

Against All Odds:
Resilience in Single Mothers of Children with Disabilities

By
Kathryn A. Levine

A Dissertation submitted to the Faculty of Graduate Studies of
The University of Manitoba
In partial fulfillment of the requirements of the degree

DOCTOR OF PHILOSOPHY
Faculty of Social Work
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ABSTRACT

There is a substantial body of literature that explores family adaptation within the context of childhood disability. However, closer analysis indicates that the primary focus of this research has concentrated on two-parent family systems. Despite evidence to suggest that single mothers are more likely to be parenting children with disabilities; their experiences have received minimal attention within social science research. Furthermore, when single mothers do become the focus of study, much of the attention is directed toward identifying the deficits within their family systems.

Grounded in family resilience theory, the intent of this study was to explore the family adaptation of single mothers of children with disabilities within a longitudinal framework, and to identify the individual, family, social and environmental factors that contribute toward resilience within this population. Study participants consisted of 15 single mothers who had previously participated in the “Family Strengths and Childhood Disability” research project. Quantitative data addressing parenting stress, family support, and parental perceptions of the impact of disability on the family was obtained approximately 6 months after mothers had entered the Manitoba childhood disability support system, and again 4 years later. The qualitative component followed the quantitative, and mothers were interviewed with the view toward identifying their perceptions of what constitutes risk and protective factors, and exploring these in the context of family adaptation and resilience.

Findings revealed a marked contrast between public discourses about single motherhood, childhood disability and the personal narratives of the mothers in this study. Concepts of family resilience were revealed by mothers who challenged definitions of

single mothers as inadequate, who disputed the definition of their children as “disabled”, and who moved from a position of received to authoritative knowledge. The study demonstrates in contrast to public perceptions, single mothers of children with disabilities view their experiences as personally transformative and as means of building confidence that empowers them to further disrupt negative expectations of their families.

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TABLE OF CONTENTS

Abstract	ii
Acknowledgments	iv
List of Tables	vii
Chapter One: Introduction	1
Chapter Two: Review of the Literature	11
Chapter Three: Research Methodology	70
Chapter Four: Findings: Qualitative Analyses	89
Chapter Five: Discussion	157
Literature Cited	181
Appendices	220

LIST OF TABLES

Table 1	Open-Coded Categories of Qualitative Data	71
Table 2	Participant Demographics	79
Table 3	Participant Scores – Parenting Stress Index	82
Table 4	Parenting Stress Index – Paired Samples Test	82
Table 5	Reliable Change Index – Parenting Stress Index	85
Table 6	Family Impact of Childhood Disability (FICD)	87
Table 7	Reliable Change Index – FICD	88

CHAPTER ONE

Introduction to the Study

I can't think of anything to write about except families. They are a metaphor for every other part of society.

*Anna Quindlen
(1953 -)*

Within the childhood disability field, there is a substantive body of research that explores stress, coping and adaptation in families with children with disabilities (Salisbury, 1987; Smith, Oliver, & Innocenti, 2001). A closer analysis indicates that the majority of this research has focused upon the experiences of mothers within traditional, two-parent family systems (Boyd, 2002; Bright & Hayward, 1997; Cameron & Armstrong-Stassen, 1991; Hodgkinson & Lester, 2002; Marcenko & Meyers, 1991; Yau & Li-Tsang, 1999). Conceptually, this perpetuates the narrow assumption that family is based solely upon the presence of two parents in a marital or spousal relationship, and does not reflect the current reality of the broader community wherein the existence of a variety of family forms challenges this definition. Families who differ from the normative construction are typically omitted from the discourse of childhood disability, and consequently, the experiences of families that do not conform to this idealized norm are either rendered invisible, or in comparative analyses, labeled as problematic.

The socially constructed ideal of what constitutes good motherhood does not typically evoke images of single or lone mothers. Although in the past two decades there has been a significant increase in the number of families that are headed by single mothers, this particular family form remains vulnerable to negative appraisals (Anderson,

2003; Gunnarsson & Cochran, 1990; Jung, 1996; Kleist, 1999). This may be especially true for single mothers of children with disabilities. In comparison to partnered mothers, single mothers of children with disabilities are noted to be more vulnerable to depression, express greater concern and worry about the future, are at higher risk of child neglect or abuse, experience increased stress related to lack of time and meeting family commitments, and access support services more than their married counterparts (Cigno & Burke, 1997; Floyd & Gallagher, 1997; Grant & Whittell, 2000; Olsson & Hwang, 2001; Salisbury, 1987; Schormans & Brown, 2004). These findings suggest that single mothers of children with disabilities are inherently more problematic and dysfunctional than families with children with disabilities in which there are two parents.

The interpretation of these results must include the identification of the theoretical assumptions, philosophical beliefs, and value systems within which the research is grounded. Within the past three decades, there have been major paradigm shifts with respect to theorizing about disability and the family. Initial research that examined the impact of childhood disability on the family was located within traditional psychodynamic and bio-medical theories. Findings subsequently suggested that families with children with disabilities experienced unresolved grief, caregiver burden, chronic sorrow, and general family dysfunction (Olshansky, 1961; Seligman & Darling, 1997; Wikler, Wasow, & Hatfield, 1983; Wolfensberger, 1983). Research paradigms were developed based on these assumptions, and knowledge-building focused upon identifying the stressors and maladaptive family processes that were considered to be an inherent outcome of childhood disability.

In contrast, contemporary interest regarding the impact of childhood disability upon a family is generating research with a view toward enacting policy changes and practice initiatives that will enable families to manage the care of their children in positive, respectful, and empowering ways (Dunst, Trivette, & Deal, 1988; McCallion & Toseland, 1993; Trute & Hauch, 1988). Within this context, there has been a movement toward understanding families from a salutogenic, rather than pathogenic, perspective. Epistemological frameworks that emphasize family deficit and dysfunction are no longer considered the only valid explanations for families with children with disabilities. They are being challenged by family-centred models that focus upon family strengths and resilience, with a view toward exploring the processes that contribute to empowerment and positive family adaptation.

Concurrently, the concepts of stress and coping have become an integral part of the nomenclature of the social sciences. The factors and processes that affect stress, coping and adaptation are embedded within knowledge of how individuals and families understand and respond to the range of life events including childhood disability. Models of family stress have broadened to reflect a bio-psycho-social or “mind-body-family” connection, with an emphasis on understanding how families manage to “do well” in spite of seemingly adverse circumstances. Contemporary explanations of family adaptation to childhood disability are expanding to include the construct of family resilience; examining how family strengths challenge and empower families to withstand and rebound from crises and persistent life challenges, and emerge transformed by these processes (Itzhaky & Schwartz, 2000; McCubbin & McCubbin, 1993; Meschke &

Patterson, 2003; Rolland & Walsh, 2005; Singer, Irvine, Hawkins, Hegreness, & Jackson, 1993).

Research paradigms are undergoing parallel shifts. Although studies utilizing quantitative methodologies have contributed to professional understandings of the impact of childhood disability on the family, they have also narrowed the range of information available for analysis. Hastings and Taunt (2002) noted the incongruence between parental narratives regarding their experiences of raising children with disabilities and results based on quantitative analyses. Hartshorne (2002, p. 268) further identified how parents' descriptions of their experiences reflected "courage" and "encouragement", in contrast to scores on standardized measures that indicated high levels of stress. This suggests that research measures typically used in childhood disability research may lack empirical sensitivity to positive parental perceptions. Parenting a child with a disability may be stressful, but this is not synonymous with family distress or dysfunction. Qualitative research methodologies which incorporate narratives of parents' experiences and explicitly focus on family resilience are beginning to address these discrepancies and expand the body of research knowledge available to practitioners within the childhood disability field (Gottlieb, 1998).

Although there is emerging evidence to suggest that these shifts are resulting in altered perspectives regarding family functioning, a closer analysis reveals that the two-parent family form continues to garner the majority of attention from researchers exploring the construct of resilience and its relationship to family adaptation. Studies that examine coping, adaptation and resilience in families with children with disabilities

overwhelmingly focus upon mothers from two-parent family structures (Bristol, 1987a; Gardner & Harmon, 2002). In contrast, the relationship between single mothers who are raising children with disabilities and family adaptation receives relatively minimal attention within the research literature, and studies that examine resilience within this population are noticeable in their absence. Single motherhood continues to be constructed as a “crisis” within the public policy domain (McKie, 1993, p. 54), and single mothers raising children with disabilities are not exempt from this viewpoint.

Taken together, these results suggest that single-parent mothers experience greater stress in parenting children with disabilities and are therefore incapable of demonstrating positive adaptation. Gottlieb (1998) observed that much of the research on single-parent families with children with disabilities has viewed the problems pathogenically, with the assumption that disability status inevitably results in less adaptive outcomes for both children and parents. However, given that single-parent families have not traditionally been the focus of study, it remains unclear as to whether or not they are able to positively adapt, and there is less information available regarding the factors that may contribute toward this process.

The scarcity of information on this particular family form has potentially significant implications for policy-makers and service delivery professionals. Knowledge developed in a context of traditional assumptions regarding disability and the family has been translated into policies, service delivery systems, and research frameworks that largely address the needs of two-parent, families of young handicapped children in which mothers do not work outside the home (Landis, 1992). Although many studies frequently

include single mothers, they do not typically constitute a numerically sufficient group from which to generate conclusions that could result in substantive change. Thus, in the absence of specific knowledge regarding single mothers of children with disabilities, service models based on the two-parent family structure are extrapolated to lone mothers. This “one size fits all” approach suppresses knowledge-building regarding the needs of single mother families, and consequently limits the capacity of policy makers to create social policies that address the needs of different family structures and subsequently constrains practitioners’ capacities to provide appropriate service to these families.

Definition and Prevalence of Single Parent Families

Single parent families are becoming an increasingly prevalent family form within North American society, and increased by approximately 17% of all families between 1991-1996 (Statistics Canada, 2004). In 1996, the number of single-parent families was estimated at 1,137, 510 which constituted approximately 14.5% of all families. Within this population, the majority of families (945, 230) are headed by women, and they are also most likely to live on poverty level incomes (Statistics Canada, 2004). This highlights one paradox of single motherhood. It continues to be constructed as a problem within the public policy domain, yet there has been minimal effort to alter women’s socioeconomic position within society (Eichler, 1993; Schmitz, 1995). A variety of social policy indices suggest that if current trends continue, the number of lone mother families will likely increase, and therefore, the number of female-headed families living in poverty will also increase (Bristol, 1987c; McKie, 1993).

Contrary to dominant perspectives, single-parent families headed by women are a heterogeneous group, as indicated by the different pathways through which lone parent families are formed: (a) through the death of a married parent, (b) through the separation or divorce of a married parent, (c) through the union dissolution of a parent living common-law, (d) through the birth of a child to an unmarried woman, and (e) through the adoption of a child by a single adult (Bristol, 1987a; Eichler, 1993). Within the last several decades, there have been distinct shifts in terms of how the majority of single-parent families are formed. Prior to the 1950's, the most common means of becoming a single-parent family was through the death of a spouse. In contrast, contemporary data suggests that the majority of families are now formed in the context of separation, divorce, or never-married status (Statistics Canada, 2001).

Single parents are equally heterogeneous in terms of family characteristics. Some single-parents are financially well off, some are poor, some are single-parents by choice, other single-parents are created in the context of loss including separation, divorce or widowhood, and some have extensive family and social support networks, while others are relatively isolated. Single parents also differ in terms of age, education, race, ethnicity and cultural backgrounds, life cycle stages, and beliefs, attitudes and expectations (Anderson, 2003; Murry, Bynum, Brody, Willert & Stephens, 2001).

Definition and Prevalence of Childhood Disability

The designation of childhood disability encompasses a multitude of different disabilities including but not limited to: (a) cognitive or intellectual disability or global developmental delay; (b) genetic and biological factors (e.g., Down Syndrome, Fragile X

Syndrome); (c) environmental factors (e.g., Fetal Alcohol Syndrome/Effect); (d) premature birth, acute or chronic medical conditions (e.g., diabetes, cystic fibrosis); (e) acute or chronic conditions of the brain or nervous system (e.g., cerebral palsy, head injuries); (f) specific developmental disorders including autism, or Asperger's Syndrome; (g) physical disabilities (e.g., muscular dystrophy); and (h) psychiatric disorders including mood/affect disturbances and major mental illnesses such as schizophrenia (Missiuna, Smits, Rosenbaum, Woodside, & Law, 2001). In Canada, in 2001, approximately one out of ten or 155,000 children required assistance in performing some activities of daily living (Statistics Canada, 2003). Therefore, although childhood disability may never be considered normal, it is more normative than previously understood.

Single Mothers of Children with Disabilities

The population of single mothers of children with disabilities likely reflects comparable heterogeneity (Boyce, Miller, White, & Godfrey, 1995; Bristol, 1987a). Although Statistics Canada routinely tracks family size, family structure, and disability status, Stats Canada does not look at the relationship between these variables, so it is difficult to discern actual percentages of single-parent families with children with disabilities. There is evidence to suggest however that the percentage of single-parents with children with disabilities replicates or exceeds the percentage of single-parent status within the general population. Based on intake data from the Government of Manitoba department that provides voluntary services to families with children with disabilities (Children's Special Services), 29% of all intakes during the four year period of July,

1999 to July, 2003 were headed by single care providers (Government of Manitoba, 2003). This is supported by American data which indicates an increase in the prevalence of childhood disability in groups specifically defined by poverty and female-headed, single-parent family status (Fujiura & Yamaki, 2000; Lloyd & Rosman, 2005). It is important to recognize these differences as Cohen and Petrescu-Prahova (2006) suggest that gendered living arrangements among children with disabilities are a neglected aspect of inequality in caring labour. However, in a comparative study of families with chronic health problems to families of physically healthy children, there was no higher proportion of single-parent families among those with a chronically unwell child (Cadman, Rosenbaum, Boyle, & Offord, 1991).

Research Questions

The purpose of this study therefore was to examine the experiences of single mothers of children with disabilities. Within this context, there are five questions that formed the foundation for this study.

- Question 1: What are the experiences of single-parent mothers who are raising children with disabilities?
- Question 2: How do single-parent mothers make meaning from their experiences? How does being a single-parent have an impact (positively or negatively) upon the experience of parenting a disabled child?
- Question 3: What are the key factors that contribute to stress and coping for single mothers? How do these processes change over time?

Question 4: How is resilience manifest in single mother families? How do single mothers define resilience for themselves?

Question 5: Are there common themes of resilience that can be identified within the parenting experiences of single mothers of children with disabilities?

CHAPTER TWO

Literature Review

Selected literature relevant to this study will be organized under three headings:

(a) family stress and coping theories (b) the Family Adjustment and Adaptation Response (FAAR) model, and (c) family resilience theories.

Family Stress and Coping Theories

The origins of research and knowledge regarding stress and coping are located within empirical investigations into the relationship between stress and illness. It has been well established that stress is positively associated with negative health outcomes in a range of illnesses including cancer, heart disease, migraines, and other physical symptoms/problems (Aldwin, 1994; Lazarus & Folkman, 1984; Somerfield & McCrae, 2000). This suggests that stress is frequently understood within a sequence of cause and effect, as research typically has explored the impact of a single event on a single health outcome. For example, within childhood disability research, stress, conceptualized as maternal depression, is noted to be a frequent outcome in families with children with disabilities (Bright & Hayward, 1997; Eisenhower, Baker, & Blucher, 2005; Keller & Honig, 2004; Manuel, Naughton, Balkrishnana, 2003; Shapiro & Tittle, 1990; Singer, Davillier, Bruening, Hawkins, & Yamoshita, 1996; Smith, Innocenti, Boyce, & Smith, 1993).

Transactional Model of Stress and Coping

The transactional model of stress and coping developed in recognition of the relational dynamic of stress and coping (Lazarus & Folkman, 1984). In contrast to other

models that define stress as a response to an event, this model specifically focused on the role of cognition or the process of appraisal in stress and coping. Lazarus and Folkman defined psychological stress as a particular relationship or process, between the person and the environment that was appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being. The salient feature of this theory is that the precipitating trigger or experience cannot be labeled as stressful until it is appraised or perceived as stressful by the individual. The evaluative process determines why and to what extent a particular transaction or series of transactions between the person and the environment is experienced as stressful. Within this framework a diagnosis of disability status may be perceived as a relief for mothers who suspected that something was different about their child, or for other mothers, as an event that results in a prolonged depression. The individualized nature of cognitive appraisal therefore provides some explanation of the substantial variation among individuals under comparable conditions. Another factor that distinguishes this model is that coping is viewed in terms of management, rather than mastery (Beresford, 1994). This is particularly relevant for disability-related issues, as they are by definition chronic conditions, and thus "cures" are unattainable. Furthermore, in contrast to models that define coping in terms of outcomes, the emphasis is on the individual's actual thoughts and behaviours in response to stressful situations, as opposed to whether these particular strategies are effective at reducing stress.

Primary Appraisal Process

Three levels of primary appraisal processes are described within the literature (Lazarus & Folkman, 1984; McCubbin & McCubbin, 1993). A potential stressor event may be appraised by the individual as irrelevant, benign-positive, or stressful. When an event occurs that is perceived as not having the potential for impact upon the individual, it is considered irrelevant. Events that have the capacity to produce positive outcomes and enhance well-being may be interpreted as benign, and result in positive affect. Stress appraisals interpret events as a loss, harmful, threatening or challenging. Events that are appraised as harmful include those where a loss has already occurred, with accompanying affect of sadness, grief and mourning. A first born child with a positive confirmation of disability may be interpreted by the mother as the loss of an idealized child. Threat refers to harm or losses that have not yet taken place but are anticipated and can elicit negative emotions of fear, anxiety and anger. A positive test on an alpha-fetoprotein level during pregnancy may suggest Down syndrome, but cannot be confirmed without the additional procedure of an amniocentesis. Although a potentially stressful event may be perceived as threatening, it may also permit anticipatory coping, and thus may contribute to adaptation. Events that are interpreted as challenge appraisals focus on the potential for gain or growth and are characterized by positive emotions including eagerness, excitement and impatience.

In the context of childhood disability, primary appraisal can refer to the evaluation of the event of learning that one's child is disabled and judgments regarding the diagnosis itself, including characteristics of intensity and expected duration. Parents

generally report increased levels of psychological distress, including feelings of insecurity, helplessness and worry upon receiving a diagnosis of childhood disability (Bartolo, 2002; Pelchat et al., 1999; Taanila, Jarvelin, & Kokkonen, 1998).

In applying the transactional model, there is some evidence to indicate that the primary appraisal of the stressor is related to the disability type, the perceived level of severity, and the impact upon the child's behaviour. Parents of children with Smith-Magenis syndrome report significantly higher stress levels than parents with mixed or non-specific developmental disabilities (Hodapp, Fidler, & Smith, 1998). Mothers of autistic children report significantly more stress-related problems than mothers of children with Down syndrome, and mothers of children with Down syndrome and congenital heart defects report significantly more stress than parents of children with a physical disability or no disability (Boyd, 2002; Pelchat et al., 1999).

One limitation of these studies is noted to be the focus on a specific time period. For example, the Pelchat et al. study focused on parental reactions when the child was 6 months old, suggesting that the disability diagnosis was relatively recent. It is not surprising therefore that parental stress would be high at this time. Moreover, closer analysis of the Hodapp study indicates that disturbances in children's sleep and behaviours were the strongest predictors of parental stress, findings that are replicated in parents with non-disabled children (Olson, Ceballo, & Park, 2002). Similar findings exist within the childhood disability research. Behavioural disturbances in the context of developmental disabilities are consistently noted to increase parental stress and are a much stronger predictor of parenting stress than children's cognitive delays or adaptive

functioning (Baker, Blacher, Crnic, & Edelbruck, 2002; Cameron & Armstrong-Stassen, 1991; Floyd & Gallagher, 1997; Hastings, 2002; Hodapp et al., 1998; Maes, Broekman, Dosen, & Nauts, 2003; Stores, Stores, Fellows, & Buckley, 1998).

According to Lazarus and Folkman (1984), even in those situations when the harm/loss has occurred, it can remain fused with threat via the presence of negative implications for the future. Therefore, after confirmation of childhood disability, parents may continue to experience stress as a function of the unknowns about their children's futures. Specific concerns include worries about the degree to which their children will be included in society, concerns regarding education, future employment and economic independence, and who will provide ongoing care when parents are no longer able to do so (Heiman, 2002; McLinden, 1990). Other studies conclude that many parents do not identify concerns for the future as primary problems (Leysner & Dekel, 1991). This suggests that in order to understand the meaning of disability-related stress for parents, it is important to include a developmental perspective, as worries, stressors and transitions will change as the family moves forward in time.

Secondary Appraisal Process

The secondary appraisal process refers to the self-evaluation by the individual as to their ability to meet the demands of the stressor event. According to Lazarus and Folkman (1984), secondary appraisals of coping options interact with primary appraisals in terms of influencing the emotional responses. Successful coping is partially predicated on realistic appraisals that lead to appropriate and effective outcomes. Under- or over-estimating the potential impact of an event may cause the individual to appraise the

stressor inaccurately, or the appraisal may fail to recognize the event as one that should not be ignored.

Lazarus and Folkman (1984, p.141) defined coping as “constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as exceeding the resources of the person.” In order to successfully cope, one needs to draw upon a range of coping processes or strategies. Secondary appraisal processes include the evaluation of personal coping resources and strategies, physical health, beliefs and ideologies, personality variables, previous coping experiences, parenting skills and socio-ecological resources including; spousal, extended family and social support, respite care, maternal employment and financial circumstances (Beresford, 1994).

Within the transactional model, there are two categories of coping processes: problem-focused and emotion-focused. Problem-focused coping strategies include defining the problem, generating alternative solutions, weighing the alternatives in terms of costs and benefits, and choosing and implementing a strategy. Practical or problem-focused coping behaviours are generally most effective when events and challenges are amenable to change and may be successfully implemented by the individual. For parents of children with disabilities, effective problem-solving processes have been found to embody five elements: (a) the ability to build on personal experience and expertise, (b) the value of having a regular routine and structure for coping, (c) having access to a trusted person to talk things over with, (d) being able to set priorities, and (e) being able to choose from a range of coping strategies (Grant & Whittell, 2000).

Emotion-focused coping includes cognitive processes directed at lessening emotional distress, strategies of avoidance, minimization, distancing, selective attention, positive comparisons, and deriving positive value from negative events (Lazarus & Folkman, 1984). Emotion-focused coping is generally used to ease painful or distressing emotions resulting from the stressor, while the function of problem-focused coping is to alter the person-environment transaction that is causing the distress.

With respect to these definitions, both Beresford (1994) and Thoits (1995) make the point that researchers have frequently made value judgments regarding the efficacy of coping strategies. There is an almost universal belief that actions directed toward problem-solving are associated with more adaptive coping, high self-esteem and perceived control. Conversely, emotion-focused efforts are associated with maladaptive behaviour, low self-esteem and passive or avoidant coping styles. Furthermore, there are gender differences as problem-focused strategies are typically associated with males, and emotion-focused coping efforts with females (Little, 2002; Reay, Bignold, Ball, & Cribb, 1998). Notwithstanding these differences, active or problem-focused coping strategies are associated with stress-resistance and coping in mothers (Margalit & Ankonina, 1991; Noojin & Wallander, 1997; Taanila, Syrjala, Kokkonen, & Jarvelin, 2002), and emotion-focused coping styles are associated with poor mental health, poor maternal adjustment, and decreased involvement with early intervention services (Bright & Hayward, 1997; Kim, Greenberg, Seltzer, & Krauss, 2003).

