as you.

Participants will be interviewed at Elves Special Needs Society. You will also be required to sort statements collected from the group into themes that make sense to you and to rate the important of the statements. There are no right or wrong answers. Your opinions and statements will not be identified by your name on the report of study and all responses will be kept confidential. This will take you approximately two and a half hours to complete the process. The data from the study will be used to help determine which professional supports would be most helpful for the families of children with disabilities. It is hoped this information will contribute to a better understanding and services for parents of children with disabilities.

Participate in this study is strictly voluntary. To participate, please contact Wanapa Intaprasert at (780) 860-2955, or wanapa@ualberta.ca. I will provide details about the focus group interview schedule when you contact me. I believe you will be a valuable contributor to the study.

If you have any questions about this study, please contact Professor Richard Sobsey at (780) 492-3755, or me. Thank you for your consideration. Your participation will be greatly appreciated.

Wanapa Intaprasert, (Ph.D.candidate) Dept. of Educational Psychology, University of Alberta, Edmonton	Richard Sobsey, Ph.D. Dept. of Educational Psychology, University of Alberta, Edmonton

APPENDIX B

UNIVERSITY OF ALBERTA
Information sheet for focus group

Title of research Project: Parents' perceptions of professional contacts during their adaptation to caring for a child with disabilities.

Investigator: Wanapa Intaprasert, PhD. candidate
Dept. of Educational Psychology, University of Alberta.

Dear Parents:

Thank you for considering participation in this study. The purpose of this study is to identify and describe which professional practices enhance or hinder parents' adaptation or role in caring for a child with disabilities.

Participation in this study is strictly voluntary. I would appreciate your cooperation in participating in the focus group and the sorting task. This will take you approximately two and a half hours to complete the process. You will be asked to respond to the following questions at a focus group session:

1) "Please describe the important things that professionals have said or done that made you feel better or more secure in your relationship with your child and your role as a parent of a child with a disability."

AND

2) "Please describe the important things that professionals have said or done that made you feel worse or less secure in your relationship with your child and your role as a parent of a child with a disability."

There are no right or wrong answers. You will also be asked to rate the important of the statements and sort statements collected from the group into themes that make sense to you. Your opinions and statements will not be identified by your name on the report of study and all responses will be kept confidential. The focus group session will be audio-recorded. The recorded tape will be kept in a locked filing cabinet for five years after which it will be destroyed. The data from the study will be used to help determine what support would be most helpful for the families of children with disabilities and will form the basis of the dissertation for my Ph.D. degree.

The questions asked in the study should not create emotional distress for you. However, if you feel that you need help in dealing with your level of stress, or if you have questions concerning the study or the questions used, please feel free to contact me at 780-860-2955 or Professor Richard Sobsey (Supervisor) at 780- 492-3755. You may also request a copy of the final results of the study by calling at my number. I greatly appreciate your participation in this study and thank you for your assistance.

Sincerely,

Wanapa Intaprasert

APPENDIX C

UNIVERSITY OF ALBERTA

Consent form for focus group

PROJECT TITLE: Parents' perceptions of professional contacts during their adaptation to caring for a child with disabilities.
INVESTIGATOR: Wanapa Intaprasert (Ph.D. candidate)
Dept. of Educational Psychology, University of Alberta.
PURPOSE OF STUDY: The aim of this study is to identify and describe which professional practices enhance or hinder parents' adaptation or role in caring for a child with disabilities.

I agree to participate in a focus group and sorting task, which will take two and a half hours.

I give my permission to audiotape the responses I made to the study questions during the focus group sessions.

The investigation carries no unusual risk to me. All information will be coded so that it cannot be identified with me and no names will appear in any documents or reports.

I may not benefit directly from this investigation; however, it is hoped that this investigation will provide further information and development of better supportive services for the caregivers of children with disabilities.

I UNDERSTAND that I can refuse to answer any questions that I prefer not to answer.

I FURTHER UNDERSTAND that I am free to withdraw my consent and terminate my participation at any time, without prejudicing present or penalty.

I HAVE BEEN GIVEN THE OPPORTUNITY to ask any questions regarding this study and all my questions have been answered to my satisfaction.

I UNDERSTAND that my signature means that I have read this form, understand my involvement in the study, and that I **voluntarily** agree to participate.

I UNDERSTAND that the information collected for this particular study may also be re-analyzed in the future in the investigation of other research questions.

The plan for this study has been reviewed for its adherence to ethical guidelines and approved by the Faculties of Education, Extension and Augustana Research Ethics Board (EEA REB) at the University of Alberta. For questions regarding participant rights and ethical conduct of research, contact the Chair of the EEA REB at (780) 492-3751.

Signature of Participant	Date
Signature of Investigator	Date

APPENDIX D

Demographic questions

Please complete the following:

1. Gender __ Male __ Female

2. Marital status __ Married __ Single parent

3. Age __ 20-30 years __31- 40 years
__ 41-50 years __ more than 50 years

4. Home region __ In the city of Edmonton
__ In a rural area of Edmonton

5. Age of your child with disability __ 2.5 to 6 years
__ 6.1 to 12 years
__ 12.1 to 18 years
__ More than 18 years

6. Your relationship with the child __ Biological parent
__ Foster parent
__ Adoptive parent
__ Others, please specify____________

7. Type of a disability of your child, please specify ______________________

APPENDIX E

UNIVERSITY OF ALBERTA

Confidentiality Agreement

Project title: Parents' perceptions of professional contacts during their adaptation to caring for a child with disabilities.

I, ________________________, the research assistant, have been hired to enter the generated statements into a computer program (MS-Word) during the focus group interview.

I agree to –

1. keep all the research information shared with me confidential by not discussing or sharing the research information in any form or format (e.g., disks, tapes, transcripts) with anyone other than the *Researcher(s).*
2. keep all research information in any form or format (e.g., disks, tapes, transcripts) secure while it is in my possession.
3. return all research information in any form or format (e.g., disks, tapes, transcripts) to the *Researcher(s)* when I have completed the research tasks.
4. after consulting with the *Researcher(s)*, erase or destroy all research information in any form or format regarding this research project that is not returnable to the *Researcher(s)* (e.g., information stored on computer hard drive).

________________________	___________________	___________
(Print Name)	(Signature)	(Date)

Researcher

____________________	_____________________	___________
(Print Name)	(Signature)	(Date)

APPENDIX F

Please rate the important of each statement on a 1 to 5 scale where:

1 = relatively unimportant;
2 = somewhat important;
3 = moderately important;
4 = very important;
5 = extremely important.

The rating should be considered a relative judgment of the importance of each statement to all the other statements on the questionnaire.

STATEMENTS in response to the question "Please describe the important things that professionals have said or done that made you feel worse or less secure in your relationship with your child and your role as a parent of a child with a disability."	**RATING**
1. I felt pre-school assessment services could have warned me better about the outcome. 2. We identified the fact that there was a problem with our child, but the doctor told us there was nothing wrong, that this was normal. 3. The initial pediatrician told us to give our daughter up because he also had a child with disability and his personal relationship broke up. 4. A doctor mentioned that our child would put us in difficult situations. 5. Social services wanted us to give back our adopted child when we found out later that she had cerebral palsy. We were pestered by them for quite awhile for refusing to give her back. 6. Multidisciplinary team at a hospital persuaded the parents to use tube feeding for their children over mouth feeding. 7. A social program at a women's shelter refused services due to my son's diagnosis of autism. 8. I had to fight to get services from the social program. 9. I had to use my son's diagnosis of autism to get help from the police in an abusive situation. 10. We have to go through the constant battles from different government agencies to get the needed help for our children that can be financially, manpower, equipment, services, on and on.	

STATEMENTS	RATING
11. The constant change of personnel at school causes frustration because we have to deal one day with one person and another day with another person. 12. With these children it takes a long time to form a bond that assists them to progress. The rate of pay from the government for staff in this field is not enough to keep them. 13. The rate of pay is not enough to hire people to work at home. I have financial resources, but have difficulty finding help. 14. The government provides funding for help, but it is not enough to be effective. 15. AISH regulation limits the amount of money that parents can leave to or save for their children with disabilities. 16. With FSCD, it's almost impossible to get funding and when we do get funding it is minimal. 17. A service worker told me if I could not control and calm my child I would not get my cheque on that day. 18. There is a lack of tolerance and understanding about children with disabilities in society. 19. A school supervisor told me not to expect my son to get any better, or expect progress so I left that school. 20. It is rude for professionals to say to parents to put their children aside or give up on them. They should be encouraging parents to help their children. 21. Professionals have a lot of knowledge but lack experience. 22. I feel disappointed when professionals promise me services that they cannot deliver. 23. Professionals are not forthcoming about all services that are available. 24. A mother once said to me "this is a first visit of me with FSCD which a staff member did not make me cry." 25. Some professionals are rude, condescending.	