However, emotion-focused coping is also associated with positive maternal adaptation, particularly at the early stage of diagnosis. Nelson (2002) concluded that

emotion-focused coping was a helpful strategy during the initial phase of diagnosis as it provided a context for mothers to process the information in manageable ways. Coping by redefinition, an emotion-focused strategy is another means by which families have been found to manage the stress of raising children with developmental disabilities. Tunali and Power (2002) suggested that mothers responded to the stress of raising children with autism by redefining what constituted the fulfillment of their personal needs. Mothers of children with autism placed less emphasis on their careers and greater emphasis on their parental roles compared to mothers of children without autism. The secondary appraisal process of what one needs in order to live a fulfilling life, and what one is able to change in order to adapt to a stressor event included the redefinition of personal needs and goals.

A limitation of categorization is that it is not always possible to label particular coping strategies as either emotion or problem-focused. McCubbin and Huang (1989), using the Coping Health Inventory for Parents, determined three coping patterns: (a) maintaining family integration, cooperation and an optimistic definition of the situation; (b) maintaining social support, self-esteem and psychological stability; and (c) understanding the health care system. Each of these categories contained both beliefs and behaviours, which suggested that emotion and problem-focused coping strategies are not necessarily independent or dichotomous factors.

In summary, the transactional model of stress and coping has important implications for understanding how mothers cope with children with disabilities. Adjustment and adaptation will be influenced by their process of cognitive appraisal

including mothers' perceptions of what constitutes family stressors and their assessments of the available resources to address the demands.

Family Adjustment and Adaptation Response Model

In 1983, McCubbin and Patterson expanded the ABC-X (Hill, 1958) model of family stress using information gathered from a longitudinal investigation. The original ABC-X model proposed that a stressor (A) interacts with the family resources for dealing with crises (B) and with the definition the family makes of the event (C) to produce the crisis (X). The double ABC-X model added four post-crisis factors, each of which corresponds to a factor in the original model. The aA factor reflects the fact that families generally deal with multiple stressors, the bB factor suggests that crises can precipitate new resources being brought into the family, and the cC factor refers to the family's perceptions about the issue, suggests potential solutions to the problem, renders the emotional strain associated with the crisis more manageable, and enables the family to re-establish its equilibrium. The xX factor refers to the end result of the family achieving a state of adaptation or adjustment to the crisis (Patterson & McCubbin, 1983).

The Family Adjustment and Adaptation Response model (FAAR) contains the double ABC-X model and integrates the process components of family adaptation to crisis over time. The FAAR model links concepts from family stress theory to the concepts of risk and protective factors, with an additional emphasis upon the importance of the construct of family meaning as a critical factor in understanding family adaptation (McCubbin, Thompson, Thompson, & McCubbin, 1993; Patterson & McCubbin, 1983; Patterson, 2002). The FAAR model consists of two phases that highlight the processes

experienced by families following a stressful event: the adjustment phase and the adaptation phase. The adjustment phase refers to how families utilize existing resources and capabilities to respond to stressor events and maintain a homeostatic level of functioning. Family adaptation is the process whereby families restore balance through reducing stress, increasing capabilities, and/or changing meanings to result in a state of family bonadaptation. The emphasis on the meaning attributed to stressor events, in addition to conceptualizing adaptation as a process, are two ways in which the FAAR model is distinguished from other models of stress and coping.

The FAAR model is based on an eco-systemic view of family functioning. Therefore, the family is conceptualized as a system of interacting individuals, both influencing and being influenced by a number of other systems including gender, race, class, economics, biology and social factors. The critical assumptions of family systems theory are: (a) the parts of the family are interrelated, (b) one part of the family cannot be understood in isolation from the rest of the system, (c) family functioning cannot be fully understood by simply understanding each of the parts, (d) a family's structure and organization are important factors determining the behaviour of family members, (e) transactional patterns of the family system are among the most important variables that shape the behaviour of family members, and (f) family functioning is influenced by the family's relationship to the environment (Epstein, Ryan, Bishop, Miller, & Keitner, 2003). Given that the FAAR model is based on the family as the unit of analysis, it can acknowledge both the diversity and complexity of contemporary families and their interactions with the environment.

In the FAAR model, family demands interact with family capabilities and meanings to result in a level of family adjustment and adaptation. Building on concepts from the transactional model of stress and coping, the FAAR model incorporates the cognitive appraisal of the stressor event, the meaning it holds for the family as a unit, and an assessment of internal and external resources that are available to the family. If there is a balance between family demands and capabilities, this will likely result in positive family adjustment. If, however, family demands exceed family capabilities, and this imbalance continues, it may produce a state of crisis. The subsequent processes undertaken by the family in response to the stressor event may include the emergence of family resilience, or bonadaptation, or an increase in vulnerability, resulting in maladaptation (Patterson, 2002).

Family Demands of Single Mothers

Family demands refer to the individual, parental, family and environmental system factors that have a direct, indirect or reciprocal influence on parental stress or any event or situation that families perceive as stressful (McDonald et al., 1999; Patterson, 2002). Family demands or stressors are conceptually similar to risk factors in that both may refer to negative life events that may predict negative outcomes. The FAAR model of family adaptation expands the definition of stressors to refer to a range of transactions that may occur between the individual, the family and the community including normative and non-normative stressors, or discrete events of change; ongoing family strains or unresolved tensions; and daily hassles or minor disruptions of daily life (Patterson, 2002). Family demands are unique and extend beyond inherent parental

duties, obligations and responsibilities that are not typically associated with risk factors or stressors.

Normative and Non-Normative Stressors

Single parent status. As previously stated, there are five developmental pathways through which single-parent families may be created. A common perception is that marital relationships are at increased risk of separation/divorce in the presence of childhood disability, and there is some evidence to support increased divorce rates (Thurston & Navarrete, 2003). However, when social class is controlled, there are no significant differences in divorce rates between parents of children with disabilities and those of non-disabled children, and longitudinal analyses indicate that separation and divorce rates for parents of children with disabilities are similar to parents whose families do not include disabled children (Beresford, 1994; Seltzer, Greenberg, Floyd, Pettee, & Hong, 2001).

Regardless of how one becomes a single-parent, there is evidence to support the idea that members from specific disadvantaged social groups including women, single individuals, and individuals with lower socio-economic status are more vulnerable to stressors (Emerson, 2003; Thoits, 1995). These factors suggest that single mothers of children with disabilities may be at increased risk of vulnerability to stressors as they are by definition single-parent women, who are more likely to be living in poverty.

In addition to marital status, one's experience of stress is also a function of role. The discourse around mothering continues to reflect the pervasive influence of psychoanalytic orientations on how society constructs the institution of motherhood

(Read, 2000). Essentially, mothers are synonymous with family, and there is an intrinsic linkage between the personality and psychological functioning of mothers and the health and well-being of children. The socially constructed prescriptions for “good” mothering are pervasive throughout all cultures, and are reflected within the social, educational, health, political and economic institutions of society. Single parent mothers are particularly vulnerable to these dynamics. The “pathology of matriarchy” describes the belief that the absence of fathers is destructive to children, with the corresponding absence of economic resources, role models, discipline, structure, and guidance (Biblarz & Raftery, 1999, p. 321).

Although all mothers are potentially influenced by the socially constructed role of the “good” mother, mothers of children with disabilities, by virtue of their compulsory involvement with paid professionals and intimate proximity to human service systems, may be subjected to even greater mother-blaming. In their roles as mothers, women who parent children with disabilities experience far greater public scrutiny than women with non-disabled children, although similar scrutiny has been applied to poor mothers, young mothers, disabled mothers, immigrant mothers, lesbian mothers and single mothers with non-disabled children (Garcia-Coll, Surrey, & Weingarten, 1998; Read, 2000). Moreover, there is significantly greater pressure for mothers to conform to professionally-determined indicators of “good” mothering including mandatory attendance at medical appointments, intrusive and contextually incongruent therapy regimes, unconditional agreement with segregated educational settings, or compliance with behavioural intervention programs for their children. The juxtaposition of dynamics

extrapolated from “normal” mother-child relationships upon mothers of children with disabilities supports the socially constructed belief that there is a singular, correct way for mothers to behave. When mothers choose not to comply with these externally-driven demands, they are subject to labels of resistance, denial, selfishness and poor mothering, or the inevitable emotional conflict that arises from the double bind of engaging in behaviour that is psychologically dystonic with personal knowledge and beliefs. In view of these social and cultural prescriptions, it is important to explore how women construct their role as single mothers of children with disabilities, and how they perceive the impact of these cultural prescriptions’ on their parenting, social support systems, and relationships with service providers.

Socioeconomic differences. Family needs of single-parent mothers can be assessed within contexts of high risk, specifically chronic exposure to adverse social conditions. The feminization of poverty remains a consistently irrefutable fact. Compared to men, women are at a significantly greater risk of experiencing poverty at some point throughout their lives, and women who are solely responsible for the financial support of their families are at the highest risk (Davies, McMullin, Avison, & Cassidy, 2001). Poverty is noted to be the most overwhelming influence on single-parents and their children, and is a crucial variable in interpreting studies of the needs and problems of single-parent households (Anderson, 2003). An unequivocal finding throughout the literature is that single-parent families are economically disadvantaged compared with two-parent families. In Canada, average family income is approximately \$55,000 for two-parent families, and single-parent families’ average income is less than half of that of

two-parent families. Given that the majority (83%) of single-parent families are headed by women, low income is particularly common for this group; 42% of all families in this category are considered to be living below the poverty line (Statistics Canada, 2004).

Socioeconomic differences based on marital status are replicated within families of children with disabilities. Research studies note that single mothers of children with disabilities report significantly lower income levels in comparison to partnered mothers (Bristol, 1987a, 1987c). This is not limited to the North American context, as 86% of single mothers raising children with intellectual disabilities in the United Kingdom were noted to be living in poverty (Emerson, 2003). A consistent finding within the literature is that socioeconomic status is strongly related to labour force participation. The presence of one or more children with disabilities, particularly preschool-aged children is negatively related to maternal labour force participation (Miltiades & Pruchno, 2001; Porterfield, 2002; Powers, 2003). Caring for children with disabilities can require full-time supervision, in a context of reduced daycare availability and/or hours or frequent medical/therapy appointments. The cumulative effect of these factors may potentially reduce the hours the parent is able to work, or place severe limitations on her choice of employment. Flexible family-friendly workplaces, although increasing for the professional or managerial classes, are not options for women who do not have post-secondary education (Howe & Pidwell, 2004).

Moreover, single mothers are noted to experience greater structural changes and longer transition times between periods of financial equilibrium (Hill, 1986; Mason, 2003). Boundary changes within the family that result in the addition of family members

are typically understood as periods of deficit economics. In two-parent families, this may result in a temporary loss of income, and is offset by an increase in non-income related contributions. Single mothers however are at a distinct disadvantage as they are required to cope simultaneously with both the loss of income and the increase in child-related responsibilities. This suggests that there are greater family demands on single mothers in the form of both economic problems and role transitions. There are however differences in terms of education, which mediate the nature of employment and income. Single mothers generally have lower levels of educational attainment, the consequences of which are low-waged or part-time jobs that result in financial strain. Therefore economics are an important beginning point for examining family stress related to maternal psychological functioning (Jackson, Brooks-Gunn, Huang, & Glassman, 2000; Olsson & Hwang, 2001).

There is also evidence to support the conclusion that financial strain is related to children's developmental outcomes, as single mother status is a significant predictor of children's behaviour problems, pre-school abilities, and psychiatric difficulties (Angel & Worobey, 1988; Jackson et al., 2000; Lipman, Boyle, Dooley, & Offord, 2002). This has also been documented within the population of children with disabilities. Children with cystic fibrosis from teenage and single mothers living in poverty are noted to have significantly worse prognoses and higher hospital admission rates when compared to children from two-parent families (Macpherson, Redmond, Leavy, & McMullan, 1998).

Disability-related expenses are also noted to have a differential impact upon single-parent families (Cameron & Armstrong-Stassen, 1991). In conjunction with

evidence that suggests that two-parent families have consistently reported economic hardship as a result of disability-related expenditures (Emerson, 2003; Knussen & Sloper, 1992), it is likely that single-parent mothers of children with disabilities will be more susceptible to stress created by financial burdens. Although in Canada, where there is universal access to a medical system that provides some degree of therapeutic resources and services, there continue to be additional costs for children with disabilities, particularly children with behavioural challenges. Parents with children with these types of difficulties are less likely to utilize family members for child care, and thus rely on the formal system that requires at times, a substantial outlay of personal financial resources (Brandon, 2002). Therefore, although two-parent families may experience some degree of financial hardship, the financial impact upon a single-parent mother can be devastating.

A second example of differential impact is in regards to transportation. Single parent mothers have reported assistance with transportation as a significant need that is reported less frequently by two-parent families (Cigno & Burke, 1997; Knussen & Sloper, 1992). This makes sense as single mothers typically do not have the financial resources for car ownership, and utilize public transportation to a much greater degree. The use of public transportation with non-disabled children may be inconvenient, cumbersome, and test the patience of many parents. However, the interaction of children with disabilities (particularly if there are mobility or behavioural issues) and public transportation can become a much more difficult undertaking for single mothers.

Ongoing Family Strains

Multiple roles. The principal structural difference between single-parent and two-parent families is that single-parents are primarily responsible to fill the majority of the expressive and instrumental roles within the family, which frequently results in role/task overload (Hill, 1986; Richards & Schmiede, 1993; Weinraub & Wolf, 1983). The combination of work and family demands on single-parents is a critical issue in family research (Heath & Orthner, 1999). Single parents by definition retain the majority of responsibilities for family income and parenting, and may not have immediate access to another adult who can provide support when the competing demands of work and parenting converge.

Research has supported the fact that child care, domestic and household work have remained primary responsibilities of women, with little paternal support, regardless of child disability status or maternal labour force participation (Boyd, 2002; Bristol, Gallagher, & Schopler, 1988; Cuskelly, Pulman, & Hayes, 1998; Marcenko & Meyers, 1991). In many single-parent families these responsibilities may be experienced as a strain, however, single mothers of children with disabilities experience significantly higher overloads due to increased caregiving responsibilities, to the point that it becomes “all-consuming” (Read, 2000, p. 71). Increased caregiving responsibilities result in the additional role demands of service broker, advocate, nurse, therapist, and/or teacher. Meeting all the required commitments is a source of ongoing stress as mothers spend less time with non-disabled children, less time in leisure activities, and miss greater amounts

of time from paid work than married mothers (Grant & Whittell, 2000; Marcenko & Meyers, 1991; Schilling, Kirkham, Snow, & Schinke, 1986).

Father involvement. Spousal support is noted to be an important coping resource within two-parent families (Beresford, 1994; Bristol, 1987b; Boyd, 2002; Knussen & Sloper, 1992). A widely held assumption is that paternal absence from the home is equated with non-involvement with the child, along with its corollary that paternal presence will result in a sharing of parenting responsibilities (Bristol, 1987a). Although it would be encouraging to provide information that refutes the first half of this assumption, the evidence from the literature indicates that for both single and married mothers of children with disabilities, there is a context of father absence. In one study that specifically addressed single mothers of learning disabled children, none of the fathers provided social or emotional support to the child or the mother, although some did provide financial support (Cigno & Burke, 1997). This appears to be representative for the majority of single mothers, as from the limited evidence available, it is only in a minority of families (approximately 12%) that when the parents do not reside together, father involvement with the disabled child continues (Simmerman, Blacher, & Baker, 2001). Moreover, their involvement is predominantly through the provision of practical and instrumental support that includes participation in teaching/therapy sessions, driving the child to appointments or providing financial assistance to the mother and child.

Relationship with service providers. Difficulties associated with negotiating the service system are an ongoing source of stress in two-parent families (Floyd & Gallagher, 1997; Stainton & Besser, 1998), and can be exacerbated for single mothers in the absence

of a supportive partner. Redmond and Richardson (2003) explored how mothers perceived the service system in terms of the usefulness of the financial, practical, and emotional supports provided. Results indicated that as opposed to the demands of their disabled children, maternal stress was a function of the inadequate, uncoordinated, and inaccessible service system. Conversely, mothers who perceived that they had a positive family-centred relationship with service providers reported higher levels of psychological well-being and family functioning (Van Riper, 1999). How relationships with service providers affect single mothers is not currently known, and there is some indication that service providers have less involvement with single mothers than with mothers in two-parent families (Floyd & Gallagher, 1997). Reasons for this discrepancy are not known, and it is important to assess whether this is a function of differential need, or inadequate responses by the service system.

In summary, stressors associated with single-parent mothers include poverty, multiple roles, minimal paternal involvement and limited or strained relationships with service providers. However, what is less well known is how single mothers perceive the impact of these demands on their experiences of parenting children with disabilities.

Family Capabilities

Patterson (2002) defined family capabilities as the tangible and psycho-social resources that are available to the family when demands threaten to outweigh existing coping resources. Family capabilities may emerge from individual family members, from the family as a unit or from the community and environment. Maternal educational level, family cohesion and available and appropriate therapeutic services are examples of

capabilities at each level. Family capabilities include resources and coping behaviours. Family resources generally refer to a range of attributes, skills, abilities, and material assets that contribute to a family's sense of well-being when it is threatened by family demands. Coping strategies and behaviours generally refer to the categories of emotion-focused and problem-focused coping styles.

Resources that have been identified as protective for mothers of children with disabilities include socioeconomic and material resources, consisting of maternal employment; personality variables such as maternal self-efficacy, problem-solving ability, and a strong sense of coherence; family functioning factors specifically communication, flexibility and cohesion; and perceived formal and informal social support (Bright & Hayward, 1997; Cameron & Armstrong-Stassen, 1991; Gottlieb, 1998; Knussen & Sloper, 1992; Olsson & Hwang, 2002; Saloviita, Italinna, & Leinonen, 2003; Van Riper, 1999).

Socioeconomic and Material Resources

Maternal employment. Maternal employment has been examined in terms of labour force participation rates and the impact upon maternal and family adjustment. There is however conflicting evidence regarding these variables. Several studies have suggested that mothers of children with disabilities under the age of three enter the paid labour force at approximately the same rate as mothers in the general population, however, the majority are employed part-time hours or do shift work (Landis, 1992; Roeher Institute, 2000). Other studies have indicated that single mothers with school-aged disabled children are more likely than married mothers to be employed outside the

home (Porterfield, 2002). Other studies report the opposite; specifically, that childhood disability status is negatively correlated with the employment status of mothers (Brandon, 2000; Breslau, Salkever, & Staruch, 1982; Cuskelly et al., 1998; Nelson, A., 2002; Porterfield, 2002; Powers, 2003). Given that single mothers as a group are, somewhat incongruously, more likely to be employed and at the same time are at the highest risk of living in poverty, it does not appear that participation in the paid labour force is sufficient to elevate the family out of poverty level incomes.

A second area of research interest focuses upon analysis of the interaction between maternal employment and positive maternal adaptation. Although mothers with children with disabilities are less likely to be employed in the paid workforce, it appears that those who are able to participate on either a full- or part-time basis benefit from the opportunity, suggesting that maternal employment outside the home is a useful coping resource. Labour force participation has been associated with lower levels of maternal depression and greater satisfaction with maternal role functioning (Bradshaw & Lawton, 1978; Cuskelly et al., 1998; Knussen & Sloper, 1992; Shearn & Todd, 2000). These findings are supported by studies that conclude that fathers, whose employment status was less affected by the presence of a child with a disability, report less stress as a direct result of having a child with a disability compared to mothers (Gray, 2003). Gender analysis of parents' depression scores with employment status indicates some support for the idea that labour force participation functions as a moderating variable and is positively associated with both paternal and maternal adaptation throughout the life course (Olsson & Hwang, 2001; Seltzer et al, 2001; Sloper, 1999).

Employment status is also related to single mothers' psychological well-being through the addition of a second role, other than mothering. In contrast to findings that indicate role/task overload can result in poor maternal coping, single mothers who hold multiple roles of both parent and employee experienced significantly less depression and fewer health problems in comparison to mothers who were not in the workforce (Gottlieb, 1997). Therefore, although the functional benefits of labour force participation for single mothers do not necessarily include a substantial increase in financial resources, it may provide respite from daily caregiving responsibilities, additional social support and creates a context that invites exploration of multiple identities other than mother. Conversely, this may reflect the "healthy worker effect" that results in physically and mentally healthier women moving into the paid labour force, while less healthy women remain at home (Jennings, Mazaik, & McKinlay, 1984, p. 422).

Maternal employment is also associated with improved child outcomes. In an examination of the effects of maternal employment and pre-mature birth on child outcomes in single-mother families, increased hours of maternal employment were related to improved child outcomes in cognition and achievement (Youngblut et al., 2001). In keeping with previous findings that indicated maternal employment does not have an independent effect (Youngblut, Singer, Madigan, Swegart, & Rodgers, 1997), the authors suggested that improved child-related outcomes may not be due to employment itself, but to increased financial resources and a greater sense of maternal well-being associated with employment.

Personality variables. Perceived self-efficacy refers to judgments about one's mastery over difficult circumstances, including the ability to perform competently at a task or situation. Research has indicated that mothers of children with disabilities who perceive themselves to be effective problem solvers reported less parenting stress compared to mothers who did not consider themselves to be effective problem solvers (Noojin & Wallander, 1997). Additionally, single, non-working mothers reported less confidence in problem-solving ability compared to other family structures, and single mothers of children with behaviour problems reported less parenting competency (Jackson & Huang, 2000; Heath & Orthner, 1999).

Self-efficacy is related to Antonovsky's (1979) construct of the sense of coherence (SOC) that is described as a stable dispositional orientation that enhances health and mitigates stress. The SOC is defined as:

A global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence that one's internal and external environments are predictable and that there is a high probability that things will work out as well as can reasonably be expected. (p. 132)

The SOC has three components: (a) comprehensibility refers to the sense that events are predictable and structured, (b) manageability refers to the sense that the available resources are adequate to deal with the demands of the event, and (c) meaningfulness refers to the sense that demands have significance and are worthy of emotional investment (Antonovsky, 1987). It is important to conceptualize the SOC as a transactional construct. A strong SOC enables an individual to combat stressors thereby

strengthening the SOC through positive reinforcement. An individual with a weak SOC may be less likely to mobilize adequate resources, culminating in health breakdown (Antonovsky, 1979). The SOC thus becomes a lens through which individuals perceive and assign meaning to their experiences.

Olsson and Hwang (2002) investigated whether the SOC could facilitate understanding of individual differences in parents of children with disabilities. Results indicated that mothers generally exhibited lower SOC than fathers, and parents of children with disabilities exhibited higher rates of depression than a control group of parents with non-disabled children. The authors concluded that parenting a child with a disability will increase the risk of experiencing threats to the central concepts of SOC.

The SOC has also been used to explore the relationship between stress, coping, resources, and adaptation of single-parent mothers of children with disabilities (Gottlieb, 1998). Mothers with a strong SOC had higher levels of education and incomes, better psychological and physical well-being, experienced relatively fewer stressful life events, and were less likely to have a child with behaviour problems. Additionally, a positive association was noted between the SOC and the frequency and variety of coping strategies utilized by single mothers.