STATEMENTS	RATING
26. A social worker told me to downplay my child’s function in order to get more funding. 27. I was starting with my three-year-old son to get him into a program and services. I tried to take one agency at a time so that I could digest all the information they gave to me. It’s so much. 28. Professionals do not have the relational skills necessary to deal with parents and children with disabilities. 29. Professionals protect their territory and their funding, particularly in a school system. 30. Lack of accountability on how professionals spend the funding they receive. 31. Parents are often excluded from important discussions and decision- making in school. 32. Parents have to fight for services and government supports. There has not been much change for decades. 33. Teachers are not willing to use strategies in school that were developed and already work at home. 34. Teachers are not willing to take into account the parents’ personal experience with the child.	

STATEMENTS in response to the question "Please describe the important things that professionals have said or done that made you feel better or more secure in your relationship with your child and your role as a parent of a child with a disability"	RATING
1. There have been many health professionals in our child's life, who have been empathetic and done what we asked them to. 2. Many professionals really go the extra mile to do what we asked them to do. 3. The hospital referred our two-and-a-half-year-old child to a special needs program. We had someone to turn to. 4. My pediatrician continues to see our son well into his adult years. 5. A hospital has been helpful in giving supplies, wheelchairs, orthotics for shoes and prosthetics. 6. Care-workers work one-on-one with my son and put their whole hearts into making sure he learns. 7. Care-workers have the means to learn the best way how to help my child. 8. A staff person provided me with the skills required to help my son myself. 9. A staff person gave me hope by showing me how to focus on the positive gains my son was making. I have more good days with my child. 10. Funding by FSCD have helped to make a home program and supportive services possible. 11. Teachers have supported me and have advocated services needed by both my son and me. 12. Teachers prompted me to access services I was unaware of. 13. A social worker at my child's school has helped us to access services for any needs my child has had. She puts us in touch with many organizations. 14. Social worker acts as an intermediary between a family and staff members to see positive change.	

STATEMENTS	RATING
15. A care-worker has developed a strong bond with my son and chose to transition with him to the school setting. 16. Because of a dedicated professional, my son's transition to school has been less stressful. 17. I have been very impressed by some teachers who stretch their creativity to reach my child with different teaching methods. 18. Therapists provide me with skills to assist my son at home. Through this he makes more gains than only seeing them twice a month. 19. Therapists provided knowledge that we needed. We are able to use it in a way that my child could understand. 20. My child's care-worker has gone above and beyond by helping to advocate for more funding. 21. A program supervisor at school is going to try to implement the home video about our family situation as a teaching tool so that staff can be more empathetic to what families are going through. 22. Some doctors are willing to see my child more frequently to maintain adequate care because of her needs. 23. Teachers praise your effort as a parent to help you remember that you do good jobs. 24. The multi-disciplinary team in the hospital told me that I did not do anything wrong during pregnancy to cause my child to become an autistic. This helped me to come out of my depression. 25. Care-workers prompt me to do other activities besides just caring for my child. They helped me to lead my life in a normal way. 26. They ask me regularly if I am fine. They really care about me. 27. She taught my child at home. This helped lessen my tension and gave me strength when I was exhausted.	

STATEMENTS	RATING
28. My pediatrician said that she will do what my child needs regardless of what I have and she will take my problems seriously. 29. My pediatrician listened to me patiently. I really appreciate him. 30. A second opinion from a pediatrician supported me for not having my son go through unnecessary testing. 31. Knowing the diagnosis made me understand the odd behaviors of my child. 32. Therapy for children with autism at school with a consistent routine has helped my child gain different skills in activities of daily living. 33. Social workers at the school were helpful with money issues (for example, by providing gift cards for food). This gave me more positive energy when I had financial difficulty. 34. Social workers were very respectful and provided a lunch program for my child. 35. A therapist went on to contact other people to help complete my child's assessment. 36. A therapist called me to offer help in case I needed it. She went beyond her duties to help me. 37. A neurologist reassured me that my son's seizures were not caused by anything that I was doing. 38. When my son was equipped by many wires at the hospital, a nurse observed him closely and gave him a book he wanted. This made him feel very happy. 39. A FSCD staff asked me "why we [FSCD staff] stressed you out?" At least she tried to identify what can keep me from having too much stress, when I am in contact with FSCD.	

APPENDIX G

Average Rating Values of the Statements

Statements relate to negative professional contacts	***Average Rating Values***
1. I felt pre-school assessment services could have warned me better about the outcome.	2.71
2. We identified the fact that there was a problem with our child but the doctor told us there was nothing wrong, that was normal.	3.71
3. The initial pediatrician told us to give our daughter up because he also had a child with disability and his personal relationship broke up.	3.43
4. A doctor mentioned that our child would put us into difficult situations.	2.57
5. Social services wanted us to give back our adopted child when we found out later that she had cerebral palsy. We were pestered by them for quite awhile for refusing to give her back.	3.29
6. Multidisciplinary team at a hospital persuaded the parents to use tube feeding for their children over mouth feeding.	3.14
7. A social program at a women’s shelter refused services due to my son’s diagnosis of autism.	3.71
8. I had to fight to get services from the social program.	3.86
9. I had to use my son’s diagnosis of autism to get help from the police in an abusive situation.	3.14
10. We have to go through the constant battles from different government agencies to get the needed help for our children that can be financially, manpower, equipment, services, on and on.	4.00
11. The constant change of personnel at school causes frustration because we have to deal one day with one person and another day with another person.	3.71
12. With these children it takes a long time to form a bond that assists them to progress. The rate of pay from the government for staff in this field is not enough to keep them.	4.14

Statements	***Average Rating Values***
13. The rate of pay is not enough to hire people to work at home. I have financial resources, but have difficulty finding help.	4.00
14. The government provides funding for help, but it is not enough to be effective.	4.43
15. AISH regulation limits the amount of money that parents can leave to or save for their children with disabilities.	3.57
16. With FSCD, it's almost impossible to get funding and when we do get funding it is minimal.	4.29
17. A service worker told me if I could not control and calm my child I would not get my cheque on that day.	3.29
18. There is a lack of tolerance and understanding about children with disabilities in society.	3.57
19. A school supervisor told me not to expect my son to get any better, or expect progress so I left that school.	3.71
20. It is rude for professionals to say to parents to put their children aside or give up on them. They should be encouraging parents to help their children.	4.00
21. Professionals have a lot of knowledge but lack experience.	2.71
22. I feel disappointed when professionals promise me services that they cannot deliver.	3.29
23. Professionals are not forthcoming about all services that are available.	4.43
24. A mother once said to me "this is a first visit of me with FSCD which a staff member did not make me cry."	2.57
25. Some professionals are rude, condescending.	3.14
26. A social worker told me to downplay my child's function in order to get more funding.	3.14
27. I was starting with my three-year-old son to get him into a program and services. I tried to take one agency at a time so that I can digest all the information they gave to me, it's so much.	3.14

Statements	***Average Rating Values***
28. Professionals do not have the relational skills necessary to deal parents and children with disabilities.	3.29
29. Professionals protect their territory and their funding, particularly in a school system.	3.71
30. Lack of accountability on how professionals spending the funding they receive.	4.00
31. Parents are often excluded from important discussions and decision-making in school.	3.71
32. Parents have to fight for services and government supports. There has not been much change for decades.	4.29
33. Teachers are not willing to use strategies in school that were developed and already work at home.	3.43
34. Teachers are not willing to take into account the parents' personal experience with the child.	3.57

Statements relate to positive professional contacts	***Average Rating Values***
1. There have been many health professionals in our child's life, who have been empathetic and done what we asked them to.	4.43
2. Many professionals really go the extra mile to do what we asked them to do.	3.57
3. The hospital referred our two-and-a-half-year-old child to a special needs program. We had someone to turn to.	3.71
4. My pediatrician continues to see our son well into his adult years.	4.00
5. A hospital has been helpful in giving supplies, wheelchairs, orthotics for shoes and prosthetics.	4.29
6. Care-workers work one-on-one with my son and put their whole hearts into making sure he learns.	3.57
7. Care-workers have the means to learn the best way how to help my child.	3.43