Family functioning factors. Although research with families of children with disabilities has typically compared levels of stress and family functioning to those of families with non-disabled children, research is currently focusing on patterns of family adaptation, examining how aspects of the child, family and social ecology interact to

influence family functioning, independent of disability status (Reddon, McDonald, & Kysela, 1992).

The concept of family environment as a resource describes two dimensions of family functioning; (1) family cohesion, defined as the emotional bonding that family members have toward one another, and (2) family flexibility, defined as the amount of potential change in leadership, role relationships, and relationship rules (Patterson, 2002; Walsh, 2003). Levels of cohesion and flexibility may range from rigid and inflexible, to chaotic and overly flexible. Several studies that examined family cohesion suggest it is a significant predictor of satisfaction and adjustment (Reddon et al., 1992; Sloper, Knussen, Turner, & Cunningham, 1991; Smith et al. 2001). However, an earlier study concluded that family cohesion was predictive of negative family adaptation (Bristol, 1987a). Additionally, in a study of parental adaptation with developmentally delayed adult children, including 21% single-parents, family cohesion was not significant (Lustig & Akey, 1999). These results suggest that family cohesion may be less significant for parental adaptation, but it remains unclear whether this is true for both single and dual parent families, and whether it has greater importance at different points throughout the lifespan.

Family functioning in single-parent families is typically investigated with a view toward identifying the problems. Although single-parents report that one benefit of lone parenting is increased emotional closeness with their children, in contrast to being interpreted as demonstrating family cohesion, these relationships can risk being labeled as enmeshed and consequently are constructed as problematic (Anderson, 2003). Single

parent families have also reported positive outcomes for their children including higher levels of autonomy, increased independence and a willingness to assume greater responsibility for household tasks (Richards & Schmiege, 1993). These dynamics demonstrate family flexibility, yet for single-parent families, can frequently result in allegations of inadequate parenting, or labels of parentified or spousal children, referring to children being elevated to parental or spousal roles within the family. McCubbin (1989) investigated family stress and strengths in a comparative sample of single and two-parent families. Although findings indicated that single-parent mothers had lower levels of maternal coping, single-parent families demonstrated higher levels of family adaptability and flexibility.

Moreover, the applicability of how family functioning variables are assessed with single-parent families is questionable, as many measures of family assessment identify the couple as the primary unit of analysis, and consequently, are not valid for single-parent families. In one of the earliest studies that compared single and married parents of children with disabilities, researchers utilized an amended version of the Feetham Family Functioning Survey that eliminated items related to marital status. Results indicated that total scores did not differ for the married and single-parents, suggesting that single and married parents have similar levels of family functioning (Schilling et al., 1986). The implications of these results for this study are that it is important to assess family functioning independent of marital status.

Social support. Social support is a multidimensional construct that has been extensively studied within the research literature. However, there is minimal agreement

regarding its theoretical and operational definitions, resulting in confusion and multiple methods of measurement (Cooke, Rossmann, McCubbin, & Patterson, 1988; Hupcey, 1998). Lazarus and Folkman (1984) distinguish between the distal variable of the number of relationships an individual has, defined as one's social network, and the proximal variable of the perception of the value of social interactions, defined as social support. Tracy and Whittaker (1990) developed a social network map to assess the structure and quantity of an individual's interconnected relationships that provided nurturance and reinforcement for coping with life on a daily basis. Social support was differentiated from the social network on the basis of structural measures that documented the existence of relationships, and functional measures that assessed the various types of supportive exchanges.

The importance of perception was emphasized by Procidano and Heller (1983, p. 2) who defined social support as "the extent to which an individual believes that his/her needs for support, information and feedback are fulfilled by friends and by family" and suggested it was the perception of availability of social support that was the key factor that mediated stress. Social support also refers to a broad range of resources including physical and instrumental assistance, material aid, information sharing, positive social interaction, and emotional and psychological support (Barrera & Ainlay, 1983). Hupcey (1998, p. 1232) identified two other categories of social support discussed within the literature. These dynamics may be conceptualized as relational in that they refer to the intentions or behaviours of the providers of support, defined as "the exchange of resources between two individuals perceived by the provider or the recipient to be

intended to enhance the well-being of the recipient”, and the degree of reciprocity, or the actual giving, receiving and exchange of support, between the recipient and provider.

The presence or absence of social support is an important predictor of parental adaptation to childhood disability, and is categorized in terms of formal or informal networks and relationships, both of which constitute sources of support for meeting families’ needs (Dunst, 1985; Dunst, Trivette, Gordon & Pletcher, 1989, Dunst & Trivette, 1990; Dunst, Trivette & Hamby, 1994). Informal social support refers to the intangible and material aid provided by friends, family members and others who function outside of the professional and bureaucratic arenas (Uehara, 1990). In contrast, formal support systems typically refer to professionally-staffed agencies that provide medical and other health-related services, information regarding eligibility criteria, accessibility and referral procedures for disability-specific services, and clinical or remedial interventions in response to identified needs of the child and/or parent. Generally, satisfaction with social support is positively associated with maternal well-being (Seybold, Fritz, & MacPhee, 1987).

Formal social support. The early intervention system functions as one of the primary mechanisms for the provision of family and parental support in the field of childhood disability. Early intervention programs refer to a broad range of services for parents and children including physical, occupational and speech therapies, respite programs, specialized day care services and information/education regarding child development. Generally, early intervention services are designed to benefit both children and parents by specifically assisting children to obtain positive developmental outcomes,

preventing secondary handicapping conditions and providing support to families.

Parental participation in early intervention programs may therefore be conceptualized as either a resource that mediates stress or as an outcome variable as an indicator of parental adaptation. The relationship between single mothers and service delivery systems is particularly salient as there is some evidence to suggest that early intervention programs serve a disproportionate number of children from single-parent families (Mahoney & O'Sullivan, 1992; Trivette & Dunst, 1992; Unger, Jones, Park & Tressell, 2001).

Unger et al. (2001) investigated why some low-income single caregivers have greater involvement with early intervention services compared to other single mothers. This study was based on an ecological and developmental framework of parenting that examined factors of parental perceptions, family needs, family functioning and parental stress and families' involvement with early intervention programs. It utilized the transactional model of stress and coping in terms of examining how coping behaviours (defined as parental participation) were moderated by caregiver beliefs (cognitive appraisal). Results of this study indicated that the child-related factors were not significantly related to program involvement. Level of caregiver stress, the cognitive appraisal of a program as helpful, and parental perception of staff support moderated the relationship between the caregiver and the program, suggesting that appraisal is an important factor contributing to parental involvement. Therefore, perception of both the need and the quality of the resource can affect the usefulness of a particular service to single mothers. Moreover, when single-parents have access to family support programs, outcome results suggest that single-parents perceived greater benefit and less stress as a

result of these programs (Brown & Bhavnagri, 1996; Hendrickson, et al., 2000; Honig & Winger, 1995; Upshur, 1994).

A second mechanism of formal social support is delivered through parent education and/or support programs. In one study of the long-term impact of a skills training program for mothers of disabled children, single mothers in the skill-building group showed greater role satisfaction than did single mothers in the comparison group or married mothers in both intervention and control groups. Additionally, at the two year follow-up, single mothers in the skill training group demonstrated improved satisfaction with their parenting roles and their relationships with professionals (Kirkham, 1993). Shank and Turnbull (1993) described the development of an intervention program for single parents that focused on developing skills in family problem-solving. Results of the evaluation indicate that parents successfully integrated the information within their own families, and developed an informal social support group that continued after the formal program was completed.

Informal social support. Social support may also be accessed through families' informal social networks that include friends, extended family members, neighbours and other parents of children with disabilities. Family members are generally recognized as the primary source of emotional, practical and social support. For parents of children with disabilities, grandparents are recognized as important sources of informal social support, yet are frequently ignored by social workers as potential resources in terms of professional activities (Findler, 2000; Findler & Taubman, 2003; Leyser & Dekel, 1991). Additionally, the type of support provided has differential impact on family adaptation.

Parents and professionals report that emotional support (providing empathy, caring, love, trust and listening) is significantly more important to parental psychological adjustment than instrumental support (providing advice, suggestions, directives, and information), yet it is the latter form of support that is most frequently provided by grandparents (Findler & Taubman, 2003; Trute, 2003). Hastings (1997) undertook a review of research on the relationship between grandparents as sources of support and adaptation in families with children with disabilities. Results of this review suggested that grandparents may function as important sources of support, but they may also constitute an additional burden because of (a) their grief reactions to the birth of disabled grandchildren or (b) diametrically different perceptions of the needs and abilities of their grandchildren. Therefore, although grandparents may be in a position to provide support to their adult children, this may be accompanied by emotional costs to the parents.

Married or partnered mothers perceive significantly greater support from their husbands' parents than single women perceive from their children's fathers and paternal grandparents (Trivette & Dunst, 1992; Marcenko & Meyers, 1991). This indicates that (a) non-custodial father involvement with children with disabilities remains limited and (b) paternal grandparent support does not necessarily continue in the event of relationship dissolution. However, this does not appear to differ significantly from two-parent families, as maternal grandparents generally provide significantly greater support than paternal grandparents (Trute, 2003).

Parent to parent linkages and connections are also an important source of informal social support for parents of children with disabilities. Parent support generally refers to

the emotional and social support offered by parents to other parents of children with disabilities. Generally, research has indicated that this type of connection is the most effective method for providing support, developing and enhancing parental coping skills, engaging in active problem-solving, and assisting in a process of identity change, specifically moving from feeling helpless and uninformed to empowered and knowledgeable (Gitterman, 1989; Roberts, Rule & Innocenti, 1998; Shapiro, 1989; Sloper, 1999; Soloman, Pistrang, & Barker, 2001).

Although there are noted benefits to parent to parent support, it is less available to single mothers who generally report smaller social networks and consequently receive less instrumental and social support (Barton, Roman, Fitzgerald, & McKinney, 2002; Weinraub & Wolf, 1983). In one study that examined the impact of parent to parent support, 13 out of the 63 mothers were single-parents. Results suggested that the desired level of both practical and emotional support was not available to these families (Kerr & McIntosh, 2000). However, when available, there is evidence to support the benefit of these relationships. In one study that specifically addressed the needs of single mothers of premature infants, mothers with larger informal social support networks were more likely to demonstrate greater parenting knowledge and use of formal parenting services (Barton et al., 2002).

Both instrumental and emotional support is important for mothers. Jones (1991) found that resource balance between instrumental and emotional support is positively correlated with adjustment to the maternal role. Having a greater quantity of instrumental support does not positively affect role adjustment unless there is also some parity with

emotional support. In addition, the balance in reciprocity is an especially important consideration for single mothers. Nelson (2000) reported that single mothers strongly adhere to the norm of balanced reciprocity in terms of instrumental and emotional support, and Tietjen (1985) reported that single mothers, more so than married mothers, maintained a balance of giving and taking in their relationships.

Family Level Meanings

The meaning factor is emerging as a salient predictor variable in understanding how families adjust and adapt to children with disabilities. The FAAR model suggests that families implicitly construct meanings about (a) specific stressful situations, (b) their identity as a family, and (c) their view of the world (Patterson, 2002, p. 243).

Situational meanings. In the FAAR model, the construct of family meaning extends beyond the primary and secondary appraisal processes to reflect both situational and global meanings. Situational meanings are created when family members discuss the stressful event and assess their access to resources to deal with the event. The construction of shared meanings therefore becomes part of the adaptation process. They are conceptually similar to primary and secondary appraisal processes as they relate to the specific stressor event and are undertaken by the family unit. Within childhood disability, situational meanings reflect parents' abilities to integrate an understanding of their children's disabilities, ensure that they receive sufficient and appropriate information and develop a plan to meet the needs of their children. High coping parents succeed in creating a shared understanding of the disability, and adopt a realistic and optimistic attitude towards their own and their children's lives (Taanila et al., 2002).

In the process of integrating the meaning of the disability for the family situation, how the disability is understood is important for adaptation. The effectiveness of resources available for stress reduction in families with children with disabilities is dependent upon how the family members define and interpret the child's needs, level of functioning and the meaning ascribed to the disability itself (Orr, Cameron, & Day, 1991). Defining the situation as a catastrophe, believing that the child's disability is one of the worst possible things that could occur to the family, and constructing the child as a burden is significantly related to parental stress (Bristol, 1987a; Saloviita et al., 2003). Conversely, positive perceptions of children with disabilities construct a more positive meaning and assist the family in coping (Hastings & Taunt, 2002; Stainton & Besser, 1998). Tunali and Power (2002) concluded coping is facilitated when families are able to interpret and conceptualize disability in a positive manner, exhibit increased tolerance for difference, and cognitively redefine or reframe events in a positive manner. Lustig and Akey (1999) further underscored the centrality of appraisal, as it facilitates family adaptation through believing that (a) dealing with the stressor is worthwhile, (b) attempts to solve disability-related problems are worth the effort, and (c) the disability is a challenge rather than a burden.

Global meanings. Global meanings transcend specific situations and comprise a more stable set of cognitive beliefs about the relationships between and amongst family members, and the relationship of the family unit to the community (Patterson & Garwick, 1998). Global meanings refer to the family's worldview wherein the focus is on how the family interprets reality predicated upon their core assumptions and existential beliefs.

The family's worldview can be instrumental in influencing family functioning and is often grounded within cultural and/or religious beliefs. King et al. (2006) explored changes in the world views, values and priorities of parents of children with autism or Down syndrome. Parents described their changes as (a) developing broader world views, (b) seeing the positive contributions of their child in terms of personal growth and in learning what is important in life, and (c) seeing strengths rather than deficits.

Family identity. A second level of meaning in the FAAR model refers to the family identity, or how a family defines itself in terms of the family structure, roles, rules, relational factors, and functioning. Within this schema, appraisal of childhood disability may alter structural and/or functional aspects of the family. For example, Nelson (2002) described how becoming the mother of a disabled child resulted in a changed identity that required mothers to negotiate a new kind of mothering that was substantially different from their idealized or constructed experiences. Families also differ in their willingness to allow individuals from outside the family to provide assistance and in their relationships with service providers. Studies of the relationship between culture, caregiving experiences and adaptation suggest that lack of appropriate information, workers' use of professional jargon, non-culturally appropriate service providers, and being patronized by the workers, are related to less adaptive outcomes for families (Lam & Mackenzie, 2002; McCallion, Janicki, & Grant-Griffin, 1997; Zhang & Bennet, 2001).

For single-parent families, the construction of family identity is located at both personal and sociopolitical levels. Paradigms of healthy family functioning have historically been constructed upon the model of the two-parent, heterosexual,

monogamous couple with able-bodied children. Within this paradigm, gay and lesbian families, single-parent families, and multi-generational families residing together are consequently assessed as less healthy or less functional (Visher, 1994). Single mother families in particular, by definition, are unable to conform to societal expectations of holding on to a partner and maintaining a nuclear family unit (Anderson, 2003). The extent to which single mothers internalize these cultural ideals will influence their perception of family identity. Mothers who are able to expunge these socially constructed beliefs and develop alternative definitions of family for themselves and their children may be more likely to exhibit positive coping and adaptation.

Family Adaptation

In the double ABC-X model (Patterson & McCubbin, 1983), the Typology Model of Family Adjustment and Adaptation (McCubbin & McCubbin, 1989), the Resiliency Model (McCubbin & McCubbin, 1991) and the FAAR model (Patterson, 2002), adjustment and adaptation are conceptualized as a measure or outcome of how well a family is coping with the individual and collective needs of family members in responding to family demands, stressors, and daily hassles (Bowen, Orthner, & Bell, 1997; McCubbin & McCubbin, 1993; McDonald et al. 1999; Patterson; 2002). Family adjustment and adaptation are a function of both internal coping strategies and external resources, and may be conceptualized as processes, referring to the family's efforts to establish a good fit between itself and the environment, or as outcomes, referring to the results of these efforts.

McCubbin and McCubbin (1991) and Patterson (2002) defined the adjustment phase as the attempts by the family to maintain regular family functioning. Family adjustment is therefore conceptually similar to Minuchin's (1974) concept of first-order change defined as change within a family system wherein the rules and functioning of the system do not change. Patterson (2002) defined family adaptation as the process of restoring balance between capabilities and demands at two levels of transaction: (a) between family members and the family unit and (b) between the family unit and the community. Family adaptation is conceptually similar to Minuchin's concept of second-order change that is defined as change in the system itself. This highlights that in order to be considered adaptation, as opposed to adjustment, the outcome of interest needs to occur at the family system level, be representative of family relationships, and demonstrate how families organize their daily routines differently in order to enhance child development and reduce stress. When the family is successful in this process, the family is able to continue to promote the development of individual family members and maintain the family unit in order to accomplish the life cycle tasks. Positive family-level outcomes have been identified as family system maintenance, good family co-operation, an ability to utilize social support, open emotional expression, the capacity of the family to feel confident and competent, and maintaining a sense of control (Judge, 1998; Margalit, Raviv, & Ankonina, 1992; Pelchat & Lefebvre, 2004; Taanila, et al., 2002).

Although none of these models of family adaptation specifically exclude single mothers from analysis, they are typically predicated on the assumption of a two-parent family structure, and identify spousal relationships as a salient factor in adaptation. For

example in the FAAR model, Patterson (2002) suggests that marital commitment and satisfaction is a positive family level outcome, with the corollary of divorce considered a negative outcome. In order for models of family adaptation to be relevant for single mothers, the definition of family needs to extend beyond nuclear family relationships to include extended family members (parents and siblings) in addition to acknowledging the potential contributions of non-spousal or non co-habiting partner relationships. Indications of positive family adaptation including family care for children with special needs, family love and support and securely attached children are all possible in the absence of a marital relationship. Although Lavee, McCubbin, and Patterson (1985) emphasized that adaptation should not be considered a defined construct with an operationalized set of measures, some indicators of positive single-parent family adaptation include good parenting skills, ability to problem solve and make decisions, ability to utilize available resources, and personal evaluations of satisfaction and success within work and family roles (Heath & Orthner, 1999; McDonald et al., 1999).

Family Resilience Theory

Building upon the concept of family adaptation, family-centred research within the social sciences is gradually moving from a deficit-based perspective toward a resilience model that seeks to identify specific factors and interactional processes that contribute to families “doing well” in spite of negative circumstances. This shift is particularly relevant for childhood disability research as historical emphases on stress and dysfunction have been successfully challenged by research findings that demonstrate that many families make a positive adaptation to having a child with a disability (Bennet &

DeLuca, 1996; Yau & Li-Tsang, 1999). Building on findings of family strength, contemporary research questions are moving beyond models of positive family adaptation, and exploring the phenomenon of how resilience is manifest in families with children with disabilities: how it is defined, how it is expressed, in addition to the factors and processes that contribute to resilient family systems.

Definition of Resilience

The construct of resilience, from the Latin *resilire*, “leap back” is derived from two bodies of literature: the physiological aspects of stress and the psychological aspects of coping (Tusaie & Dyer, 2004, p. 5). The introduction of resilience within the discipline of developmental psychopathology initially referred to children who exhibited positive developmental outcomes in spite of adverse and negative circumstances (Howard & Dryden, 1999; Waller, 2001). One of two major concepts in the resilience model is risk, originally developed within the epidemiology literature to refer to “any influence that increases the probability of onset, digression to a more serious state, or maintenance of a problem condition” (Kirby & Fraser, 1997, p. 23). The construct of risk is assessed through risk factors which are characteristics that are associated with a high probability of undesirable outcomes, difficulties and problems for individuals and groups. Risk factors or exposure can also be assessed within an ecological framework, identifying factors at the individual, family, community and social/cultural levels. Individual risk factors can include demographic variables, including age, sex, and ethnicity or genetic/biological factors including the presence of disabling conditions; family-level factors may include parental conflict, marital violence or mental health disorders;

community factors can include inadequate educational opportunities or chronic poverty; and social or cultural factors can include discrimination based on gender, class, race, sexual orientation or ability.

However, not all individuals who are exposed to risk exhibit negative outcomes. Rutter (1985, p. 600) found that “even with the most severe stresses and the most glaring adversities, it is unusual for more than half of children to succumb.” This introduced the second major concept in the resilience literature, specifically the recognition of protective factors. These are defined as individual or environmental characteristics that enhance one’s ability to resist stressful events, and promote adaptation and competence (Garmezy & Rutter, 1983). Protective factors are similarly situated within an ecological framework, and may be internal, including personality types, or external, such as a supportive family environment, strong social support and social and economic resources. Taken together, two key components of resilience are (a) the individual demonstrates a positive response to an adverse situation and (b) the individual emerges feeling “strengthened, more resourceful, and developmentally advanced” (Simon, Murphy, & Smith, 2005, p. 427).

Family Resilience

There are emerging theoretical and practice models of family resilience that extrapolate ideas from theories of individual resilience, ecological theory, systems theory, and family stress and locate them within the context of family systems (Hawley & De Haan, 1996; McCubbin, 1989; McCubbin & McCubbin, 1993; Patterson, 2002; Shapiro, 2002; Simon, Murphy & Smith, 2005; Walsh, 1998, 2002, 2003). As with theories of individual resilience, family resilience has not been exempt from the debate of whether it

is a construct that is best defined as a property, process, or outcome. Some models of family resilience developed from a crisis framework to understand how families specifically overcome crises and adapt to stress, with the view toward returning to previous levels of functioning. In this context, family resilience was defined as the characteristics, dimensions, and properties that help families to be resistant to disruption in the face of change and adaptive in the face of crisis situations (Boss, 1987; McCubbin & McCubbin, 1993; Cohen, Slonim, Finzi, & Leichtertritt, 2002).

Other models of family resilience define it as a process ranging from (a) being synonymous with functional patterns of family interaction (Heiman, 2002), (b) demonstrating family competencies in managing problematic situations (Costigan, Floyd, Harter, & McClintock, 1997), (c) “an enduring force” (Lee et al., 2004, p. 644), (d) avoiding family breakdown (Owen, Gordon, Frederico, & Cooper, 2003), and (e) the recognition of the family as knowledgeable and in possession of the necessary expertise to solve their own problems (Singer & Powers, 1993).

The underlying premise is that all family members are influenced through exposure to negative circumstances. However, in contrast to theories of individual resilience, family exposure to significant non-normative stressors is not viewed as a necessary precondition. The inclusions of developmental and family life cycle perspectives in family resilience theories suggest that all families will experience disruption, challenge, or difficulty at some point. How each family manages these events will vary depending upon their resources, capabilities, and additional stressors. Moreover, the location of the family within an ecological framework recognizes that

stress may also be a function of the family's relationship to the environment.

Experiences of poverty, racism, and social isolation will increase the risk for families, and can negatively impact family functioning. As Walsh (2003) notes, a basic premise in a systemic view of family is the idea that stressful crises, developmental transitions and persistent challenges affect the entire family and key family processes mediate the recovery of all family members. Therefore, the salient factor in the shift toward a family level understanding of resilience is the contribution of family relational processes and exploration of how these affect the family over time (Hawley & De Haan, 1996).