Statements	***Average Rating Values***
8. A staff person provided me with the skills required to help my son myself.	4.71
9. A staff person gave me hope by showing me how to focus on the positive gains my son was making. I have more good days with my child.	4.57
10. Funding by FSCD have helped to make a home program and supportive services possible.	4.00
11. Teachers have supported me and have advocated services needed by both me and my son.	4.14
12. Teachers prompted me to access services I was unaware of.	4.29
13. A social worker at my child's school has helped us to access services for any needs my child has had. She puts us in touch with many organizations.	4.43
14. Social worker acts as an intermediary between a family and staff members to see positive change.	3.29
15. A care-worker has developed a strong bond with my son and chose to transition with him to the school setting.	3.14
16. Because of a dedicated professional my son's transition to school has been less stressful.	3.71
17. I have been very impressed by some teachers who stretch their creativity to reach my child with different teaching methods.	4.00
18. Therapists provide me with skills to assist my son at home. Through this he makes more gains than only seeing them twice a month.	4.43
19. Therapists provided knowledge that we needed. We are able to use it in a way that my child could understand.	4.00
20. My child's care-worker has gone above or beyond by helping to advocate for more funding.	3.71
21. A program supervisor at school is going to try to implement the home video about our family situation as a teaching tool so that staff can be more empathetic to what families are going through.	3.00

Statements	***Average Rating Values***
22. Some doctors are willing to see my child more frequently to maintain adequate care because of her needs.	4.14
23. Teachers praise your effort as a parent to help you remember that you do good jobs.	3.43
24. The multi-disciplinary team in the hospital told me that I did not do anything wrong during pregnancy to cause my child to become an autistic. This helped me to come out of my depression.	4.14
25. Care-workers prompt me to do other activities besides just caring for my child. They helped me to lead my life in a normal way.	3.14
26. They ask me regularly if I am fine. They really care about me.	3.14
27. She taught my child at home. This helped lessen my tension and gave me strength when I was exhausted.	4.00
28. My pediatrician said that she will do what my child needs regardless of what I have and she will take my problems seriously.	3.57
29. My pediatrician listened to me patiently. I really appreciate him.	3.00
30. A second opinion from a pediatrician supported me for not having my son go through unnecessary testing.	3.43
31. Knowing the diagnosis made me understand the odd behaviors of my child.	4.29
32. Therapy for children with autism at school with a consistent routine has helped my child gain different skills in activities of daily living.	4.43
33. Social workers at the school were helpful with money issues (for example, by providing gift cards for food). This gave me more positive energy when I had financial difficulty.	3.86
34. Social workers were very respectful and provided a lunch program for my child.	2.86
35. A therapist went on to contact other people to help complete my child’s assessment.	3.71

Statements	***Average Rating Values***
36. A therapist called me to offer help in case I needed it. She went beyond her duties to help me.	3.14
37. A neurologist reassured me that my son’s seizures were not caused by anything that I was doing.	4.00
38. When my son was connected with many wires at the hospital, a nurse observed him closely and gave him a book he wanted. This made my child and I feel very happy.	3.43
39. A FSCD staff asked me “why we [FSCD staff] stressed you out?” At least she tried to identify what can keep me from having too much stress, when I am in contact with FSCD.	2.86

APPENDIX H

Cover Letter for Sorting Task

Dear participant:

I would like to thank you for agreeing to participate in the sorting task which is a part of the study on “Parents’ perception of professional contacts during their adaptation to caring for a child with disabilities”. I would like to remind you that your participation is strictly voluntary and you may drop-out any time. All information will be confidential.

The enclosed package contains two sets of statement slips in two different envelopes, and instructions for the sorting task. Please sort each set of the statements into common themes. Detailed, step-by-step instructions are provided. This task requires about 20 minutes to complete. A stamped, self-addressed envelope is also enclosed so that you can conveniently return your sorted statements to me.

The sorted statements will be used to create concept maps that reflect the common experiences and themes of parents who have contacted with professionals in relation to caring for a child with disabilities. It is hoped this information will contribute to a better understanding and services for parents of children with disabilities.

If you have questions concerning the study please feel free to contact me at 780-439-0143 or Dr. Richard Sobsey at 780-492-3755. Thank you for your time and assistance.