Building on this, Walsh (1998) developed a conceptual framework of family resilience that is useful to understand how families cope and adapt through transitions, crises and adversity. This framework consists of key processes in three domains of family functioning (a) family belief systems, (b) family organizational patterns, and (c) family communication processes. According to Walsh, family belief systems "broadly encompass values, conviction, attitudes, biases, and assumptions which coalesce to form a set of premises that trigger emotional responses, inform decision-making and guide actions" (p. 45). Family organizational elements include flexibility, emotional connectedness, and access to social and economic resources. Communication skills include clarity, capacity for emotional expression, and collaborative problem solving. An advantage of the family resilience framework is that it recognizes the diversity of family structures, and thus acknowledges that the same stressor may lead to different outcomes, depending upon the family.

The key advantage to incorporating a family resilience perspective (Walsh, 1998) is that it acknowledges that all families have something valuable to contribute within their individual contexts. The family resilience framework has been successfully utilized in examining parental contributions to children's academic success (Amatea, Smith-Adcock, & Villares, 2006), and in clinical practice with high-risk substance affected families (Sandau-Becklar, Devall, & de la Rosa, 2002). Although how each of the family processes is represented within individual families/situations will vary, a resilience framework provides a conceptual map to guide researchers to explore the resilience of families and their abilities to work toward positive outcomes.

Family Resilience Theory and Childhood Disability

The shift toward identifying family resilience in childhood disability may be traced to the identification of family strengths. Within the childhood disability literature, family strengths are defined as the competencies and capabilities of various individual members and the family unit that are used in response to crises and stress, to meet needs, and to promote, enhance, and strengthen the functioning of the family system (Dunst et al., 1988).

Several studies have explored the qualities of families who were identified on the basis of having been assessed as exemplary with respect to their coping strategies and positive adaptation. Trute and Hauch (1988) were amongst the first to note that key family processes including marital adjustment and the use of social support resources were indicative of strong, well-organized family units. Within this study, families with children with disabilities utilized similar strategies to those used by strong families who

were not parenting children with disabilities, suggesting that family functioning variables were indicative of how well parents cope. Snell and Rosen (1997), in their study of parents identified as having positively adapted to their children's disabilities, concluded that cognitive coping, a high level of family congruence, and skill in managing outside resources were indicative of family resilience. Within the context of a phenomenological framework, Gardner and Harmon (2002) explored maternal resilience in families with children with intellectual disabilities. The research participants consisted of six mothers who were in long-term relationships with their partners, and who had been identified by service providers as "exemplary" in their adaptation. The identified themes of resilience for these women included seeing life positively from an early age, recognition of their own strengths, the ability to be organized, problem-solving and decision-making abilities, realistic beliefs about their own limitations and relying upon their partners and outside resources for support.

Similar findings have been reported in other studies that examined factors related to family strengths. Self-esteem, seeking social support, active problem-solving, positive communication skills, and maintaining a positive outlook on life were identified as the key coping strategies that are significant predictors of family strengths, positive coping, and improved child outcomes (Heiman, 2002; Judge, 1998; McCubbin & Huang, 1989).

Longitudinal Analysis

As with all research on families with children with disabilities, it is important to consider the temporal element and how stress, coping, adjustment, and adaptation evolve throughout the family life cycle. For example, much of the literature on family stress and

childhood disability is often undertaken at a point that is relatively close to diagnosis, when children are young. Results suggest high levels of family stress at this time may be a function of “novelty shock” and disbelief (Wolfensberger, 1983), the manner in which diagnostic results were shared by professionals, insufficient or poorly explained information, or an inadequate response by the service system (Taanila et al., 2002). Lazarus and Folkman (1984) also identified the importance of timing in the life cycle. How one appraises a stressor will be influenced by whether it is perceived to have occurred within a normative time frame.

Support for the need for longitudinal analyses is found in several studies. Glidden and Schoolcraft (2003) concluded that the long-term prognosis for adjustment to raising children with disabilities is primarily positive, although multiple measures are necessary in order to accurately portray the complexity of family adaptation over time. Seltzer et al. (2001) conducted a longitudinal, comparative analysis of family functioning and concluded that parents of children with disabilities exhibited similar levels of psychological well-being compared to parents who did not have children with disabilities. Additionally, a longitudinal study of parental adaptation determined that stress related to non-disabled siblings was noted to have greater predictive value than stress attributed to family members with disabilities (Baxter, Cummins, & Yiolitis, 2000).

Therefore, it is important to include longitudinal perspectives in terms of understanding single-parents' abilities to adapt to childhood disability. A majority of single-parent families of non-disabled children indicate that single-parenting becomes easier over time, largely because of increased organizational abilities, coping skills,

flexibility, and the recognition of the unique characteristics of their families (Richards & Schmiede, 1993). Although this type of longitudinal analysis has not been done with single-parents of children with disabilities, longitudinal perspectives may be needed to reveal positive outcomes.

In view of the importance of examining family resilience over time, Hawley and De Haan (1996, p. 7) provide the following definition:

Family resilience describes the path a family follows as it adapts and prospers in the face of stress, both in the present and over time. Resilient families respond positively to these conditions in unique ways, depending on the context, developmental level, the interactive combination of risk and protective factors, and the family's shared outlook.

In summary, key elements of family resilience have been identified as the recognition of resilience as: (a) dynamic; (b) demonstrated in response to specific stressors; (c) adopting a developmental perspective as factors which may be initially considered protective may place the family at risk in the future; (d) involving responses that are congruent with the particular stressor; and (e) based on the knowledge that every family is unique, and thus, risk and protective factors will vary accordingly (De Haan, Hawley, & Deal, 2002).

Consequently, current studies of family resilience focus less on the identification of individual or environmental traits and place greater emphasis on the interaction between the multitudes of family functioning variables.

Integration of Models

Based on the results of this literature review, the transactional model of stress and coping (Lazarus & Folkman, 1984) and the FAAR model (Patterson, 2002) can be integrated with theories of family resilience (Walsh, 1998) and used to describe the processes by which families are able to adapt and function competently following exposure to significant adversity or crisis. The key contribution of the transactional model of stress and coping is the emphasis on appraisal processes. How an individual perceives the stressor in the context of one's available resources will influence the individual's adaptation. The FAAR model includes the examination of family risk and protective factors, and the shared family worldview in understanding how families can demonstrate resilience through successful adaptation to a range of stressor events. This framework identifies resilience as positive family adaptation within a context of significant adversity. Family resilience theory identifies the key processes which are necessary for families to undertake in order to arrive at a state of adaptation.

There are a number of similarities between theories of family resilience, family stress and the FAAR model that suggest potential for integration. First, each recognizes the family as the unit of analysis. As such they acknowledge the interactional components between individual family members, as well as between the family and the community. Second, each acknowledges that families will be exposed to a variety of normative or non-normative stressors throughout the family life cycle. The family's ability to adapt or emerge strengthened from their experiences will vary as a function of family-based relational processes. These include: (a) family functioning variables of flexibility and

cohesion, (b) family belief systems, or meaning-making processes, (c) the importance of social, economic and environmental contributions to family well-being, and (d) the family's relationship with external systems. Finally, each emphasizes the necessity to understand family adaptation and resilience as a process that occurs over time.

The advantage to utilizing an integration of models is that they each provide guidance as to the specific components that constitute family resilience. Further, they each offer an empowering and respectful approach to understanding family resilience by emphasizing family strengths, abilities and meaning-making systems as the keys to positive adaptation. They represent, therefore, paradigmatic shifts in how single-mother families are conceptualized and the nature of childhood disability.

Summary of Literature Review

In summary, the literature review highlights the following points that are relevant for this study of single-parent mothers of children with disabilities. Resilience research within childhood disability has focused both on identifying the risk and protective factors that are associated with resilient families, in addition to identifying the interactional processes that foster resilience between individuals and family members, and the family and the environment. However, the majority of this research has focused upon parents in two-parent family structures, and thus what is absent from the literature is how these processes occur within single mother family systems, and how single mothers negotiate these processes in order to undertake the job of parenting children with disabilities. In fact, it has been noted that single mothers of children with disabilities are often excluded from studies of resilience, and that much of the research on this population continues to

focus upon pathogenic outcomes (Bristol, 1987a; Gottlieb, 1998). Given that the number of single mother families is increasing, they can no longer be considered an atypical family form. Moreover, there is also evidence to support the position that the number of single mother families with children with disabilities is also increasing (Fujiura & Yamaki, 2000; Lloyd & Rosman, 2005). Models of family service and support that are predicated on the two-parent, father employed, at-home mother family cannot be considered valid with this population. It is therefore important for this study to examine the experiences of single mothers in the context of the current service delivery system to assess whether it is effectively meeting their needs, and to identify potential areas of change.

Secondly, caring for a child with a disability as a single parent is generally considered to be a non-normative stressor which could increase parental stress and result in poor family functioning. This is in addition to stressors related to the social construction of single parent status as failed marriage or motherhood, low socioeconomic status, and role and task overload. Therefore, it is important to determine the characteristics and processes of single-mother families that contribute to children's development and maternal well-being. Notwithstanding these demands, single mother families are also able to demonstrate competence in two areas: relationships and accomplishments. Single mothers report greater cohesiveness, positive parent child relationships and the ability to develop strong networking skills with formal and informal support resources. From the perspective of policy makers and service providers, if there

are specific factors or processes that facilitate the adaptation of single-parent families, then service provision models can undertake the shift toward prioritizing these needs.

In terms of expanding ideas about family resilience, this study will utilize an integrated theoretical model of family stress and coping theory, the FAAR and family resilience frameworks and apply this to the experiences of single mothers of children with disabilities. Are there specific risk factors, belief systems, supports and resources, and relational patterns that single mothers identify as particularly helpful in their processes of adaptation? Understanding the answers to this question will ideally begin to address some of the gaps that currently exist within the research and practice literatures.

CHAPTER THREE

Research Methodology

The process of understanding the experiences of single mothers raising children with disabilities within a resilience framework is complex. This research was guided by three conceptual theories of family functioning; the transactional model of stress and coping (Lazarus & Folkman, 1984) the Family Adjustment and Adaptation Response model (FAAR) and a family resilience framework (Walsh, 1998). The transactional model introduced the concept of appraisal, and highlights the evaluation of whether something is considered stressful, and if so, further evaluation of the availability of coping resources. The FAAR model was developed to describe how family strengths, resources, and meaning-making processes are critical in determining families' responses to normative and non-normative events (McCubbin & Patterson, 1983). A family resilience framework refers to the relational processes that families use to emerge from stressful events and return to previous or enhanced levels of functioning (Walsh, 1998). According to the integration of these models, the essential dimensions of family resilience include (a) non-normative risk exposure (family demands), (b) family protective processes including cohesion, flexibility, emotional expression, and social/economic resources, and (c) family belief systems at situational and global levels that encourage families to create meaning from their situations, and maintain a positive outlook. Taken together, assessment of these dimensions will determine the family's level of adaptation.

Resolution of Ethical Issues

Ethics approval for this study was obtained from the Joint Faculty Research Ethics Board at the University of Manitoba (Appendix A).

Study Context

This study was located within a research project entitled “Family Strengths in Childhood Disability” (Trute, Hiebert-Murphy, & Wright, 1999). This was a three year project, funded by the Social Sciences and Humanities Research Council (SSHRC #828-1999-1037) that incorporated both qualitative and quantitative research methods, and explored families’ experiences with Children’s Special Services, the Manitoba government agency whose mandate is to coordinate the provision of therapeutic and support services for families of children with disabilities. Additional objectives of this project included the identification of factors that facilitated or hindered the implementation of family-centred practice within Children’s Special Services, and establishing norms specific to the Manitoba population on a set of standardized measures. The study had two phases: Time 1 occurred approximately 6 months after families’ entrance into the service system and Time 2 occurred approximately 12 months later (18 months after intake). At each phase, parents were requested to complete a series of standardized measures that assessed parenting stress, family needs, family support, the impact of the child’s disability on the family, and the family’s relationship with service providers. In addition to the standardized measures, approximately one-third of the families were interviewed about their experiences entering the service system and their relationships with service providers. For the purposes of this dissertation, Time 1 refers to

the first data collection period that occurred approximately 6 months after families' entered the service system (hereafter referred to as 'prior research'), and Time 2 refers to the data collection period for this dissertation, that occurred approximately four years after families entered the disability service system.

Study Methods

This study integrated both qualitative and quantitative methods to address the research questions, although qualitative methods were predominant. Individual interviews were used as a means of exploring women's experiences as single-parents of children with disabilities in-depth. In addition to the interviews, participants completed a set of standardized measures that had been used in the prior research study. The research data consisted of the transcripts of the interviews, and two sets of standardized measures; those that were collected at Time 1 in the prior research, and those that were collected at Time 2, at the time of the interviews for this dissertation. The purpose of the sequential design was to use previously-collected quantitative findings to assist in the development of the interview guide for the qualitative study. Although a typical drawback of this design is the time frame required in order to complete each phase, the prior completion by research participants of one set of measures facilitated this use of this design. There were several advantages to incorporating this sequential strategy. First, it allowed for the utilization of existing information in a manner that allowed for further exploration from the standpoint of the participant. Second, it provided the foundation for an individualized interview with participants that were unique to their situations, and therefore contributed to an understanding of individual experiences. Third, in contrast to examining static

outcomes at specific time periods, resilience is a dynamic and developmental process that requires longitudinal analysis.

Sampling Frame

The sampling frame for the prior research study were families who had entered the service system between October, 2000 and July, 2001. From the sample of 124 families who agreed to participate in the research study, there were 21 lone mother families. Given that the primary purpose of this study was to examine the process of how single mothers adjust and adapt to a child with a disability, eligible participants were single mothers who were caring for children with disabilities who had participated in the prior research. At the conclusion of the prior research study, families were invited to provide consent for future contact, and all 21 lone mothers agreed. Therefore, this study employed a purposeful sampling strategy, as only single-parent mothers who had participated in the prior research and who had agreed to be contacted in the future were approached to participate (Patton, 1992).

Research Participants

Using the contact information provided at the conclusion of the prior research, attempts were made to contact the 21 single mothers by telephone. For mothers whose information was no longer valid, the researcher accessed updated contact information through the Children's Special Services computer-based information system. From this process, the researcher learned that two mothers had relocated to different provinces and two mothers were no longer involved with the service system. The sample for this study was therefore limited to 17 families who were currently involved with the Children's

Special Services system. Two mothers, although initially agreeing to participate, did not attend the scheduled meetings and/or did not respond to follow-up contacts to reschedule. Therefore, the final study sample totalled 15 participants.

Data Collection: Quantitative > Qualitative

The procedures utilized in this study followed a modified two interview series pattern of data collection (Creswell, 2003). Mothers were initially contacted by telephone, informed of the purpose of the study, and invited to participate. If the mother agreed to participate, an initial interview time and place was arranged. Due to severe time constraints, one mother was unable to meet in person, and agreed to respond to the interview questions via email. The researcher sent the package of consent forms and research measures to her home, and these were completed and returned by regular mail.

Initial Interviews

Prior to beginning each interview, the researcher reviewed the consent form with each mother and specifically advised that her signature would indicate permission to use the data that had previously been collected as part of the prior research, in addition to the new data generated by this process. All mothers signed the written consent form, assuring them of confidentiality and ability to withdraw from the research study at any time (Appendix B).

Data from the prior research was utilized in the development of the interview questions for each participant. For each participant, data from Time 1 measures were analyzed to identify individual scores of parental stress, family support, family impact of child's disability, self-esteem, and parent morale. Scores on individual measures provided

a beginning point of reference for the qualitative interview. From this, general questions for the interview were developed. For example, if a participant had a high score on the Family Support Scale, she would be asked if there had been any changes in her support network from Time 1 to Time 2. All interviews were conducted using a semi-structured interview guide designed to elicit information about mothers' experiences raising children with disabilities (Appendix C). The interview guide was sufficiently detailed to allow for a focussed discussion using the integration of family stress, the FAAR and family resilience theoretical frameworks. Questions were developed with the view toward exploring family needs, resources, and strengths but sufficiently open to allow for examination of emerging themes and constructs. The interview began with the question about how the mother came to be a single-parent, and subsequently explored with her what it was like to be the parent of a child with a disability. After the basic narrative was obtained, the questions focused on identification of the specific tasks and challenges she encountered at each phase, the individual and family strengths that have assisted her in meeting these challenges, her description of the supports and resources that she found helpful, and a description of her current situation compared to the time that she and her family had entered the disability support system. Dependent upon the information provided, the researcher asked for clarification of descriptions of incidents or time periods that were identified as particularly stressful, or particularly positive, using the benchmark of single-parent as the point of reference. In addition, there were a number of questions that asked the participant to compare her experiences at point of entry to her current situation. These questions were designed to elicit information regarding family

adaptation over time that may not have been directly addressed in the narrative. The interviews ranged in length from 45 to 90 minutes.

This study incorporated the “purposeful” approach described by Boeije (2002, p. 391) wherein the analysis process begins with comparison within a single interview, and then shifts to comparisons between interviews within the same group. Therefore, each interview was analyzed prior to conducting the next in order to identify important areas for exploration that the researcher had not initially identified in the interview guide. As new information emerged from later interviews, four mothers who were interviewed at the start of the study were contacted for follow-up interviews. The purpose of the follow-up interview was to review the major themes and sub-themes that had been extracted from the later interviews, and to ensure that all participants had the opportunity to comment on the themes that had emerged. As a result of the follow-up interviews, several changes were made to the sub themes.

Data Analysis: Qualitative

Data analysis occurred in two phases. All interviews were audiotaped, and the tapes were subsequently transcribed for analysis. Once the transcript was complete, they were checked for accuracy by the researcher reading the transcript while concurrently listening to the audiotape. Through this process, several missing words were added to the transcript. Notwithstanding replacing omitted words, there were no substantial errors noted. After this initial check, the researcher met with the participant to review the transcript for accuracy. All of the participants indicated that the transcripts were accurate.

The transcripts were first read with the view toward obtaining a general overview of the information. All transcripts were then loaded into the NVIVO qualitative data software program, which facilitated the process of storing and coding the data. Data analysis consisted was completed in two stages. The foundation of the first level of analysis consisted of classifying each interview according to the components of the theoretical framework. Analysis through directive or deductive coding is driven by theory, and the goal is to “validate or extend conceptually a theoretical framework” (Hsieh & Shannon, 2006, p.1281). This is conceptually similar to template analysis (Crabtree & Miller, 1992), which involves using an a priori codebook developed from pre-determined concepts based on existing theory. In this study, the integration of family stress, the FAAR and family resilience models formed the conceptual framework and provided the pre-determined categories of family demands or risk status, protective factors and resources, meaning-making processes and family adaptation. Deductive content analysis techniques were applied to each transcript in its entirety, forming a data set for each of the categories. The second level of analysis was completed using the constant comparative method of analysis (Glaser, 1965). This method was originally suggested as an approach that is inclusive of the need for explicit coding procedures and as a foundation for theory development. The principle of constant comparison is used for all analytic tasks: forming categories, establishing the boundaries of the categories, assignment of the interview segments to categories, summarizing the content of each category and finding negative evidence (Yin, 1994). Each category was further analyzed using open, axial and selective coding. Open coding involves categorizing the narrative

into units of meanings. This process included forming initial categories and subcategories based on comparison of similarities and differences. Initially, codes were assigned to reflect the actual words of the participants. Next, axial coding involved examining how each category connects with other categories, and different labels were assigned. Finally, selective coding involved the development of a single category to which other categories are subsidiaries. Each interview was coded line by line. The initial process of open coding produced 94 categories. Some examples of open codes included “autism”, “independence”, “friendship support” and “school”. Each of these categories was subsequently linked according to shared dimensions and clustered into broader categories, which were constructed following the guidelines for axial coding set forth by Guba and Lincoln (1989). Criteria for inclusion within a category were: the data were relevant to the category, data that described, explained, exemplified or reinforced the category, data that sub-linked categories and data that denoted new aspects of a category. Category closure was achieved when data saturation occurred, and no new information was generated through additional analysis. Saturation is generally assessed at the point wherein there is a shift from reporting of substantive data to theorizing about the concepts (Horsburgh, 2003). These clusters formed produced 60 categories and formed axial codes. Examples of axial codes included “coping strategies”, “family strengths” and “personal attributes”. These categories were further collapsed, which produced the final 17 categories (Table 1). From this, the core category that encompassed all axial codes was developed.

Table 1

Family Demands, Resources and Meaning Themes

Family Demands/ Exposure	Family Resources/ Protective Processes	Family Meaning/ Family Belief Systems	Family Adaptation
	Cohesion/Flexibility		
	Social/Economic Resources		
Becoming single mothers	Mother-presence	Single = preferable	Child change
Diagnosis Issues	Disability-specific adaptations	Disability as normal	Authoritative knowledge
Future Worries	Emotional Connections	Providing hope Chosen mothers	
Financial/Health	Perseverance	Optimism	
Interactions with formal support systems	Extended family		

The central focus of the analysis was the development of an understanding of the differences between participants, and the ways in which resilient single mothers of children with disabilities may be distinguished from less resilient mothers. Differences in terms of family demands, resources and meaning-making processes suggest that there are two patterns related to the emergence of resilience in single mothers. Mothers were categorized as resilient if they described qualities, characteristics and processes that indicated they had adapted to their situation. They described utilizing effective coping strategies, appraised the challenges associated with single-parenting children with disabilities as positive and perceived their situations to be less severe when compared to others. Furthermore, mothers were also characterized as resilient if they described themselves as having undergone significant personal and family transformations as a

result of their situations. Several resilient mothers had moved beyond adaptation and developed new patterns of functioning, coping strategies and resource utilization patterns. Their narratives suggested they were functioning significantly better at Time 2 when compared to Time 1.

Data Collection: Quantitative Measures

All participants in this study completed the following standardized measures at Time 2:

1. The Parenting Stress Index-Short Form (PSI-SF) (Abidan, 1990); The PSI-SF is a direct derivative of the Parenting Stress Index full length test. Factor analysis results in three factors: Parental Distress, Parent-Child Dysfunctional Interaction, and Difficult Child. The PSI-SF has been widely used in both general parenting and childhood disability research to assess levels of parental stress (Jackson & Huang, 2000; Smith et al., 2001). The PSI-SF test-retest reliability was assessed as .84, and has been used to discriminate parenting stress in mothers of children with disabilities from mothers of non-disabled children.
2. Family Support Scale (FSS) (Dunst, Jenkins, & Trivette, 1984; Dunst, Trivette, & Hamby, 1994). The FSS is an 18 item scale that measures perceived helpfulness of available social support from family, informal networks, and formal support systems. The sources of support include both individuals and groups at different ecological levels. Participants are asked to rate the helpfulness of sources of support ranging from (1) "not at all helpful" to (5) "extremely helpful". Normative scores are not available for the FSS. A total score is obtained by adding the score for each item. Higher scores indicate higher

levels of social support. Dunst et al. (1994) reported a coefficient alpha of .79, and test-retest reliability over a one month interval of .91.