Sincerely,

Wanapa Intaprasert, PhD. candidate
Dept. of Educational Psychology
University of Alberta.

APPENDIX I

Sorting Instructions

In this task you are asked to sort the statements into groups based on conceptual similarity or themes that make sense to you. This will reflect how you perceive and categorize the statements. Please also provide a label for each group. This label should be a word or short phrase that best describes the statements in that group. This task will take approximately 20 minutes to complete. There are two envelopes containing a different set of final statement slips. Please sort the statements from each envelope separately and follow these instructions:

1. Read through all the statements.
2. Sort the statements into groups that make best sense to you.
3. All statements cannot be placed into a single pile.
4. All statements cannot be put into their own pile. However, there may be a few statements that cannot fit into any groups with other statements and thus becomes its own group.
5. Please write a label or title for each group of statements.
6. Please clip each pile and a label together and place all piles into a provided envelope.

Thank you for your participation

Sincerely,

Wanapa Intaprasert

APPENDIX J

Incidence survey

Please rate your agreement on each statement according to your experience with professional contacts in relation to caring for your child with a disability on a 1 to 5 scale where: SDis. = Strongly Disagree, Dis. = Disagree, Neu. =Neutral, Ag. = Agree, SAg. = Strongly Agree, and NA = Not applicable.

Statements	SDis.	Dis.	Neu.	Ag.	SAg.	NA.
1. There have been many health professionals in my child's life who have been empathetic and done what we asked them to.	1	2	3	4	5	NA
2. Teachers have supported and have advocated services needed by both my child and me.	1	2	3	4	5	NA
3. Therapists provided knowledge that we needed. We are able to use it in a way that my child could understand.	1	2	3	4	5	NA
4. A health professional told us to give our child up because he/she also had a child with disability and his/her personal relationship broke up.	1	2	3	4	5	NA
5. Parents are often excluded from important discussions and decision-making in school.	1	2	3	4	5	NA
6. Teachers are not willing to use strategies in school that were developed and already work at home.	1	2	3	4	5	NA
7. A therapist called me to offer help in case I needed it. She/he went beyond her/his duties to help me.	1	2	3	4	5	NA
8. Care-workers work one-on-one with my child and put their whole hearts into making sure he/she learns.	1	2	3	4	5	NA
9. I have been very impressed by some teachers who stretch their creativity to reach my child with different teaching methods.	1	2	3	4	5	NA
10. Some doctors are willing to see my child more frequently to maintain adequate care because of her/his needs.	1	2	3	4	5	NA
11. My pediatrician continues to see our child well into his/her adult years.	1	2	3	4	5	NA
12. I feel disappointed when professionals promise me services that they cannot deliver.	1	2	3	4	5	NA

STATEMENTS	SDis.	Dis.	Neu.	Ag.	SAg.	NA
13. Some professionals have a lot of knowledge but lack experience.	1	2	3	4	5	NA
14. Therapy for children with disabilities at school with a consistent routine has helped my child gain different skills in activities of daily living.	1	2	3	4	5	NA
15. Care-workers have the means to learn the best way how to help my child.	1	2	3	4	5	NA
16. Social services wanted us to give back our adopted child when we found out later that she/he had cerebral palsy. We were pestered by them for quite awhile for refusing to give her/him back.	1	2	3	4	5	NA
17. With FSCD, it's almost impossible to get funding and when we do get funding it is minimal.	1	2	3	4	5	NA
18. Therapists provide me with skills to assist my child at home. Through this my child makes more gains than only seeing them a few times a month.	1	2	3	4	5	NA
19. A neurologist reassured me that my child's seizures were not caused by anything that I was doing.	1	2	3	4	5	NA
20. Multidisciplinary team at a hospital persuaded the parents to use tube feeding for their children over mouth feeding.	1	2	3	4	5	NA
21. A FSCD staff asked me "why we [FSCD staff] stressed you out?" At least she/he tried to identify what can keep me from having too much stress, when I am in contact with FSCD.	1	2	3	4	5	NA
22. Social workers at the school were helpful with money issues (for example, by providing gift cards for food). This gave me more positive energy when I had financial difficulty.	1	2	3	4	5	NA
23. Care-workers prompt me to do other activities besides just caring for my child. They helped me to lead my life in a normal way.	1	2	3	4	5	NA
24. A program supervisor at school is going to try to implement the home video about our family situation as a teaching tool so that staff can be more empathetic to what families are going through.	1	2	3	4	5	NA
25. The constant change of personnel at school causes frustration because we have to deal one day with one person and another day with another person.	1	2	3	4	5	NA