3. Family Impact of Childhood Disability Scale (FICD) (Trute & Hiebert-Murphy, 2002).

The FICD was originally developed as a 15 item (5 positive and 10 negative) uni-dimensional scale of parent appraisal that includes both positive and negative items. Parents are asked to respond to the question "In your view, what consequences have resulted from having a child with a disability in your family?" Positive items include statements such as "The experience has made us come to terms with what should be valued in life." Negative items include statements such as "It has led to a reduction in time parents could spend with their friends." Each item is scored on a four-point Likert scale: (1) Not at all, (2) To a mild degree, (3) To a moderate degree, or (4) To a substantial degree. Higher scores were hypothesized to represent more positive appraisal. Initial analyses of the measure on a sample of parents in two-parent families resulted in two independent factors of positive and negative appraisal. Trute and Hiebert-Murphy (2002) reported a coefficient alpha of .88 for the negative subscale and .71 for the positive subscale. The FICD also demonstrated good internal validity and was found to discriminate between parental appraisal and assessments of family functioning or positive reframing.

Trute and Hiebert-Murphy developed a second version of the FICD to include an equal number of positive and negative items. The second version of the FICD is a 20 item (10 positive and 10 negative) scale and was used in this study to measure the meaning or parent appraisal factor in childhood disability. The second version is composed of two

subscales: positive and negative appraisal. Five positive items were added; (1) Family members do more for each other than they do for themselves, (2) This experience has helped me appreciate how every child has a unique personality and special talents, (3) Family members have become more tolerant of differences in other people and generally more accepting of physical or mental differences between people, (4) The experience had made family members more aware of other people's needs and struggles which are based on a disability and, (5) The experience has taught me that there are many special pleasures from a child with disabilities. Each subscale is scored independently, according to the original scale.

In this study, scale items #6 "Having a child with disability has led to an improved relationship with spouse" and #17 "The situation has led to tension with spouse" were deleted, and the subscale mean for each participant was substituted, as these items were not relevant for single mothers. Participant scores were compared to scores obtained from the participants from the "Family Strengths in Childhood Disability" project.

4. Parent Morale Index (Trute & Hiebert-Murphy, 2005). This scale was used to assess parental morale. This is a 10 item scale that assesses the parent's affect on a daily basis. Five items reflect positive affective states (contented, happy) and five items reflect negative affective states (lonely, stressed). Negative items are reverse scored. A total score is obtained by adding the score for each item. Higher scores on the PMI indicate higher levels of positive parent morale. An alpha coefficient of .84 was found for the

Total PMI score from the total sample (N=171) of the Family Strengths in Childhood Disability study.

The trend toward evidence-based social work practice suggests that current programs, policies and practice occur in the absence of evidence. The use of traditional quantitative measures is one means social work practitioners have resisted the claims that social work is neither professional nor empirical. As stated by Humphries (2003), "Social work has had limited success in achieving a professional status and is currently pursuing a particular identity through what is presented as a scientific approach to research" (p. 85).

There are several reasons to support the use of self-report measures. First, in terms of researching family resilience, longitudinal studies that demonstrate positive adaptation over time recognize the dynamic nature of resilience. De Haan, Hawley, and Deal (2002) suggest that the family trajectory be examined at different time points: prior to the crisis point, at the time of crisis, and some time or times after the crisis. Although this study did not provide for data to be collected prior to the diagnosis of a child with a disability, it did allow for longitudinal comparison at the time of crisis (entry into the service system) and four years post-Time 1.

One critique of solely relying upon quantitative data is that results are limited to a description of the "who, what, and when" changes, but do not address the "why" or "under what circumstances" issues. For example, in this study, the PSI-SF specifically measures parental stress, and does not accurately reflect other parenting issues that are important for parents. Additionally, the emphasis on stress and deficiencies does not

allow for the exploration or illumination of positive experiences of parenting.

However, a second rationale for the use of quantitative methods is that they can serve to inform the qualitative data. The introduction of mixed methods approaches initially referred to a combination of data sources to describe the same phenomenon under study (Denzin, 1984). Although this was not a classic mixed methods study, the use of qualitative and quantitative methods served as a complementary means of triangulation and yielded quantitative data (multiple-choice responses) and qualitative data (participants' explanations for choices of response). Therefore, the combination of qualitative and quantitative data was useful for exploring the validity of findings.

Data Analysis: Quantitative

The standardized measures were scored and entered into SPSS 13. Descriptive and comparative statistical analyses were done that compared participants scores at Time 1 to Time 2. T –tests were used to compare scores from Time 1 to Time 2. In addition, participants scores on measures were compared with scores obtained from the sample for the prior research study.

CHAPTER FOUR

Results: Quantitative Analysis

The results of this study are presented in two chapters. This chapter presents the demographic information for each participant and a summary of the results of the quantitative analysis. Findings from the qualitative analysis will be presented in Chapter Five.

Participant Demographics

Maternal characteristics. Participant demographics were updated at Time 2 and are summarized in Table 2. Twelve of the women resided in Winnipeg and three resided in the rural area of Brandon, Manitoba. Seven women were employed on a full-time basis, one woman was attending a post-secondary institution and worked part-time, five women received income assistance as their primary source of income, one woman worked part-time, and one woman was employed part-time and received income assistance as a supplement. Three women reported incomes above \$34,999 and 12 reported incomes under \$34,999. Their ages ranged from 30 to 47 years ($M = 38.06$, $SD = 6.55$). Ten women described themselves as never-married, four women described themselves as divorced, and one woman described herself as widowed. None of the participants had remarried, however four women were currently involved with non-resident partners.

Child characteristics. Twelve of the children with disabilities were male and three were female. Their ages ranged from 6 to 20 years ($M = 9.53$, $SD = 3.62$). Seven children were diagnosed on the Pervasive Developmental Disorder spectrum. Three boys and one

girl were diagnosed with Autism, and two boys and one girl were diagnosed with Asperger's Disorder. Six boys and one girl were diagnosed as developmentally delayed, not otherwise specified. The oldest child in the study was a young man diagnosed with congenital toxoplasmosis that presented itself as cognitive and developmental delays. It is important to note that none of the children in these families had multiple or severe disabilities or were considered medically fragile. All of the children were physically mobile, none had significant hearing or vision loss, and all were capable of verbal communication. The children's disabilities were manifest primarily as behavioural difficulties, cognitive impairments, poor social skills and speech and language delays. Therefore, the experiences of the mothers in this study are not representative of mothers caring for children with severe or multiple handicaps, or mothers coping with medically fragile or technology-dependent children. All of the children attended educational programs within the public school system. The mean number of children per participant was 2: Four women had one child, four women had two children, five women had three children, and two women had four children ($M = 2.33$, $SD = 1.04$).

Table 2

Participant Demographics

Family #	Mother's Age	Child's Age	Child's Sex	Pathway to Single Parent Status	Disability Status	Employment/Income Status
1	30	6	Male	Never married	Autism	Income Assistance
2	46	8	Female	Never married	Developmental Delay	Full Time
3	30	8	Male	Never married	Developmental Delay	Income Assistance Student
4	34	8	Male	Divorced	Developmental Delay	Full Time
5	45	13	Male	Never married	Asperger's	Full Time
6	45	20	Male	Divorced	Congenital Toxoplasmosis	Full Time
7	36	7	Male	Never married	Autism	Income Assistance Part Time Employment
8	47	8	Male	Never married	Autism	Part Time
9	43	14	Male	Widow	Asperger's	Full Time
10	32	7	Male	Never married	Autism	Full Time
11	31	8	Male	Never married	Developmental Delay	Income Assistance
12	33	8	Male	Never married	Developmental Delay	Income Assistance
13	43	10	Male	Divorced	Developmental Delay	Income Assistance
14	33	8	Female	Never Married	Autism	Part Time Employment Student
15	43	10	Female	Divorced	Asperger's	Full time

Quantitative Analysis

All participants completed the following measures for this study: The Parenting Stress Index-SF (Abidin, 1990), the Family Support Scale (Dunst, Jenkins, & Trivette, 1984), the Family Implications of Childhood Disability Scale, (Trute & Hiebert-Murphy, 2002), and the Parent Morale Index (Trute & Hiebert-Murphy, 2005).

In addition, the Reliable Change Index (RCI) (Jacobson & Truax, 1991) was used to assess whether clinically significant change had occurred between Time 1 and Time 2. Clinical significance refers to situations where the level of functioning subsequent to intervention falls (a) outside the range of the dysfunctional population, (b) within the range of the normal population, or (c) closer to the mean of the functional population than the dysfunctional population. The RCI is calculated as:

$$RC = \frac{X2 - X1}{S \text{ diff}}$$

where X1 represents a subject's pre-test score, X2 represents that same subject's post-test score, and S diff is the standard error of difference between the two test scores.

According to Jacobson and Truax (1991) if the RCI score is above 1.96, it is likely that the post-test score reflects clinically significant change.

The inclusion of quantitative measures was intended to assess whether participants had experienced changes in social networks, parenting stress or parent morale between the point that they entered the service system, and the time frame of the current study. Quantitative data was also used as a validity check for the qualitative data by comparing results from the measures to the analyses of the participants' narratives.

The discussion section will address the consistencies and discrepancies between the quantitative and qualitative results.

Parenting Stress Index-SF. All 15 participants completed the PSI-SF at Time 1 and Time 2. However at Time 1, the responses of one mother met the criteria of the PSI for Defensive Responding (DR). The DR score is designed to identify participants who may respond in a manner they perceive to be socially desirable. Abidin (1990) has further noted that a low DR score may also occur in situations where the parent is highly competent, there is a strong social support network, and the parent is not struggling financially. Given that the researcher could not confirm these factors were present for this participant, the data from Time 1 was not included in the analyses. Individual scores for each subscale are reported in Table 3. Results for Total Stress and subscales are reported in Table 3.

Table 3
Participant Raw Scores for PSI-SF

Time 1 and Time 2

Participant #	Parental Distress TIME 1	Parental Distress TIME 2	Parent-Child Dysfunctional Interaction TIME 1	Parent-Child Dysfunctional Interaction TIME 2	Difficult Child TIME 1	Difficult Child TIME 2
1	27	16	22	20	22	23
2	56	37	36	31	42	33
3	36	28	20	23	43	33
4	35	29	27	19	46	43
5	37	26	37	27	60	56
6	26	44	28	32	22	25
7	61	45	38	34	56	46
8	12	23	15	27	20	35
9	38	32	37	35	44	36
10	25	29	25	20	25	24
11	27	29	31	36	35	46
12	55	31	27	22	43	29
13	26	23	22	23	28	46
14	42	21	23	19	42	29
15	38	38	28	25	34	21

Table 4

PSI-SF

Paired Samples T-Test

Parental Stress	Time 1	Time 2	<i>p</i>
PSI-SF Total Stress	M = 104.14 SD = 26.11	M = 91.93 SD = 18.78	.04
PSI-SF Parental Distress	M = 36.78 SD = 13.53	M = 30.06 SD = 8.18	.014
PSI-SF Parent- Child Dysfunctional Interaction	M = 27.71 SD = 7.20	M = 26.20 SD = 6.04	NS
PSI-SF Difficult Child	M = 37.46 SD = 12.29	M = 35.00 SD = 10.38	NS

The Total Stress score of the PSI-SF was used to measure maternal stress. The Total Stress score is the sum of the Parental Distress, Parent–Child Dysfunctional Interaction, and Difficult Child subscale scores. Mean scores were calculated for the Total Stress score at Time 1 ($M = 104.14$, $SD = 26.11$) and Time 2 ($M = 91.93$, $SD = 18.78$). Analysis of the proportion of mothers who experienced levels of parenting stress above the clinical cutoff indicated that 10 participants (71.42%) scored above 90 at Time 1 and 6 participants (40%) scored above 90 at Time 2. The Paired Samples T-Test was used to compare the Total Stress and subscale scores at Time 1 to Time 2. Total stress scores were significantly higher at Time 1 ($M = 104.14$, $SD = 26.11$) compared to Time 2 ($M = 92.42$, $SD = 19.38$), $t = 2.2$, $p = .04$ (two-tailed). Parental Distress was significantly higher at Time 1 ($M = 36.78$, $SD = 13.53$) compared to Time 2 ($M = 29.07$, $SD = 7.48$), $t = 2.85$, $p = .06$ (two-tailed). There were no significant changes in the Parent-Child Dysfunctional Interaction or Difficult Child subscales. At Time 2, an examination of the subscale scores indicated that nine out of 15 mothers (60%) scored above the clinical cut-off on the Difficult Child subscale. This subscale focuses on some of the basic behavioural characteristics of children that describe whether they are easy or difficult to manage. Given that the majority of children's diagnoses were along the Pervasive Developmental Disorder spectrum, it is not surprising that the majority of mothers described their children as experiencing behaviour problems. However, only four out of 15 mothers scored above the clinical cut-off on the Parental Distress subscale, suggesting that even in a context of behavioural difficulties, the majority of mothers continued to be confident in their parenting role.

Abidin (1995) reports mean scores for a normative sample for the PSI-SF as $M = 71.0$, $SD = 15.2$. A t -test indicated that the mean for the present sample at Time 1 ($M = 33.14$, $SD = 26.11$, $p = .00$) and Time 2 ($M = 20.93$, $SD = 18.78$, $t = 4.7$) was significantly higher than for the normative sample, indicating that the participants in this study experienced overall higher stress than the normative sample.

The RCI was calculated using the standard error of the difference (8.49). This was calculated as follows:

$$S_{diff} = \sqrt{2(Se)^2}$$

$$(26.11)(26.11)/14 + (18.78)(18.78)/15 = 72.20766$$

$$S_{diff} = \sqrt{72.20766}$$

$$= 8.49$$

Five participants' scores all exceeded the 1.96 indicator of clinically significant change. RCI scores are reported in Table 5. These results indicate that although parenting stress remains high, 5 participants underwent clinically significant change since the time of entry into the disability service system. Two participants' Total Stress scores increased from Time 1 to Time 2, also within the clinically significant range. These results suggest that these mothers were experiencing increased levels of parenting stress. This was confirmed by one mother; however the narrative of the other participant indicated that she had experienced a decrease in overall stress.

Table 5

Reliable Change Index: Total Stress

Family #	PSI-SF TIME 1- TIME 2	RCI Difference/8.49
1	12	1.41
2	33	3.88
3	15	1.76
4	17	2.00
5	15	1.76
6	+25	2.94*
7	21	2.47
8	N/A	
9	16	1.88
10	2	.235
11	+18	2.12*
12	43	5.64
13	+16	1.88 *
14	24	2.82
15	15	1.76

* PSI-SF score increased

Family Support Scale. All participants completed the FSS at Time 1 and Time 2. Perceived availability of family support was measured by the sum total of the individual item scores. Results indicate that perceived availability of total formal and informal social support for this sample did not change from Time 1 ($M = 31.28$, $SD = 15.32$) to Time 2 ($M = 31.66$, $SD = 8.79$). These scores are lower compared to those of a sample of primarily two-parent families with children with developmental delays ($M = 48.42$, $SD = 10.73$) (Dunst, Trivette, & Hamby, 1994). However, they are higher than from the sample of two-parent families at Time 1 ($M = 23.47$, $SD = 7.59$) and Time 2 ($M = 23.18$, $SD = 8.25$) (Trute, et al., 2005).

Family Impact of Childhood Disability. The FICD contains two subscales; Positive Impact and Negative Impact. Mean scores for each subscale were calculated for Time 1 (Positive: $M = 30.53$, $SD = 4.9$; Negative: $M = 25.06$, $SD = 9.04$) and Time 2 (Positive: $M = 30.66$, $SD = 5.23$; Negative: $M = 26.09$, $SD = 7.29$). Using the paired samples t -test, there was no significant change. The scores for the sample from this study are within one SD from the mean scores of the two-parent sample from the larger study at Time 1 (Positive: $M = 27.64$, $SD = 5.4$; Negative: $M = 22.04$, $SD = 6.77$) and Time 2 (Positive: $M = 27.15$, $SD = 5.55$; Negative: $M = 21.78$, $SD = 7.46$). This suggests that the impact of childhood disability on single mother families is similar to that experienced by two-parent families. Individual subscale scores are reported in Table 6.

The RCI was calculated for each subscale of the FICD. Results from calculations for the positive subscale indicate that two participants underwent clinically significant change, and became more positive about the impact of their child's disability on the family. The RCI for three participants indicated that they had become less positive regarding the impact of the disability on the family. On the negative subscale, two participants underwent clinically significant change in terms of the impact being less negative and five participants indicated that the impact had become more negative.

Table 6

Family Impact of Childhood Disability

#	FICD Positive TIME 1	FICD Positive TIME 2	Difference	FICD Negative TIME 1	FICD Negative TIME 2	Difference
1	30	37	+7	13	12	-1
2	30	31	+1	34	34	=
3	29	26	-3	13	27	+14
4	36	36	=	26	33	+7
5	36	31	-5	38	29	-9
6	37	38	+1	18	32	+16
7	27	29	+2	33	34	+1
8	37	38	+1	12	15	+3
9	29	23	-6	30	16	-14
10	31	28	-3	21	31	+10
11	26	26	=	12	31	+19
12	24	24	=	26	21	-5
13	23	26	+3	36	31	-5
14	37	36	-1	33	29	-4
15	25	31	+6	31	29	-2

Table 7

Reliable Change Index: FICD Positive & Negative

Family #	FICD Positive T1- T2	RCI (1.925)	FICD Negative T1-T2	RCI (3.191)
1	7	3.63	-1	-.31
2	1	.052	=	0
3	-3	1.56	+14	4.38
4	=	0	+7	2.19
5	-5	-2.60	-9	-2.82
6	1	.052	+16	5.01
7	2	1.03	+1	.31
8	1	.052	+3	.94
9	-6	-3.11	-14	-4.38
10	-3	-1.56	+10	3.13
11	=	0	+19	5.95
12	=	0	-5	-1.56
13	3	1.56	-5	-1.56
14	-1	-.052	-4	-1.25
15	6	3.11	-2	-.62

Parent Morale Index. Mean scores were calculated for TIME 1 ($M = 34.69$, $SD = 7.96$) and TIME 2 ($M = 34.16$, $SD = 7.09$). These scores were higher, but not significantly different from those reported by the larger sample ($M = 31.91$, $SD = 5.67$).

CHAPTER FIVE

Findings: Qualitative Analysis

The findings from this study are presented in relation to the primary research question: How does the integration of the family stress and coping theory, the Family Adjustment and Adaptation Response (FAAR) model (Patterson, 2002) and the family resilience framework (Walsh, 1998) apply to the experiences of single mothers of children with disabilities? This study examined this question by interviewing single mothers regarding their perceptions of the factors they experienced as stressful (risk exposure), the current supports and resources that they identified as helpful in managing the stressors (family resources), the ways in which they created meaning about their situations (family belief systems), and their perceptions of their current family environments compared to their time of entry into the disability service system (family adaptation/resilience).

In view of the dynamic nature of stressors and protective processes, the presentation of findings focuses on the interactions between mothers' identified family demands, their use of resources, capabilities and belief systems to manage these stressors, and how these processes result in a level of family adaptation. The analysis of the qualitative data resulted in the following five themes of family demands; (a) becoming single mothers, (b) diagnosis issues, (c) future worries, (d) interactions with formal support systems, and (e) financial and health-related issues. Participants managed these demands through the following strategies: (a) developing a positive appraisal of single-parent status, (b) reframing of disability as "normal", (c) the belief that they had been

chosen by God, (d) maintaining an optimistic outlook, (e) engaging in faith-based or spiritual practices, (f) transforming father-absence into mother-presence, (g) forging a strong emotional bond with their children, (h) undertaking disability-specific adaptations, (i) perseverance, (j) fostering relationships with extended family, and (k) acknowledging child-related change. Ultimately, the analysis of the interview data led to the conclusion that positive adaptation and resilience is expressed in single mothers of children with disabilities as authoritative knowledge.

In this study, the intent of using quantitative and qualitative methods was to triangulate different data sources as a validity check. The analysis of the quantitative data in the context of the qualitative themes became an important means of establishing the credibility of selected findings and ultimately, the synthesis led to a more complete understanding of how resilience is manifest in single mothers of children with disabilities.

The findings will be presented in four parts. The first section will present a general summary of the stressors identified by the participants. Then, building on the suggestion that the meaning factor has predictive value in family adaptation, and occurs prior to the appraisal of resources (Orr, Cameron, & Day, 1991) the second section will review the themes that reflected the intersection of mothers' belief systems and identified stressors. The third section will present the themes that highlighted the intersection of how mothers' managed particular stressors by drawing upon their family resources. The fourth section will present the themes that reflected issues of family adaptation.

Family Demands/Stressors

The theoretical framework used in this study is predicated on the assumption that childhood disability may contribute to an increased vulnerability for lone parent women and their families. However, “the punctuation point for defining significant risk exposure is less clear, particularly with regard to high-risk status as a necessary precondition to be viewed as resilient” (Patterson, 2002, p. 239). Participants reported that a complex range of stressors, including financial, health, social and environmental factors challenged their abilities to promote the health and well-being of their families. The most frequently reported stressor was financial stress, followed by health-related concerns.

Financial Stress

It is well established that financial and economic resources make an important contribution to overall family and child well-being (Mistry, Vandewater, Huston, & McLoyd, 2002). Therefore, it is not surprising that the majority of the mothers in this study identified inadequate income from employment, children’s fathers and the income support system as a significant source of stress.

Three mothers reported income levels above \$35,000. The remaining 12 mothers had incomes below \$35,000. Within the lower income group, six women were employed on either a full or part-time basis and six mothers were in receipt of income assistance benefits. None of the mothers received any direct financial assistance from the children’s fathers. Within the low-income group, women from both the employed and income assistance groups reported financial issues as a source of stress. Specifically, the women on income assistance identified food security as their priority, and worrying that their

groceries would run out before receiving their assistance was a frequent source of stress. Tracy* recognized the importance of always planning ahead to ensure that her children had access to healthy food. "Food is a good thing for the kids, cause I'm always scared that, well, what if there no money left this month, then we can make it through to next month because we always have food in the house."

Other financial stressors included costs related to transportation, child care and school fees. For Corinne, even to attend doctors' appointments with her children (an event that occurs more frequently with children with disabilities) created financial hardship. As she described "I have to make sure, okay, there's my bus fare, and then the kids, 2 of them, it's like \$6, \$7, \$8, \$10 for us to even go to the doctor's."

The concept of stress extended beyond financial hardship to include environmental and community-related factors such as the location, quality and availability of housing. Mothers in receipt of income assistance frequently reside within public housing complexes that set rental costs based on family income. Living within the constraints of public housing is associated with increased exposure to crime and violence, problematic social relations and residential instability (Curley, 2005). Tracy identified that the key contributing factor to her stress came from the constraints of living within public housing. She had resided in one complex that was located within a particularly dangerous neighbourhood. As a result of a drive-by shooting, she was able to transfer to a different unit in another area; however, this too was located within an equally unsafe neighbourhood.

* All names used throughout this dissertation are pseudonyms.

The importance of safe housing was confirmed by two other participants. Since the time of the prior research study, they had each purchased their own home to ensure a stable, long-term residence for their families. For these women, improvements in their economic status led to improvements in their housing and consequently, greater well-being.

Mothers were fully cognizant of the implications of financial stress on family well-being. One high-income mother specifically identified that her access to financial resources was the critical factor in her family's well-being. She noted that as a single mother, she is typically categorized with all single mothers, regardless of age or income. To her, the use of the overarching category "single" was an imperfect way to assess family functioning as in her opinion, financial resources were the more significant factor.