STATEMENTS	SDis.	Dis.	Neu.	Ag.	SAg.	NA
26. Many professionals really go the extra mile to do what we asked them to do.	1	2	3	4	5	NA
27. Teachers are not willing to take into account the parents' personal experience with the child.	1	2	3	4	5	NA
28. Because of a dedicated professional my child's transition to school has been less stressful.	1	2	3	4	5	NA
29. A social program at a women's shelter refused services due to my child's diagnosis of autism.	1	2	3	4	5	NA
30. When my child was connected with many wires at the hospital, a nurse gave him/her good care. This made my child and I feel very happy.	1	2	3	4	5	NA
31. With these children it takes a long time to form a bond that assists them to progress. The rate of pay from the government for staff in this field is not enough to keep them.	1	2	3	4	5	NA
32. A staff person gave me hope by showing me how to focus on the positive gains my child was making. I have more good days with my child.	1	2	3	4	5	NA
33. I was starting with my three-year-old child to get him/her into a program and services. I tried to take one agency at a time so that I could digest all the information they gave me. It's so much.	1	2	3	4	5	NA
34. A social worker at my child's school has helped us to access services for any needs my child has had. She/he puts us in touch with many organizations.	1	2	3	4	5	NA
35. I identified the fact that there was a problem with my child, but the doctor told me there was nothing wrong, that this was normal.	1	2	3	4	5	NA
36. There is a lack of tolerance and understanding about children with disabilities in society.	1	2	3	4	5	NA
37. A school supervisor told me not to expect my child to get any better, or expect progress so I left that school.	1	2	3	4	5	NA
38. Parents have to fight for services and government supports. There has not been much change for decades.	1	2	3	4	5	NA
39. Funding by FSCD has helped to make a home program and supportive services possible.	1	2	3	4	5	NA

STATEMENTS	SDis.	Dis.	Neu.	Ag.	SAg.	NA.
40. The hospital referred my two-and-a-half-year-old child to a special needs program. I had someone to turn to.	1	2	3	4	5	NA
41. My child's care-worker has gone above and beyond by helping to advocate for more funding.	1	2	3	4	5	NA
42. A service worker told me if I could not control and calm my child I would not get my cheque on that day.	1	2	3	4	5	NA
43. She/he taught my child at home. This helped lessen my tension and gave me strength when I was exhausted.	1	2	3	4	5	NA
44. The multi-disciplinary team in the hospital told me that I did not do anything wrong during pregnancy to cause my child to have disabilities. This helped me to come out of my depression.	1	2	3	4	5	NA
45. It is rude for professionals to say to parents to put their children aside or give up on them. They should be encouraging parents to help their children.	1	2	3	4	5	NA
46. A social worker told me to downplay my child's function in order to get more funding.	1	2	3	4	5	NA
47. Social workers were very respectful and provided a lunch program for my child.	1	2	3	4	5	NA
48. A therapist went on to contact other people to help complete my child's assessment.	1	2	3	4	5	NA
49. Some professionals do not have the relational skills necessary to deal with parents and children with disabilities.	1	2	3	4	5	NA
50. AISH regulations limit the amount of money that parents can leave to or save for their children with disabilities.	1	2	3	4	5	NA
51. My pediatrician said that she/he will do what my child needs regardless of what I have and she/he will take my problems seriously.	1	2	3	4	5	NA
52. We have to go through the constant battles from different government agencies to get the needed help for our children that can be financially, manpower, equipment, services, on and on.	1	2	3	4	5	NA

STATEMENTS	SDis.	Dis.	Neu.	Ag.	SAg.	NA.
53. A second opinion from a pediatrician supported me for not having my child go through unnecessary testing.	1	2	3	4	5	NA
54. The rate of pay is not enough to hire people to work at home. I have financial resources, but have difficulty finding help.	1	2	3	4	5	NA
55. A mother once said to me “this is my first visit with FSCD which a staff member did not make me cry.”	1	2	3	4	5	NA
56. I had to use my child’s diagnosis of autism to get help from the police in an abusive situation.	1	2	3	4	5	NA
57. A hospital has been helpful in giving supplies, wheelchairs, orthotics for shoes and prosthetics.	1	2	3	4	5	NA
58. Knowing the diagnosis made me understand the odd behaviors of my child.	1	2	3	4	5	NA
59. The government provides funding for help, but it is not enough to be effective.	1	2	3	4	5	NA
60. Some professionals are rude, condescending.	1	2	3	4	5	NA
61. My pediatrician listened to me patiently, I really appreciate him/her.	1	2	3	4	5	NA
62. A doctor mentioned that my child would put me in difficult situations.	1	2	3	4	5	NA
63. A care-worker has developed a strong bond with my child and chose to transition with him/her to the school setting.	1	2	3	4	5	NA
64. I felt pre-school assessment services could have warned me better about the outcome.	1	2	3	4	5	NA
65. Lack of accountability on how professionals spend the funding they receive.	1	2	3	4	5	NA
66. Professionals are not forth coming about all services that are available.	1	2	3	4	5	NA
67. A staff person provided me with the skills required to help my child myself.	1	2	3	4	5	NA
68. Social worker acts as an intermediary between a family and staff members to see positive change.	1	2	3	4	5	NA

STATEMENTS	SDis.	Dis.	Neu.	Ag.	SAg.	NA.
69. Professionals protect their territory and their funding, particularly in a school system.	1	2	3	4	5	NA
70. Teachers praise your effort as a parent to help you remember that you do good jobs.	1	2	3	4	5	NA
71. They ask me regularly if I am fine. They really care about me.	1	2	3	4	5	NA
72. Teachers prompted me to access services I was unaware of.	1	2	3	4	5	NA
--THE END/ THANKS --						

APPENDIX K

Participants Pile Labels

The Parents' Positive Perception Concept Map

Cluster Labels	Closest Individual Sort Pile Labels
Cluster 1: Supportive Services from Health Professionals	- Medical professionals - Specialized supports - Support from multidisciplinary team - Supportive hospitals - Positive care from medical professionals - Positive experiences with professionals' care and resources.
Cluster 2: Psychological Support from Health Professionals	- Caring and Compassionate Professionals - Listen to parents opinions and help based on what the parents said - Emotional supports/ respect/ encouragement - Professionals help us feel better about parenting a special needs child - Listening and putting family need first - Emotional supports from health care professionals
Cluster 3: Supportive Care-Workers	- Care-workers - Home support lessens tensions and exhaustion - Services that help families integrate into society - Care workers/ frontline - Immediate support/ day to day - Care-workers providing help
Cluster 4: Social Services Help With Home Life Balance	- Service that affects home life - Funding/Social service system - Tools to make home-life easier - Occasions where funding is adequate - Helping parents to keep balanced - Parents need break in order to continue to fulfill their responsibility
Cluster 5: Supportive School Professionals	- Supportive teachers/School staff - Support at school - Positive statements involving teachers and schools - School has positive influence - Education system

APPENDIX L

Participants Pile Labels

The Parents' Negative Perception Concept Map

Cluster Labels	Closest Individual Sort Pile Labels
Cluster 1: Inadequacy of School Professionals	- Inadequate school services - School professionals work against rather than with parents - Difficulties in education system - Professionals need to take into account parents' personal experience with their child - Team work issues
Cluster 2: Conflict with Health Professionals	- Problems with health professionals - Negative opinions from health professionals - Doctors need to know how to talk in a helpful manner - Professionals focus on the problems the child will cause the family rather than on helping the families
Cluster 3: Professionals' Ignorance	- Unsupportive professionals - Parental concerns in general - Bad service - Dealing with ignorant professionals
Cluster 4: Social Service Professionals' Lack of Empathy	- Lack of empathy/sensitivity for parents - Lack of understanding - Professionals do not take the time to understand parents' situation - Frustrations caused by lack of compassion and understanding
Cluster 5: Fight for Social Services	- Constantly fight with professionals so your children receive the care they require - Fighting for services - Struggling with agencies to receive supports
Cluster 6: Funding Issues	- Funding given not always enough to be effective - Funding problems/issues - Scattered/limited funding and services