And you know, a lot of it is income based. You know, the income that I have has made a big difference. I can afford to get things for (child). And there are a lot of single professional women who are single mothers. Income and the single mom is a huge, huge thing.

Health-related concerns.

A second area of stress for single mothers was identified as a complex range of health-related concerns. Mothers described that worries about their children's and their own physical and emotional health contributed to the stress of being single-parents. As Rochelle noted "Like there's a saying, a mother can never afford to get sick." This sentiment was expressed by the majority of mothers and referred to the concrete issue of loss of income as a result of illness, as well as the negative physical, emotional and/or

psychological impact upon the family. Employed mothers described the stress associated with having to negotiate the demands of caring for a sick child and employment in the absence of concrete supports. Oxsana explained,

And I think that's one of the toughest things I think with being a single-parent because if the kids get sick and you have them in daycare, like in my case, I don't have any family that can do it for me. So if for instance (child) gets sick and I'm working, I am going to have to take that time off from work.

The majority of the women in the study further identified that their own physical well-being, at the present time and in the future, was a source of stress for them. Health problems negatively interact with employment which, particularly for low-income mothers, increases the risk of poverty. For lone mothers, becoming physically ill or incapacitated, even for a brief period of time, can exacerbate pre-existing financial difficulties, and lead to a slippery slope of additional problems. Patricia had been diagnosed with ovarian cancer, and had completed several rounds of chemotherapy which required her to take time off work.

And then I had to take time off work cause I was sick and that led to my being laid off from my job, which led to financial problems and I couldn't really start working right away because I was sick, so it's just ... yeah, it all kind of compounded and it was a really, really hard time.

In this study, health-related stress was expressed differently by the participants. For some participants, it referred to their physical health. For other participants, health-

related stress referred to their mental health status. Three women described that they had been diagnosed with depression that at times, made it difficult for them to care for their children.

Family Belief Systems

The integration of family stress, family adaptation, and family resilience theories converge on the importance of family belief systems. Family belief systems help members understand crisis situations, foster a hopeful, positive outlook and reflect a family's spiritual beliefs and purpose (Walsh, 1998). Moreover, families ascribe personal meanings to their experiences that are not always evident to others. Patterson and Garwick (1994) have referred to these as "situated meanings" and suggest they are an important component of family belief systems. Taken together, this highlights the importance of the meaning-making process for families of children with disabilities and family resilience.

It is generally perceived that the cumulative impact of single-parent status and childhood disability is inevitably negative. Margaret described the common perception of how others view the interaction of these issues.

I think that it's probably an obvious statement but I think single moms, whether they have kids with special needs or not are I think, I wouldn't wish it on my worst enemy quite frankly. I feel, you know, I hear people talking 'oh she's whining, she's a single mom' and I kind of keep that to myself sometimes but I'd just like to say that it's the hardest thing that anybody could even fathom.

Despite these perceptions, mothers created meaning from their family situations through their perspectives that every experience, even negative ones, had a purpose. Their descriptions of how they viewed their lives signified the importance of redefining what constituted personal/individual needs, stressors, and developmental progress within their children. Resilience-building was most clearly demonstrated in their abilities to make emotional sense of negative or adverse situations, to sustain a positive outlook, and by incorporating spirituality into their daily lives.

Making Meaning of Adversity

As a beginning point, participants in this study by definition experienced the perceived adversity of being single mothers of children with disabilities. As such, their meaning-making processes were most discernible in their appraisals of their family status and children's diagnoses.

Becoming single mothers. For the participants in this study, the term "lone mother" is an accurate representation of their experiences of parenting special-needs children. Their narratives described a context of father-absence and abdication, both passive and active. Of the 15 women who participated in this study, 3 of the (living) thirteen fathers maintained some form of contact with their children. Two fathers had died prior to the family's first contact with the Family Strengths in Childhood Disability project (Trute et al., 1999). However, only one had lived with his family and one other father had not had any contact with his children since their births.

From the outset, the categorization of the participants as single mothers is only possible if understood specifically in opposition to the normative two-parent family form.

The socially constructed ideal of family suggests that the primary challenge to resilience for single mother families originates from a context of father-absence. As women, the participants in this study can never be free from the historical and socially reinforced judgments that suggest children are significantly worse off in single mother families compared with two-parent families. Consequently, the value and quality ascribed to their maternal identities is subject to the meaning that social and cultural forces assign to the status of single mothers. Inevitably, this status is constructed as having considerably less value than that accorded to two-parent families.

Although their personal responses to becoming single-parents ranged from positive to negative, participants described that their experiences were typically interpreted by others through dominant narratives that consistently defined lone motherhood in negative terms. Moreover, participants themselves were acutely aware of how they too had internalized these stigmatized images. In the following excerpt, Hannah's reasons for remaining in an unhealthy relationship reflect the enduring legacy of the perceived superiority of the two-parent family that she had initially embraced.

I was raised by two parents. And it's almost ironic cause when I was in grade nine I was the only person in my class that was raised by both my parents. And my parents were together for 41 years when my dad died. They were married for 38 but they were.... they were together forever. And so when I had (child) I was willing to deal with anything so that my child would be raised with both parents. And I would put up with crap because I was raised with two parents.

For one participant, the “stigma of the single-parent” began with her pregnancy. Patricia described how her initial feelings of elation were in direct conflict with others’ perspectives regarding the appropriate composition of family.

When I was pregnant and I told people that I was pregnant and the situation the way it was, I was actually happy and excited to be pregnant even though I was puking my guts out. And people said, people said, “Oh no! Oh my God, how awful.” And I thought to myself, you know, my sister-in-law who’s married to my brother, when she announces that she’s pregnant, everybody’s like so happy and so overjoyed, and for once I would just like someone to be happy for me, you know.

For other participants, the stigma occurred post-divorce. As Sarah described,

There’s the stigma of being a single mom, especially in a conservative community. If I was in a big city, lots of women have babies and don’t even want the father involved. And you don’t see that much in this town. I knew that when I moved back that was one of the tough things. It’s so conservative. Like I am the only single mom in this area, right? People are really quick to blame single-parent families if there’s any trouble. You know, if I was ever having trouble with (child), that’s the trouble. It’s because I am not married. So that part is tough. So you just kind of have to get used to it.

Single mothers are perceived to be an at-risk group, even when obtaining medical care for their children. Patricia described the potential risk to herself if she needed to take her children to the emergency centre at the hospital. In addition to having to deal with the

stress regarding her children's health, she also worried about being labeled a neglectful parent. For her, the stigma associated with being a single-parent translated into the implicit policy that mandated child welfare involvement on the basis of marital status.

One thing that I find that's rather frustrating and stressful is that if they ever get hurt, if anything ever happens to them and if it's anything where I would need to take them to the hospital, like to Children's, the first thing they do when you're a single-parent is assume that you've abused them or been negligent in some way and that it's your fault. And if you're married they don't do that, but as a single-parent they figure that you're in the high risk category and all of a sudden, there's this full blown investigation into your behaviour and how you deal with your kids and all that kind of thing, and I find that very stressful. Sometimes things happen, you know.

Rather than internalizing the "stigma of the single mother", the participants enacted strategies of cognitive appraisal to create positive meanings from their situations. In contrast to accepting single-parent status as inherently negative, mothers described their decisions to become single-parents as choices that were in their children's best interests. When faced with the decision of whether to remain in an unhealthy two-parent relationship, or protect their children and deal with the potential loss of social and economic support that typically occurs with separation/divorce, mothers overwhelmingly prioritized their children's needs. When asked how she came to be a single-parent, Tracy responded,

By choice. His dad and I no longer got along. He was a drug addict and I chose not to live in that life anymore. So here I am. It took me a long time, yeah. I never left until, well I wanted to be with him because I raised an older one by myself, and I had the three younger ones and I wanted to stay with him for that reason. I didn't want to be a single-parent, but it's easier being single than having nothing with him.

Sarah described a similar meaning-making process where her decision to leave was predicated on prioritizing her son's needs.

I was living in the United States with my husband and um, he is an alcoholic so things really weren't going well and um, it was a kind of at one point it was either me or him and I had a three year old son, and I thought I have to look after him from now on and (father) can worry about himself. And things weren't going well. I knew I could look after myself and (child). But, when I had a tough husband, it was really getting too much for me.

Mothers who did not make the decision to leave their relationships enacted similar meaning-making strategies. Although they may not have consciously decided to become single mothers, the recognition that they were singularly responsible for caring for their children became the vehicle through which they created meaning. As Tanya indicated, "It was thrown at me and uh, well as a parent you do your best to raise and love your child, so. There was no choice about that. There was no question. Who wouldn't raise their children and love them?" Although the choice of ending the relationship was not within

her control, she describes how she created meaning from a difficult situation by becoming “more responsible”.

I think that it made me more of a responsible person, knowing that, okay I had to do it, I was doing it alone most of the time anyways. I sued for sole custody, but I think it's better for him not to have that negative influence in his life. As far as I see it, he's got a mommy. I mean some kids are better off without two parents.

Samantha echoed similar feelings. She too had been in the position where becoming a single-parent was not her choice. Initially, she describes how she accepted her partner's blame for their son's disability. However, later on, she describes the moment when she recognized that she had assumed continual care and responsibility for her son. This resulted in a shifting of her self-view from victim to agent.

Well I know I didn't make a choice. I met a guy, right, so. I guess I was seeing him for a couple of years, and when I had my son, with a disability, I didn't know anything until I think, 17 months, that I noticed that he wasn't talking. And things were okay, but then they got more intense as the truth, the diagnosis, came out. Because his thing was, I think he was more blaming me for something but I don't think it was me, and it was really hard on me. But it got to me and then I thought, this is crazy. So I have to turn it around and say, I have to think positive, right. So, that's what happened. The dad, I don't think, he didn't, he couldn't handle it, but he's saying that I couldn't. But I know I could because I'm taking care of him, you know, he's my son, right and I said you know, the hell with it. I manage. I

told you it was really intense, but now I'm more responsible, you know, I'm getting older.

Mothers also used strategies of cognitive appraisal by acknowledging that the two-parent family structure is not synonymous with a shared parenting experience. Although spousal support is consistently noted to be a crucial source of assistance in two-parent families (Beresford, 1994; Boyd, 2002; Bristol, 1987b; Knussen & Sloper, 1992), it does not appear that single-parent mothers are automatically disadvantaged by the loss of a partner. For several mothers, their personal experiences of two-parent family structures suggested that fathers' involvement was often a greater hindrance than a help. As Sarah philosophically remarked, "On the other hand, you know, depending on your relationship, it can be no different. Lots of men don't help around. And in fact they add to the workload."

Although single-parenting occurs in a context of sacrifice and loss of personal time, mothers identified that independence, reduced time spent on conflict, an increased focus and direction for family and timelier decision-making held greater value. Samantha expressed,

I can do whatever I want, not in a bad way though. If I want to take my children and go here, I don't need to have a second opinion. I'm able to make my own choice without having any conflict with the father. When I make decisions, I think I make the right one without you know, the kids' dad talking negative. You just feel you have more choices to make and more freedom.

Sarah summarized the feelings of many participants when she described the benefits of single-parenting as “The freedom. Yeah, the decision-making is a good one. The independence.”

The process of creating meaning from their experiences as single-parents reflected two levels of awareness: their stigmatized locations as single mothers within the social structure, and the location’s relationship to their own experiences. Although participants were aware that lone mothers are not considered ideal family types, they chose not to accept the essentialist notions of single mother families as inherently flawed through their recognition that the safety and protection of their children is paramount, the physical presence of a partner does not automatically provide emotional support, nor result in a shared workload and, can increase conflict. As reported by participants, it may in fact exacerbate the burdens on mothers who are parenting children with special needs. The participants created meaning from adversity by making informed decisions to protect their children and becoming “more responsible” parents. In the face of prevalent discourse that uses single parent as a code phrase for problem family, the participants created meanings from becoming single mothers that embodied practices of freedom, independence, and responsibility.

Diagnosis issues. Generally, learning about their children’s diagnoses is an extremely stressful process for parents (McLaughlin, 2005; Quine & Pahl, 1986; Read, 2000). In this study however, the diagnoses provided opportunities for mothers to create new meanings or understandings about their children and their maternal roles.

Anticipated reactions to the diagnosis of developmental disability continue to emphasize negative emotions including shock, grief, loss, anger and devastation. Perhaps as a result of the negative perceptions surrounding disability, participants stated that prior to their children being diagnosed, others adamantly disputed their concerns and subjective experiences regarding their children. Oxsana described how her daughter's father consistently denied that there was a problem, even when it became apparent that their daughter's development was clearly atypical based on her absence of speech.

And he would always say, well you know, nothing is wrong with her. She's just fooling all of us, and I think it was just the cover for himself, you know, like he didn't want to admit it and I know it's hard because I didn't want to admit that anything was wrong with (child). But I mean I'm with her every day and I know something is wrong.

Debra described a similar exchange that occurred with her husband.

I saw a program when (child) would have been about 5 or 6 and it was about people, or young men, who had no social capabilities. I don't think I knew about Asperger's, the name, but I watched this program. I kept saying, you know that's like (child). (Father) kept telling me, don't be so bloody stupid. I don't know whether he saw images of himself and didn't want to accept it or whether he just thought I was grasping at straws to find out what was wrong with (child).

However, in addition to experiencing some stress, participants created constructive meanings from the diagnostic process as it affirmed their subjective

knowledge of their children. Margaret described that although overwhelming, confirming the diagnosis was a “relief” as it validated her own suspicions of a “problem”.

But I was suspecting before...well, once (child) started to have her seizures at the age of one, I started to feel that may be problems here. So it was a great relief in a sense to have her diagnosed at Children’s Development Clinic. Then it was overwhelming the amount of appointments and assessments and people calling for varying purposes. But...and I did kind of keep track of it and uh, but I was relieved, very relieved.

Samantha described how her perceptions of her situation improved after receiving her son’s diagnosis.

It’s getting better, you know. But I don’t know, it’s really difficult to explain but it just got a little bit better after that (diagnosis) and then I know that like sometimes, you know, in life, you know, you can’t expect everything to be like perfect and everything’s going to go away, but you know I worked it out slowly, slowly, and things are a little bit better now.

Theresa, whose six-year old child was diagnosed with global developmental delay, described how she used the diagnosis to dispute her mother’s perception of her son’s abilities. She stated, “Well, my mom was telling me when he was little that I should just admit that he’s retarded. Well, he’s not retarded, he’s slow. There’s a big difference.” She created a different meaning for her son’s diagnosis through the cognitive transformation of the word “retarded” into “slow”, with the implicit suggestion that he had potential to catch up.

In contrast to mothers who sought out explanations for their children's atypical development, several mothers created meaning by interpreting the diagnostic process as limiting, as it was incongruent with their subjective experiences. Tanya expressed her ambivalence regarding the label of "autism". She believed that labels were uninformative as they did not describe the broad range of impairment and may operate as stereotypes that limit or constrain others' expectations of her son's abilities. For her, the use of the label "autistic" categorized her son as severely impaired and did not acknowledge her subjective experience that included variations in her child's behaviour that were atypical of children with autism.

I think Autism is...I consider Autism a label. Whereas Autism Spectrum Disorder puts them somewhere on the scale, instead of just labeling them. To me Autism is a label. I mean not every child who is Autistic acts the same way.

She preferred to interpret the label "autistic" within a range of diagnostic indicators. She was fully mindful of her son's limitations, specifically in terms of his language development; however, she did not accept that the impairment was sufficiently severe to warrant the all-encompassing label of autistic.

Recognizing the range of behaviours that can fall within a single diagnostic category emerged as an important aspect of participants' meaning-making processes, as they placed greater value on their subjective experiences of their children, rather than clinical descriptions. Tanya, Jessica and Samantha fully acknowledged that their sons experienced some degree of impairment in their social relationships, language development and behaviour. At the same time, they all described their children in ways

that confounded the stereotypical behaviours associated with autism. They experienced their sons as affectionate and able to sustain emotionally close relationships. As Jessica stated, “Well, his behaviour isn’t really autistic, because he’s very affectionate.” Choosing to step outside the limitations of the diagnostic indicators was an important aspect of resilience-building as it created space for participants to develop positive meanings from their children’s disabilities.

Even in situations where mothers consciously resisted the label given to their children, they recognized that the use of the label was beneficial in establishing eligibility for additional educational and therapeutic services. Jessica had found support in her dispute of her son’s label of autism from his pediatrician, although both she and the pediatrician acknowledged that her son presented behavioural challenges, and was considered “a difficult child”. As Jessica stated, “they were saying autism just so that they could get him into the program and get him started on, you know, getting the attention that he needed.” This highlights one tension that is created when support services are based on categorical, rather than family-defined needs. Although Jessica expressed disagreement with the constraints of her son’s diagnosis, she recognized the necessity of acknowledging the label as the primary means by which to access services. In essence, mothers are left to choose between resisting the cultural constructions of their “children as disabled”, thereby denying the provision of support and risking further blame for medical or psychological neglect, or accepting the definitions to ensure that their children receive the assistance they require, at the cost of accepting the stigma and constraints of the label.

Several participants identified that the diagnosis shifted their perceptions and expectations of their children. After her daughter was diagnosed with autism, Oxsana described how she consciously made the decision to refocus her attention toward remedial or therapeutic actions she could undertake, rather than fixating on her daughter's limitations. The positive impact of her meaning-making process became evident as she focused on the abilities of her daughter, rather than the disability.

But then I started taking a different approach and what I did was start focusing on the things that (child) could do rather than the things that she couldn't do. And then I found that I was more relaxed and things started falling into place for me, and wherever I can go and, like for seminars or classes or you know, talking to other families or anybody that know a little bit more about autism, I find that really helps.

Moreover, the label itself held minimal meaning in terms of mothers' relationships with their children. Several mothers perceived the diagnosis as one event that was less significant than other events they had faced. As Tanya noted, "He comes home and I feed him and I bathe him and put him to bed like any other child. There's not a whole lot of difference between him and another child." Oxsana expressed similar thoughts about her daughter.

I never really, like even though that she was diagnosed with autism, I never really, I don't know. I don't really think of her as having a disability because it's a part of my routine, you know. She's my child. It's something that I would do no matter what, disability or no disability.

Within the childhood disability field, children are by virtue of their disability perceived by others as different. In this study, it is important to note that none of the children had physical disabilities, were medically fragile or technology-dependent. All of the children were diagnosed with non-visible developmental disabilities. These were manifest as developmental delays, impairments in language and communication, cognition and social relationships, and behavioural problems. Therefore, although the children were diagnosed with disabilities, the diagnoses were not immediately apparent. Within this context, mothers created positive meanings from their children's diagnoses by moving from the position of "children as disabled" toward the subjective position of "children as different". The majority of participants negotiated these shifts by rejecting others' characterizations of their children, and instead, defined them as individuals with their own unique attributes and abilities. Mothers consciously reframed their children's disabilities in ways that did not minimize the challenges, but developed alternative perspectives that incorporated children's difference. Reframing allowed mothers to process their thoughts and feelings, to challenge others' beliefs regarding their children's abilities, and to re-evaluate their expectations and parental roles. Caroline summarized the "disability as normal" position when she stated, "Disability is not the term I use when thinking about my child."

Spirituality and Faith

Mothers' found meaning in their lives through consciously embracing aspects of the spiritual domain. Faith may encompass convictions about religion, defined as organized belief systems, including shared and institutionalized moral values, beliefs

about God, and involvement in a religious community (Walsh, 1998). Faith may also refer to spirituality, a concept that transcends formal institutions, and embraces internal values that bring a sense of meaning, peace, wholeness and connection with others. In this study, beliefs and practices regarding faith were a key process in family resilience as they contributed toward mothers' abilities to manage stressful circumstances and consequently, their capacities to adapt. The intersection of spirituality and women's well-being was reflected in mothers' conscious embracing of faith in a multiplicity of expressions. Participants referenced spiritual beliefs and practices as critical processes that provided a sense of meaning, purpose and hope to their lives.

Providing hope and social support. For some participants, their expressions of spirituality included affiliations with formal religious organizations and regular church, temple or mosque attendance. Other participants described engaging in less formal practices that held significant cultural meaning. Still other participants specifically rejected structured religious adherence in favour of connections with nature and self-defined spiritual communities. These spiritual practices provided participants with social support through connecting with others, a belief in a higher power and hope.

Samantha described how she connected with others in her Temple to access social support as a means of coping with stress.

I believe going to the Temple, it's just a way for me to express how I feel and what stress I'm having at home, and there's people there that you can talk, you can sit down, eat with each other, you know. It just makes you feel better, like there's hope.

Patricia also described how she recognized that she needed additional support, and how she intentionally looked to her neighbourhood church to fill this need.

And actually, what I find to be a real support to me is I recently became a member of the church across the street. And I'm finding the people to be very supportive and I'm getting involved in some activities there and I'm really finding that very helpful and very supportive. I don't feel so much a sense that I'm completely all alone anymore, cause I feel that we have kind of a church family now for me and the kids, and that they'll be keynotes sort of for the kids too and that and kind of guide them in the right direction, and that means a lot to me.

Other participants engaged in more solitary spiritual practices, including meditation and yoga, as a means of coping with stress. Rochelle explained how she drew upon her faith during periods of struggle and "hard times" as means of coping.

A lot of people don't believe in the natural healing of herbs, of certain, well I call them rituals. But it does help. The Sweat Lodges and the different types of herbs. There are medicine bags which do work. I've had one now for 6-1/2 years and through every hard time that I've went through, it's been there for me. It's almost as if, you know, my forefathers as I put it, they're there, they're watching, they're guiding.

Chosen mothers. Several mothers described how their expressions of faith affirmed their beliefs in a higher power, by acknowledging that they were specifically chosen to raise children with disabilities. Mothers expressed how the personal meaning of spiritual resources, in the context of their children's disabilities, extended beyond

providing social support toward providing an explanation for their situations. It was not uncommon for mothers to express their perceptions that God had chosen them because of their particular strengths and abilities. As Marta described,

Having a child with disabilities puts your feet on the ground and I think that God chose me because He knew in my heart that I was a good person. So when He gave me (child) it kind of brought me to reality and caused me to put my feet on the ground.

Samantha expressed similar thoughts.

Well, God wouldn't give you the child if He, you know, didn't know you were going to be able to do it. And I think He knew I could do it, and I don't want to think anything negative. You know you have a child and I think that's very good. Some people can't have children.

For some participants, these ideas came from others, but helped participants to create meaning for themselves. Oxsana described, "I remember talking to this older lady once and she said to me, you know dear, God only gives us what we can handle, and you know, I was like really serious and I thought, you know, she's right." Mothers expressed that even at the most difficult times, they embraced the task that God had given them, and relied upon their spirituality to cope with the stresses they encountered in their lives.

Positive Outlook

Optimism. Maintaining a positive outlook is a key attribute of resilience, and families who embrace optimism are more likely to successfully manage when faced with difficult or crisis situations (McCubbin, 1998). Optimism may be defined as the degree to

which one tends to expect positive outcomes to life events. Although participants encountered a number of challenges associated with single-parenting and childhood disability, they did not perceive these as reasons to feel hopeless or helpless. There is emerging evidence to support the hypothesis that positive perceptions and cognitive appraisal function as key strategies to assist families in adapting to raising children with developmental disabilities. Moreover, positive perceptions can occur concurrently with negative or stressful events (Hastings & Taunt, 2002). The mothers in this study were not assessed as being in “denial”. They concurrently acknowledged the challenges of single parenting special needs children and at the same time, articulated positive aspects of their experiences. This highlights the importance of a two factor model when examining parental response to childhood disability (Margalit & Ankonina, 1991). Furthermore, mothers who identify positive perceptions of their experiences also reported higher levels of psychological well-being. Mothers described themselves as “not usually down in the dumps about things”, “I’d rather be happy than miserable,” to “I’m a pretty positive person so that makes a lot of difference I think,” to “I am happy to be a single mom. I...if (child) was a different kid I would have easily had another kid on my own.” Oxsana highlighted the necessity of maintaining a positive outlook on parenting a child with a disability.

It (optimism) helps to put things into perspective. I mean if it’s not me, it’s going to be somebody else and I think it helps me to become a stronger person. I think I’m a strong person to begin with. I never used to think that, but I mean I’ve been through a lot over the years and you know, had to deal with a lot of things on my

own, with very little help. And you know, it's just, for me, when I look back at things, it's like everything that has, that's been thrown at me, I've been able to deal with it, you know. It hasn't been easy but you know, you figure out a way and you deal with it and you move on, you know.

The Parent Morale Index (Trute & Hiebert-Murphy, 2005) may be used to assess how transient mood states influence an individual's perspective on parenting. Results from this study indicate there were no significant changes for the participants between Time 1 and Time 2. This may suggest that to begin with, even in a context of high stress at Time 1, the participants in this study were generally positive and experienced fewer negative mood states. Positive mood states, success in addressing the challenges associated with dealing with systems and children's behaviours, and satisfaction in one's maternal role may lead to greater self-definition as a "strong", capable and competent mother.

Family Resources/Protective Processes

Family functioning is a multidimensional construct reflecting a family's activities and interactions that are either effective or ineffective in enabling a family to meet its goals, provide for its members' material and emotional support, and foster members' well-being and development (Walsh, 2003). The integration of family stress, family adaptation and family resilience models emphasize the importance of family cohesion and flexibility.

Family Cohesion

Family cohesion refers to elements of emotional bonding, supportiveness, family boundaries, and interest in recreational and leisure activities (Olson, 1986). It is noted to be an important coping resource for both low and higher income, single-parent families, as previous studies found it has a positive influence on low-income families' abilities to cope with difficult situations (Orthner, Jones-Sanpei & Williamson, 2004). In this study, family cohesion was reflected through participants' narratives that highlighted the primacy of the mother-child relationship, and the strategies they undertook in order to strengthen their relational connections with their children.

Mother-presence. As previously discussed, the participants arrived at single-parenthood through a variety of avenues. Regardless of the means by which it occurred, mothers described the end result as reflecting their true priorities in terms of their relationships with their children. In contrast to socially constructed perceptions that female-headed, lone-parent families are deficit due to the absence of one parent, the majority of mothers in this study transformed the context of father-absence into positions of "mother-presence". For the majority of mothers, being physically, emotionally and unconditionally available to their children was the essential component of their role as single-parents. Hannah discussed the choices she had made, notwithstanding the limitations it placed on her social and emotional needs. She stated, "I think I chose to be a stay at home mom and I chose to make my life revolve around my children's needs and I

chose to have the social life of a four year old.” Tracy’s position on her maternal role further illustrates this theme.

I’m the one who gives him breakfast, getting him up in the morning, and getting him out the door, and I’m going to be there when he comes home from school.

That’s a big thing. You never miss, you never miss anything. You’re always there.

Debra’s husband had completed suicide several years earlier. Although the death of her husband was tragic, the meaning for her became one of ensuring that her children could participate in numerous social and recreational opportunities within the community. She was well aware that she would not have had the time for these activities if her husband were alive.

Maternal self-sacrifice remains a powerful theme in both private and public discourse. However, the data suggests that rather than maternal sacrifice being constructed as a “giving up”, it reflects their choice of “giving to”. Sarah stated “You know, women will give up everything for their kid. I mean I would. Whatever he wants I can do it.” Marta, whose 20 year-old son lived with her, expressed some disillusionment over her financial situation, but prioritized spending time with her child.

My budget is tight but I’m used to it you know. I think because my needs are covered, but to be able to go to the movies or holidays, or something, there’s no money left over. There’s no money left to buy new things. That’s why something I think I should do is take another part-time job but then I say no, because then I would have less time to spend with (child).

Patricia also described the importance of her maternal role.

Well, I guess just that I make them my first priority and you know, I always think of them first and do everything for them and they know that they're loved and so, that's a good thing I think.

For Samantha, "mother-presence" extended into her children's future.

I'm there for them all the time and I plan to do that when they get to high school.

I want to know, be there, the graduation, everything, from sports, I want to be there. I'm committed. If I say I'll be there, I'll be there. That's my thing.

The theme of mother-presence was further demonstrated through participants' decisions to remain single. Women who were not in current relationships linked their decisions to the fact that they prioritized their relationships with their children over their own needs. They believed that partner relationships would reduce the amount of time available to spend with their children. Their decisions were also motivated by their concerns that partner relationships could potentially harm their children. Patricia clearly identified that maintaining the best interests of her children precluded any thoughts of intimate relationships.

No, I don't have any relationships. My kids are my whole life. I don't have time for relationships, and I'm really committed to giving them my time and don't have enough time as it is. And also, I don't want to have my kids exposed to, I don't want my kids hurt by men in my life, and what I mean by that is, even by the positive turning into a negative, like if someone comes into their life and they start seeing this person as a father figure and then one day he walks out the door

and he's gone. It seems to be so easy to walk away, and I don't want them to be hurt by that.

Participants who were in relationships maintained clear boundaries around the role of the non-resident partner. Hannah clearly outlined the limits of her family's relationship with her non-resident partner. "I still define myself as a single mom. The kids call him our guy and he's not their dad and he never will be. We will never get married or anything."

The Parental Distress subscale of the PSI-SF assesses stressors described as restrictions on life roles, an impaired sense of parenting competence, conflict with the child's other parent, and depression. Scores above 36 are considered to be in the clinical range. Therefore, this subscale is appropriate for examining issues related to participants' perspectives on their maternal roles. At Time 1, eight participants' subscale scores were in the clinical range. At Time 2, 11 of the 15 participants scored had decreased (73.3%), and 4 remained above the clinical cut-off (Table 3). In calculating the RCI for the Parental Distress subscale, 6 participants' scores indicated clinically significant change.

Although initially mothers may have reacted to the diagnosis of their children with feelings of worry and concern regarding their ability to manage the challenges of parenting a child with special needs, four years later the subscale scores indicate the majority of mothers experienced less parental distress. As indicated by the qualitative data, participants found meaning in their maternal roles and did not perceive their situations to be personally limiting. Additionally, the fact that only three fathers maintained some form of contact with their children eliminated the potential for conflict.

Although not all the women chose to be single parents, resilient mothers were able to move beyond the challenges of single parenting children with disabilities and embrace their maternal roles. Despite the challenges of disability-related issues, single-parent status and significant time pressures, mothers described thoughtful and intentional actions directed toward strengthening and prioritizing their relationships with their children.

Emotional bonding. Walsh (2001) has identified that open emotional expression between and amongst family members is a key process in family resilience. The importance of family cohesion was made evident through participants' expression of emotional connectedness with their children. Mothers described the emotional expression within their families as "everyone loves each other", "loving", and "lots of love and laughter", "we all love each other, you know" and "we laugh a lot and they really love each other, and we're a very close family."

In comparison to mothers of typically developing children, mothers of children with disabilities are frequently unable to celebrate the achievement of developmental milestones within normal parameters. Notwithstanding the relatively delayed time frame, mothers described their children's "firsts" as a source of great pleasure. Tanya stated "We're very close. We like doing things together. We like family outings. Going to parks and um, this summer (child) learned how to feed the ducks at the park and he loves that." Jessica stated, "Last year he learned how to ride without the training wheels for the first time. It was really neat." Hannah also highlighted the importance of her children's "firsts",

I like seeing their expression when something happens for the first time. The first time my kids felt snow. Or the first time they learned how to walk. And now they're taking swimming lessons. So the first time they learned how to swim. Um, we went camping this summer, for the first time. Just the two of us. Playing with beavers. I like um, I like the fact that (child) is learning how to read now. Like he comes home with his home reading book and he reads the whole book.

Emotional attachments between parents and children are enhanced when parents initiate positive interactions with their children that are joyfully received. Additionally, emotional attachments partially develop from parents' abilities to interpret children's expressions of need and respond appropriately. Despite their children's developmental challenges and limited capacities for emotional expression, the data revealed mothers' tireless efforts to promote relational connections with their children. Participants recognized that despite their children's limitations, a critical component of their role was to provide the secure emotional base from which attachment develops. Mothers recognized their children struggled to express themselves, and they believed their ability to act as an emotionally "safe" outlet for their children was a necessary part of their maternal role. Tracy indicated that for some parents, the capacity to interpret their children's emotional expressions may be challenged if they are not fully cognizant of the limitations of the disability. She highlights how even though she is at times the recipient of her child's expressed emotion, she intentionally moves beyond the superficial negativity with the goal of acting as the secure base.

Being the mother of a disabled child makes a difference in your life. As long as I know, when he's having a bad day, you know, "I hate you mommy", like as soon as he's finished then "I'm sorry, I love you." So that's a big thing.

The capacity to emotionally connect with their children is exceptionally salient for mothers of children whose diagnoses were within the autism spectrum. Despite the perceived limitations associated with this diagnosis, Samantha expressed her pleasure in her son's unique abilities and his capacity for communication.

When I look at my child, I'm so happy. I don't know just something inside that makes me happy. He laughs and he giggles. He just, he makes me happy when I see that he's trying to motivate himself and he wants to play with me or, he wants to go outside or whatever it is you know. He's trying to talk back to me. He'll come to me and go ahh, the ahh sound. And he's really trying. He's telling me he wants to talk. That's when I'm happy that he's, you know progressing,

Mothers recognized the importance of separating issues related to children's delays from the nature of their relationships. Margaret described how she was frustrated by some of her daughter's challenges, but chose to locate the difficulties within the disability. In essence, she established a context in which the "problem" became the disability and not the emotional relationship with her daughter.

I think (child) and I have a pretty good relationship. I um, you know, I am frustrated with her uh, in ways that I think are related to her delay. But she's a lovely child. I think we have a really nice, close relationship, uh, hopefully, you know, I am hoping we do. I certainly enjoy my child tremendously.

The Parent-Child Dysfunctional Interaction subscale of the PSI-SF focuses on the parent's perception that her child does not meet her expectations, and that the interactions and relationship are not reinforcing for the parent. In this respect, it assesses family cohesion in terms of the emotional bonding between parents and children. Parents who score above 27 project the feeling that their child is a negative element in their life. At Time 1, seven participants' scores were in the clinical range. Although there was a decrease in the Time 2 mean, the difference was not statistically significant. Ten participants subscale scores decreased between Time 1 and Time 2 (66.6%), and five remained elevated. In conjunction with the interview data that indicated mothers expressed feelings of empathy, emotional warmth, closeness and affection for their children, the quantitative results suggest that mothers had developed ways of emotionally connecting with their children, notwithstanding their children's limitations.

Family Flexibility

Family adaptability or flexibility generally refers to the capability of the family functioning to change when the situation requires. Both Patterson (2002) and Walsh (1998) note that the ability to achieve a balance between change and stability is a key process in effective family functioning. Mothers negotiated this balance of retaining stability, in ways that were appropriate to the different needs and developmental capabilities of their children. Family flexibility was most evident through participants' undertaking disability-specific adaptations in their interactions with their children, with extended family members, and in their interactions within community.

Disability-specific adaptations. All mothers described situations in which they had undertaken disability-specific adaptations in response to the needs of their children. Green (2003) has noted that coping with the reactions of others to children with disabilities contributes toward mothers' emotional distress. Mothers identified that although they did not experience their child as disabled, they frequently needed to negotiate with both family and community members, social or behavioural adaptations that took into account their children's difference. Sarah described the need to do some things differently as "We're a little bit apart from people. We're a little bit different. Um, we have to be a little bit tougher I think. And just...we just gotta get through. And not everybody understands." Rochelle described the importance of integrating a "normal and special" understanding within her extended family.

Exactly, and here like with my family understands now. You know, like this is what is wrong with them. Like they're normal children, but it's just that they just have something a little bit more special and we have to deal with it on an ongoing basis, one thing at a time.

Mothers also undertook disability-specific adaptations within their social contexts. When a child is disabled, it is the mother who enacts strategies to promote her child's integration into the outside world (Deatrick, Knafl, & Walsh, 1988; Morse, Wilson, & Penrod, 2000). How mothers negotiated public spaces became exercises in creativity and flexibility. Debra described how she and her son would attend community events, with her undertaking the necessary adaptations to address his disability-related

discomfort in social situations. Debra's modifications encouraged both a sense of normalcy and a sense of belonging, while remaining mindful of her son's limitations.

He's not too keen in crowds and he's not too keen in noises but I still take him out to things. We still go to hockey games. We still, okay we might not go anywhere, we go and we sit in our seat and we don't move, because we've got our seat. But that doesn't mean we don't go and mix with two or three thousand other people at a hockey match.

For mothers whose children have behavioural issues, negotiating public spaces can be extremely difficult due to environmental and structural constraints. In response to these challenges, mothers undertook specific adaptations to emulate a normal appearance of family life through inclusion in activities in public spaces. They acknowledged that although spending time together may be accompanied by public disapproval, it was important for them to tackle these challenges and not internalize others' perceptions. As Sarah stated,

Like you can't even worry about that. Like who cares what other people think. I mean I don't care. We just have to get through this. It just doesn't bother me what people think. I like to get along with them and things like that but we have to do what we have to do to kind of get (child) through.

Establishing protective boundaries around the family unit was a common theme amongst the mothers. However, often when socializing in the community, Sarah noted that her active and necessary involvement in her child's social relationships was interpreted as being "over-protective".

Some people would say I am over protective of him if they don't know the situation. Once they know then they, you know, they can understand it. But he appears normal so if...you know, he appears normal and I am kind of the buffer so it can seem a little odd. But I find if I don't do that, he has a lot of meltdowns and things just don't go well for him.

Other mothers, while undertaking the necessary adaptations in their parenting practices, expressed some distress regarding their need to alter their behaviours in response to their children's disabilities. However, they too were able to develop strategies that accommodated their children's needs. As Margaret described,

This evening for example, I am not going to be able to care for her and uh, my sister is going to be picking her up after school. She's going to be going to my mom's house and she doesn't like going to my mom's house as much as she does my sister's. And uh, so I didn't even tell...discuss it with her this morning, which I feel crummy about. But I just didn't...because she wouldn't process the fact that she's going to grandma's but not to stay overnight. And when I think of some of her little friends. They understand that and grasp that immediately, whereas she will have such a convoluted thought with that and I can't even express it.

She clearly expresses her feelings of guilt over her need to adapt how she manages communication with her daughter in a way that she will understand. However, despite the expression of guilt, Margaret's experience highlights how mothers undertake disability-specific adaptations on a daily basis in order to make life as easy as possible for their children.

Disability-specific adaptations also included utilizing outside resources and services. Although parents of typically developing children may attend parenting seminars or other voluntary programs, mothers of children with disabilities need to develop a different level of comfort with these types of services. Patricia identified that utilizing respite was an important adaptation for her, as it allowed her the opportunity to “step back” from particularly difficult days, giving her the chance to regroup and continue to deal with her children’s behaviours.

The respite that I get is important because even if I just need to take a step back and let somebody else deal with their difficult behaviours and their tantrums and their moods and their fighting for a change, you know, if I can just kind of take a deep breath and take a step back, because I like to be really patient with them all the time, but unfortunately sometimes when I get really stressed out and I just kind of am at my wit’s end and don’t know what to do, you know, it gets hard.

Participants also described attending disability-specific information sessions that required considerable initiative, and demanded an outlay of energy and time that was not always available. Oxsana made it a priority to attend information meetings about autism in order to promote her daughters’ development to the best of her abilities.

I find for me, I really like to get involved, like I can’t get involved in volunteer and stuff and all that, because I mean, it’s hard, I have to work and stuff, but anything that has to do with (child), meetings, anything like that, I make sure I go. If it’s something that I can’t go to and I can call and talk to them about it, I do that.

Although all mothering entails a variety of caregiving and advocacy tasks, mothering a child with special needs has been described as “mothering plus extras” (May, 1997, p. 18). The extras include needing to inform themselves about the diagnosis, educating others about the needs of their children and adapting both the social and physical environment to facilitate the development of their children. Single mothers assume these additional responsibilities in the absence of a second parent. These findings suggest that participants became extremely adept at changing their behaviours in order to accommodate the needs of their children. Although at times difficult, resilience-building was facilitated by mothers’ conscious decisions to undertake whatever steps or actions were necessary in order to make life as easy as possible for their children.

Social and Economic Resources

The family stress, FAAR and family resilience frameworks emphasize the ability to effectively utilize social and economic resources to manage family demands as a key resilience-building process. Findings indicate that regardless of whether supports were available or not, resilience was facilitated through mothers’ abilities to “carry on” particularly when they encountered barriers. This required mothers at different times to utilize existing resources or to develop new resources.

Perseverance. According to Walsh (1998), resilient families persevere when they encounter difficult situations, exhibit courage, sustain hope, maintain confidence and direct their energy toward what can be changed. In this study, mothers’ decisions to persevere when they encountered structural and/or institutional barriers were most apparent in their interactions with the formal support system. As an example of the

dynamic nature of risk and protection, the data indicated that mothers' encounters with the formal support system were at different times, both stressful and supportive.

Within the childhood disability field, formal support systems typically refer to professionally-staffed agencies that provide disability-specific services, including clinical or remedial interventions in response to identified needs of the child and/or parent. Previous research concluded that as a group, single mothers tend to have less access to resources, but when available, will utilize formal services to a greater degree than two-parent families (Mahoney & O'Sullivan, 1992). Findings from this study however suggest that the formal disability service system does not function in a manner that meets single mothers' needs. In fact, mothers acted in a resilient way when they chose to step outside of the constraints of the formal system, particularly at times when it was clearly inaccessible. As Hannah's description of a particularly negative experience suggests, the formal system may be perceived as an avenue of first choice to provide support for single-parent families. However, it was her ability to persevere and utilize her informal support system that resulted in her accessing the support she required on an especially difficult day.

I phoned (worker). I phoned (a second worker). And I phoned my mom. And I said I cried on everyone's answering machine. And it was horrible. And I said to my mom you have to come get this kid cause if you don't come get him I'll just phone social services and tell them to take him away. I said I can't deal with this. And no one called me back. If I am this upset, somebody should have phoned me back. Even if it wasn't her. And I can't say she never called back. She may have I

don't remember, but I know she didn't call back the same day. Or even like the next couple of days.

Other participants described that their education and support needs were met by the informal parent support network available through the internet. Tracy found this to be a useful source of information for parenting special needs children.

I go there and then I have my little bit of chat. If I just want to hear other people's problems, then I sit and watch what they're saying or I can hear something, there's a lot of people you meet on there that have kids with the same thing, and it helps talking and they will give me points on what they tried, so I will try that and sometimes it works and sometimes it doesn't.

In comparison to married mothers, single mothers are more socially isolated, and receive less emotional and parental support (Keating-Lefler, Hudson, Campbell-Grossman, Fleck & Westfall, 2004). Findings from this study suggest that single mothers of children with disabilities have additional information or support needs that require them to access different support strategies. For mothers who may not be able to access traditional forms of parent support groups, connecting with others through the internet appears to be a viable alternative as it is a useful means of accessing information and services (Blackburn & Read, 2005). Moreover, the use of computer-assisted social support is emerging as an important factor in reducing parenting stress for single mothers (Dunham, et al.1998).

Within the context of formal support services, tension was created particularly when participants challenged "professional" knowledge regarding how best to manage

their children's behaviours. This became most apparent in mothers' interactions with educational systems. Participants expressed how school staff did not consider them to be knowledgeable about the educational needs of their children. This translated into school staff taking the position of "expert" with respect to knowing what was best for children with special needs and minimizing input from mothers. Debra described how her son failed physical education because he was not able to answer the questions on a test that focused on initiating friendships.

He failed PE because the teacher was not tuned into him. He received only 1 out of 30 on the tests. I said, but what were the tests on? "Well, how to make friendships and develop relationships." And I just threw my hands up in the air and said, he doesn't get that. He makes friends a different way than you make friends. "Oh" she said, "but he's got to know this."

Despite Debra's vigorous attempts to inform school staff about the dynamics of Asperger's (impairment in social relationships being the primary diagnostic criteria), she was met with:

'I've heard it all before. I've taught for 20 years. I know what I'm doing.' I think, okay, you've got problems. I had a run-in with one of the counselors at school who told me she'd been to a lot of seminars and knew all about Asperger's, and yet what she was advocating was just not suitable at all. 'I've been to this and I know what I'm talking about.'

Debra went on to describe how her attempts to deal directly with the problem were met with considerable resistance. As she stated, "Well they just see me as that mother that's

always phoning the school.” Through her continued effort, she was able to enact some change in the school environment.

It’s like the boomerangs. I have to go and throw it in the principal’s office and it comes back. I think I’ve created a problem here but if this will help things get on in grade 10, I think we really should move. I did it in a kind of roundabout way, the same way as I’ve treated (child). I’ve treated the school in the same way and we got changes. You never go in the front door. You never go in the front door. Go in the side door.

The socially constructed representations of single-parent family structures can further result in women being blamed for challenging the status quo. Decisions made by single mothers that do not conform to what is expected of them are vulnerable to critiques, and mothers identified that their interactions with formal support systems often created additional barriers. Oxsana chose to return to post-secondary education as part of her long-term plan to secure better employment and lessen her financial stress, but was met with considerable resistance and a distinct absence of both emotional and financial support.

It’s hard and I do what I have to do and you know, I find, when I first started the course I was taking, I was really having a hard time financially because I, you know, you fall behind in things and I wasn’t able to work as much as I had hoped. And just trying to get help and one of the things that, I never really followed up on it, but I wasn’t really impressed with the way this one lady dealt with me. She was like, “oh you know, we never, we never sent you to school. You should quit it

and if you're this early into the program and you're having financial problems maybe you should quit it, you know. It's not like you're a couple of months from finishing and you know there's other people out there with children that, you know, that have children with disabilities or whatever who are working."

Oxsana had chosen to return to school, and cope with the increased multitude of role demands of child care, work and studying with the view toward improving her family's well-being. For her, the stress was not a function of juggling the roles of parent, worker and student, but from the attitudes expressed by others that diminished her feelings of knowledge, competence and self-confidence. She illustrates how others constructed the "problem" as her decision to attend post-secondary school, which speaks to the power of professionals to objectify single mothers. Even when they are acting in opposition to the dominant images, mothers are penalized for their efforts. Social workers and other professionals continue to perceive lone mother families to be victims of their own choices, and thus, their interactions with single mothers are more punitive, rather than supportive (Rhodes & Johnson, 2000; Schmitz, 1998). It remains difficult to challenge the belief that problems experienced by single mothers are a result of inequitable social policies, and far easier to retain beliefs that locate the problem within mothers' poor decision-making.

In contrast, Rochelle's experience highlighted the discrepancies within the income assistance system wherein she experienced significant pressure to return to the workforce. In the following excerpt, Rochelle (who resided in a rural area) described how her choice to remain at home with her children was severely criticized by her income support

worker, with the implication being that she “lacked motivation”. Currently, single mothers who do not become employed within a certain time period risk losing the financial support that provides for their families’ food, clothing and health care needs. Although Rochelle strongly felt that returning to work would increase the stress upon her family due to the significant depletion in financial resources, the current welfare reform policy of the provincial government that requires women with school-aged children to return to the workforce manifest the conflict between what she believed to be best for her family and what others believe to be appropriate for single mothers.

And I do want to go back to work. That’s the thing. I do want to go back to work, but it’s, I feel it’s not feasible cause by the time I pay my babysitter, pay my gas, pay my registration, I’m no further ahead. I’m more in the hole.

Especially a babysitter. Like you’ve got to have one here that’s on call all the time when you’re at work. Then there’s your gas, and there’s your registrations. There’s medication. Medication alone for the 3 kids plus myself, I’m looking at \$300 a month. And then that’s not including eyeglasses for (child), and then with dental costs, you know, it’s not feasible.

Despite the pressure, she continued to advocate for what she believed to be in the best interests of her family. In contrast to external perceptions of lone mothers as “irresponsible”, several mothers interpreted their positions of remaining in receipt of assistance as the most responsible decision. Clearly, working at an unstable or low-waged job that did not cover their families’ needs would place them and their children at further risk of financial, and consequently, emotional stress. Although mothers expressed a

desire and willingness to work outside of the home, employment would not necessarily protect the family against a loss of income, and would limit their flexibility to be readily available to their children. Oxsana was criticized for challenging the stereotyped images through displaying too much motivation, and Rochelle was criticized for conforming to the stereotyped images of single mothers. In both situations, their abilities to challenge service providers' ideas about the best interests of their families became acts of courage. Oxsana's capacity to manage the multiple role demands of parent, student and worker was fueled through perseverance, and her desire to "prove" that she was the expert on her family's best interests. She accomplished this by pursuing her education, albeit in the absence of any institutional support. Oxsana's experience highlights the tension that is created when perseverance or personal agency is necessary to overcome structural barriers.

Something that drives me is to have somebody tell me, 'Oh no, you could never do that, you know'. That's like a challenge for me, and I mean, when you get into it, you know, you're really not sure you can do it yourself either. But you want to prove to them, prove to them that you can do it and prove to yourself that you know, you might be able to do that. So that's what keeps me going lots of time.

The issue of mothers' knowledge regarding appropriate services provides another example of mothers' needs to keep going, particularly when mothers expressed disagreement with their children's diagnoses and subsequent recommendations for interventions. When reflecting upon the time of her child's diagnosis, Hannah described

how her knowledge regarding her son's behaviours and subsequent request for specific services was neither heard nor respected.

My thoughts were I did not have a special needs child. And I still don't think I have a special needs child. I have a very angry child. A very angry child and in 2001 I asked for a behavioural specialist. I still haven't got one. I've had occupational therapists. I've had a child development worker. I've had a home visitor but I've never had a behavioural specialist yet. Which is the only thing I asked for.

Although Hannah's personal and subjective knowledge of her son was re-interpreted by the "expert" knowledge of the disability support worker as sensory, developmental or parenting issues, she continued to retain her perspective on her child as the more accurate viewpoint.

Even in a context where the problem has been acknowledged, mothers are constructed as being responsible for its creation. Upon the recognition that her son's development was markedly atypical, Debra described how several professionals labeled her as "interfering" in her attempts to access appropriate intervention services.

"Don't make so much fuss and let go the apron strings and you've got to let him go." I even had a psychiatrist tell me I was too domineering and I had to let him live his own life. I was "an interfering mother" and I had to learn to let go the apron strings.

The experiences of Hannah and Debra reveal the importance of the relationship between perseverance and resilience. Mothers repeatedly needed to advocate with service systems in order to access the appropriate services for their children.

The theme of perseverance was further made evident in relationship to the construct of time. Time obligations to extended family, domestic labour, and employment were experienced as highly stressful, yet mothers continued to negotiate these challenges on a daily basis. Patricia's narrative clearly describes the time pressures participants were subjected to on a daily basis.

The everyday life is a challenge. I mean, every morning I have to get them up when they don't want to wake up at all, at all, and get them dressed and get them off to daycare and school, when they really, really, really don't want to go. And then rushing off to work and then dealing with the stresses of work and then rushing to go pick them up and then trying to force (child) to do his homework. Oh god, that can be such a battle, and just being really, really tired and needing to care for them and all their needs.

Her words reflect the cultural expectation that mandates mothers to simultaneously undertake unpaid caring work, be emotionally and physically available to their children, and participate in paid employment, and/or attend school. Time is of central importance to single mothers as they are expected to provide for both the instrumental and affective needs of their families, but with significantly fewer resources, of which time is the critical factor. Despite these stressors, participants described how they negotiated the multiple demands on their time in a manner that represented their

capacities for perseverance. As Patricia described, although life as a single parent is not without its challenges, she continued to “keep going”.

Well, very busy. It's race, race, race from when you get up in the morning till when you go to bed at night. Very, very busy. Hard to keep up with everything that needs to be done. It's very rewarding in a lot of ways. I mean, I know that my kids need me and that kind of keeps me going sometimes and you know, keeps me kind of putting on a good face even when I'm not feeling the best, and I know that I'm all they have to depend on, so I have to be okay even if I have a really bad headache or whatever, I still have to function no matter how bad I feel. So but I can do it because I know I have to and I really love them, so you do what you have to do, you know.

Marta expressed a similar focus on the needs of her children as her motivation for juggling the multiplicity of demands as a single parent.

Sometimes you feel there's mornings that I remember that you feel, oh my God, I'm alone. What I'm going to do? You know, but then you start thinking, no, that's the thing. You are alone and the kids have nobody but you, so you cannot fail them. Get up and go, go, go. Push yourself.

Participants' words revealed how single mothers make decisions every day to “keep going”, even in the face of at times, seemingly insurmountable barriers.

Family of Origin. The intersection of disability and the future required mothers to undertake more active planning processes for their children. Although all parents likely have some worries about their children, single mothers of children with disabilities are

acutely aware that their children's futures are inherently more challenging. Specific concerns range from worries about the degree to which their children will be included in society, concerns regarding education, employment and economic independence, and who will provide ongoing care (Heiman, 2002; McLinden, 1990). In this study, mothers expressed worry about the impact of the disability on their children's future education, employment and relationships. They worried that their children would not be safe without appropriate supervision in the future. They worried about where their children would live, and with whom they would live. Several participants tried not to perseverate on their worries. Samantha expressed, "I worry a lot about what will happen to my children. But I don't think, I try not to think about it so much, you know, that's the only thing. I think it's everybody too, not just me, you know." Margaret stated "I have a lot of worries about her future. I have a tremendous amount of worries uh, which I try and not think about. Um, you know, I have worries that she's going to be looking for love in all the wrong places, having not had a father figure in her life." Tanya described her worries regarding her son's future, but within a context of hope for him to be as "normal" as possible.

I think about what kind of independence he could have. If he'll ever be able to function on his own or what kind of job he'll be able to do and I think about that kind of thing. Having a family of his own if that's even possible. Yeah, I have concerns for his future. I just wish somehow I could see in the future and know that he's going to be able to be as normal as he can.

Whereas mothers of daughters expressed worry about their future relationships, mothers of sons expressed greater concern regarding their future education and employment opportunities. In the following passage, Debra expresses her dilemmas regarding her son's employment-seeking prospects.

I'm quite worried about how he's going to get on when he has got to apply for a job on his own. Like whether I get to go in to speak to the management or do I just sit back and hope he manages on his own. I don't want to give him a stigma and I don't want him, I don't want the management sacking him because he's useless, just because they haven't given him the proper enough directions.

Resilient families are able to mobilize support from extended family and community networks when needed (Walsh, 1998). For the majority of participants in this study, the boundaries around typical definitions of family were considerably more fluid than those that define single-parent families as limited to only the mother and children residing within the same household. When defining family, all participants named at least one blood relative, primarily mothers, fathers, and siblings. Moreover, mothers identified their extended families as their primary source of social support. Although other studies have noted that extended family can be a source of "negative support" (Ghate & Hazel, 2002), mothers did not indicate that the benefits of family support were accompanied by psychological costs or intrusions into the lives of their families. Instead, the majority of women described emotionally close and helpful relationships, without any degree of reluctance in requesting assistance when needed. For some mothers, their extended

families were a significant presence in their lives from the beginning of their parenting experiences. As Hannah described,

My mom and my sister (are the most important supports). When the kids were born, they were in the delivery room. So it started like way back then. And with finding a babysitter they help look after the kids. If I need money, depending on what...I mean they wouldn't give money if I was going to go drinking for example, they would never do that. Not that I do that. Maybe if I said I was going to go drinking, they might. I've never tried. (Laughs) But they help me financially.

Findings from this study suggest that the value of family relationships extended beyond being a source of social support. A key process by which participants alleviated their worries about the future was by solidifying relational connections with their extended family. Participants described how they enacted thoughtful plans in order to foster and cultivate relationships with extended family to ensure that their children had access to social support, at the present time and in the future. These relationships did not happen merely as a function of geographical proximity, but required mothers to act in ways that would actively promote them. After the dissolution of her marriage, Sarah had consciously chosen to return to her home town, as she recognized that her relationships with her parents and siblings were meaningful not only for herself, but also for her son. She viewed her family as being a critical source of emotional support for herself, and a current and future support for her son. As she stated, "It's important to have my family

around. You know, if I need to go some place or so that (child) knows he has a good support system in place.”

The meaning of extended family was most pronounced in terms of participants’ future care plans for their children. Walsh (1998) notes that family stress typically coincides with developmental transitions within the family, and it is therefore expected that all parents will express some degree of concern about their children and their children’s future. For parents of typically developing children, worries tend to diminish somewhat as children mature, and “launching children” has become an accepted, and often eagerly anticipated, phase of the family life cycle. Parents strive to nurture and develop their children’s life skills so that as adults, they can embark upon their journey toward independence to the best of their abilities. For parents of children with disabilities, however, the worries of parenting children do not diminish upon children’s transition to an adult stage of chronological development. What is taken for granted by parents of typically developing children is fraught with anxiety for parents of adult children who will remain vulnerable throughout their lives. For these parents, the future represents a time of increasing apprehension and worry regarding their children’s safety, happiness, and quality of life. Lone mothers are confronted with the inevitable knowledge that they are unlikely to outlive their children, in the absence of another parent who can step into the roles of provider and protector. Participants overwhelmingly described their worries about their children’s future care plans.

What’s going to happen to her later on when I’m not around or if something was to happen to me? That’s my biggest thing, because right now it’s like, my biggest

problem with that is I'm really not sure what I'm going to do about (child). I don't know anybody. I mean I'm not going to live forever and you know, my thing is at least if I live long enough that, you know, I can see her grow up into an adult and then that's okay. (Child's) dad has some mental issues and I know he loves her and everything, but I can't say I'll go to my grave feeling really comfortable that she has to be left with him. And at the same time, who else?

Oxsana's description of her future worries represents the dilemma that many mothers experienced. Although she was clearly realistic regarding her own mortality, the decision regarding future guardianship of her daughter was complicated by the mental health issues of the father and the absence of any extended family in Canada. Moreover, none of the participants had identified the children's fathers as the potential guardians, nor members from the fathers' extended families. Instead, mothers relied upon their relationships with extended families and named their family members as future guardians for their children. This process was highlighted by Patricia, as she had appointed her brother as the future caregiver for her children.

My brother means a lot to me. I really love him and also I really kind of feel that I depend on him in a sense. My brother and sister-in-law are the godparents of my kids, and so it's a security for me to know that if something should happen to me, that they would take the kids.

Marta had also ensured that her son would be cared for when she was no longer able to do so by consciously fostering the relationship between her son and his sister.

I talk to my daughter. I try to get her involved because she will be in charge of him when I die, so I want us to be together and also to spend a lot of time with him. I bought life insurance for the kids, because you don't know if you're going to die young or not die young, so just in case, I have a little something.

Jessica also expressed worry about what would happen for her son, particularly because she considered herself an "older" mother. She had always relied on her sister for support, and had named her sister as her son's guardian. For those women who had not yet determined the solution, it was clear that that future plans was uppermost in their minds.

Support for the importance of establishing close relationships with extended family was found in the analysis of the Family Support Scale (Dunst, Jenkins, & Trivette, 1984). Although between Time 1 and Time 2, there was a trend toward a decrease or consolidation of overall available support, individual item analyses indicated scores for extended family (parents, siblings or other children) remained the same or increased. This was in contrast to a decrease in the perceived helpfulness of the formal service system. This suggests that the importance of extended family becomes more pronounced for single mothers as their children develop.

Extended family networks are "vital lifelines" that provide families with practical and emotional support (Walsh, 2003, p. 11). The ability to forge strong, supportive relationships with their families, in addition to their abilities to persevere in a context of significant challenges and barriers, fueled mothers' abilities to manage the myriad of daily challenges they experienced as single parents and to care for their children in meaningful ways.

Family Adaptation

A primary objective of this study was the exploration of how single mothers of children with disabilities cope and adapt within a longitudinal timeframe. This is based on the fundamental principle that the life of a family is not static. Family relationships, relational realities, coping processes and environmental influences shift and change over time, all of which play a significant role in family adaptation. Four years after families first entered the disability support system, the data indicated that the majority of participants had successfully adapted to the challenges of parenting children with disabilities as lone parents. Participants were asked to provide a retrospective analysis of their perceptions of the factors to which they attributed these changes, and the relationship of these changes to their current family situation. In terms of understanding family resilience, findings from this study indicate a significant effect for time. Although mothers continued to experience periods of stressful circumstances, they generally described lower levels of emotional distress, compared to the time periods when their children had been diagnosed. Comments ranged from "Actually, it's better. A lot better." to "I have so much more freedom now" to "Well, you know, I think I've come to terms with a lot in the last three years. I think prior to that I was, you know, really shell-shocked I guess would be the right term." Oxsana described her adaptation in terms of continuing to "think" about things, and feeling more knowledgeable about her abilities to cope.

I think actually I'm not as stressed anymore. I think in the beginning I was stressed at everything, you know. Not knowing what I'm going to do. Not

knowing what is going to happen with her. Now I think about a lot of things but I don't think I'm really stressed about it.

Results from the analysis of the quantitative data confirm participants' statements that four years after entry into the service system, life had become significantly less stressful. The overall level of family adaptation was assessed using the Total Stress score of the Parenting Stress Index – SF (PSI-SF). Between Time 1 and Time 2, there was a significant decrease in participants' Total Stress scores. Although six participants' scores remained elevated, closer analysis indicated that these were related to their children's behaviours. Therefore, the results of the PSI-SF supported the reports by participants that they were currently experiencing less parenting stress compared to when they had first entered the service system.

Child-related change. Mothers noted improvements in their children's adaptive behaviours as factors that enhanced their overall sense of well-being. Changes in children's functioning affect the whole family unit, and mothers attributed child-related change as one of the salient factors in their adaptation. These changes were inclusive of both disability-specific improvements and normative developmental transitions. Child-related factors included progression in their children's communication, language development, cognitive functioning, emotion regulation and behaviour management. Patricia indicated that her son had "matured a bit and learned a bit to cope with his feelings and to ... he's learned a bit to self-regulate his feelings". Both she and Jessica indicated that their sons did not experience as many "melt-downs" as they had previously. Tanya and Samantha noted how their sons were learning to communicate

through language. Oxsana's daughter's abilities to use picture symbols to communicate highlight the importance of understanding disability within a temporal context.

About 2 years ago, she really started using (pictures). I was using them all the time and sometimes you get a little frustrated because you're not sure if it's working or not because she wasn't interested at all. Like she showed no interest in it at all. And then just out of the blue one day, she'll come and bring you something. And I think the first symbol that she started using a lot was juice because she drinks a lot. And it's gotten to the point now where she doesn't even bring you a symbol for juice because she can say juice now.

In addition to their children's progress, mothers also attributed change to their own abilities to manage the situations. Tracy identified that in response to her son's improvement, she herself was able to cope better.

Oh, everything is easier now. He's not as demanding anymore, because he doesn't want so much anymore. You can trust him to go to the store now. He won't get lost in the car on the way. He doesn't leave anymore when I'm sleeping. Pretty much everything. It's all been easier. As he gets older, it's not so much that he's getting easier; maybe I'm just learning how to deal with it better as he gets older.

Positive change was also attributed to children transitioning to school. This was identified as a natural progression in the family life cycle, and contributed toward normalizing their family situations. Additionally, the school setting provided tangible support and opportunities for therapeutic interventions for the children. The majority of

participants specifically attributed the positive changes in their children to the fact that they were receiving extensive help in school which contributed toward increased independence.

When reflecting upon their current situations, participants identified typical parenting issues, in a context where the normality of family life was expressed by children experiencing normative developmental issues. Sarah described stress related to her son's age, independent of his disability. Moreover, in contrast to parents who experience developmental transitions as periods of difficulty, Sarah perceived the normalcy of adolescence as a "good thing".

Well, just basically...his age. You know, coming into the teenage, he wants to do more himself and uh, you know, the sarcasm, the moods. Mood swings are big. I feel for him because he's so unhappy and then he'll just switch and he'll just be the same old little boy he always was.

The Difficult Child subscale of the PSI-SF was used to assess child-related change. This subscale assesses parenting stress specific to characteristics of the child that contribute toward their being easy or difficult to manage. Scores above 36 are considered to be in the clinical range. At Time 1, eight participants' scores were elevated. Although the change was not statistically significant, at Time 2, 10 participants' scores decreased, and five remained elevated. Comments made by the mothers served to support the position that their parenting stress had decreased as their children's behaviours had improved. Although their children continued to present behavioural challenges, they did not consider these to be as stressful as they did at the time of entry into the service system.

Authoritative knowledge. The advantage of qualitative analysis is that it can reveal change that may be overlooked within quantitative formats. When reflecting upon the previous four years, the majority of participants identified that their lives had considerably improved. Although participants attributed these improvements primarily to changes in their children's developmental prognoses, a second theme that contributed toward positive change was mothers' process of gaining and expressing authoritative knowledge regarding their children.

Single mothers are subject to dividing practices wherein others' knowledge about their lives and experiences becomes privileged, and the cultural constructions of power subjugates personal, subjective knowledge that does not conform or contradicts that which is privileged. For the participants in this study, family adaptation was facilitated by shifting from positions of received knowledge toward authoritative knowledge. Received knowledge is a position of "listening to the voices of others", wherein individuals are more likely to accept others' knowledge as being more trustworthy, valid and authoritative in relation to their own knowledge or experiences (Belenky, Clinchy, Goldberger, & Tarule, 1986).

The dynamic between positions of received knowledge and authoritative knowledge was represented by the tension created when authoritative voices of others, including fathers', professionals', and family members' perspectives on the participants, their children, their beliefs, and their choices were believed to hold greater validity than participant's personal knowledge and experiences. Participants described a history of struggle between what they believed to be best for their families and others' ideas regarding what constituted appropriate choices or behaviours. Family members, friends,

and professionals were described by the participants as typically negative and highly critical of mothers' choices, knowledge, and parenting practices. Their voices were expressed at various points in the women's lives and in different contexts. However, four years later, participants described how they felt more in control with their own decision making. Family adaptation or resilience became a process of moving from knowing through listening to others to knowing developed in the context of listening to self.

Results from the quantitative analysis of the Family Impact of Childhood Disability (FICD) (Trute & Hiebert-Murphy, 1999) highlight mothers' capacities to concurrently maintain positive and negative appraisal as a key factor in resilience in single mother families. From Time 1 to Time 2, ten participants' positive scores remained the same or increased, suggesting that over time, parents are able to acknowledge and express the positive impact of having children with disabilities. At the same time, participants remained realistic about the stresses associated with special needs children. Between Time 1 and Time 2, eight participants' negative scores decreased or remained the same. Mothers' choices to remain optimistic risk being labeled as engaging in "Pollyanna" illusions that reflect their cognitive distortions rather than subjective experiences. However, it appears mothers' decisions to remain optimistic and to create positive meanings from difficult circumstances, while acknowledging the problems, contributed to their abilities to manage stressors in resilient ways. As described by Hannah,

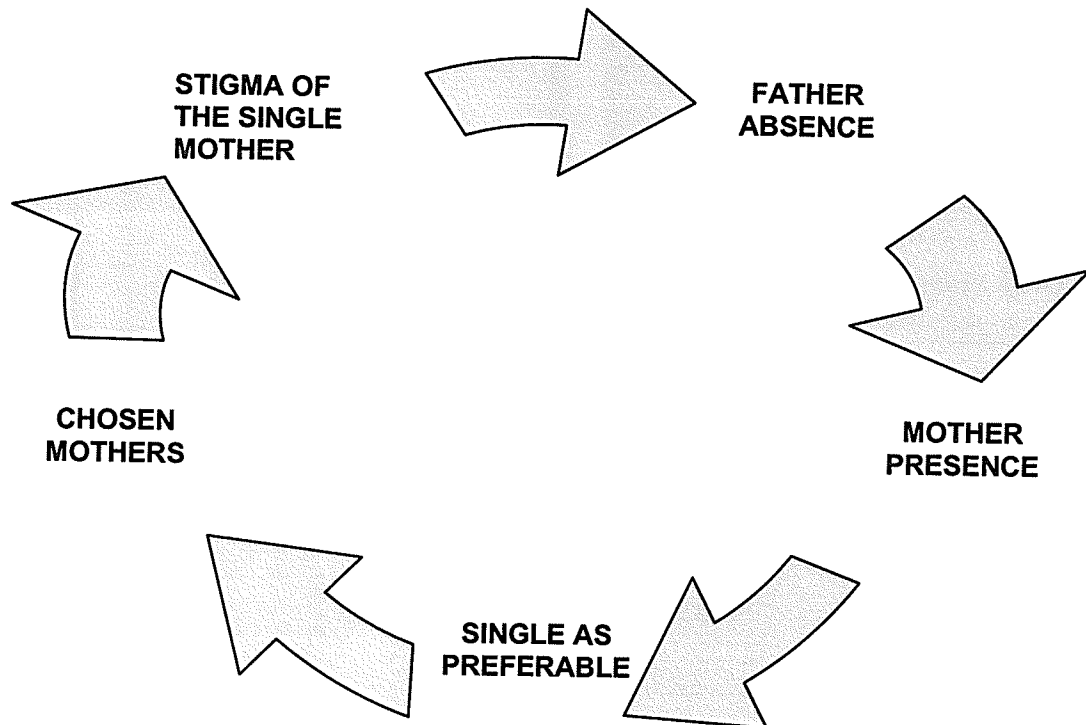
We're all still pretty much happy and I think a lot people used to say how do you do it? And I say you just have to do what you have to do. I've heard many times in my life and I've heard this in a religious aspect and I've heard it in a just a

regular, everyday aspect, that when, you know, if you were given a choice of which problems you would take, you would still pick your own. You know, if you were put in a room and said take any problem you want you'd walk out with the problems you have because those are the ones you're used to and it's better than the unknown.

Thematic Integration

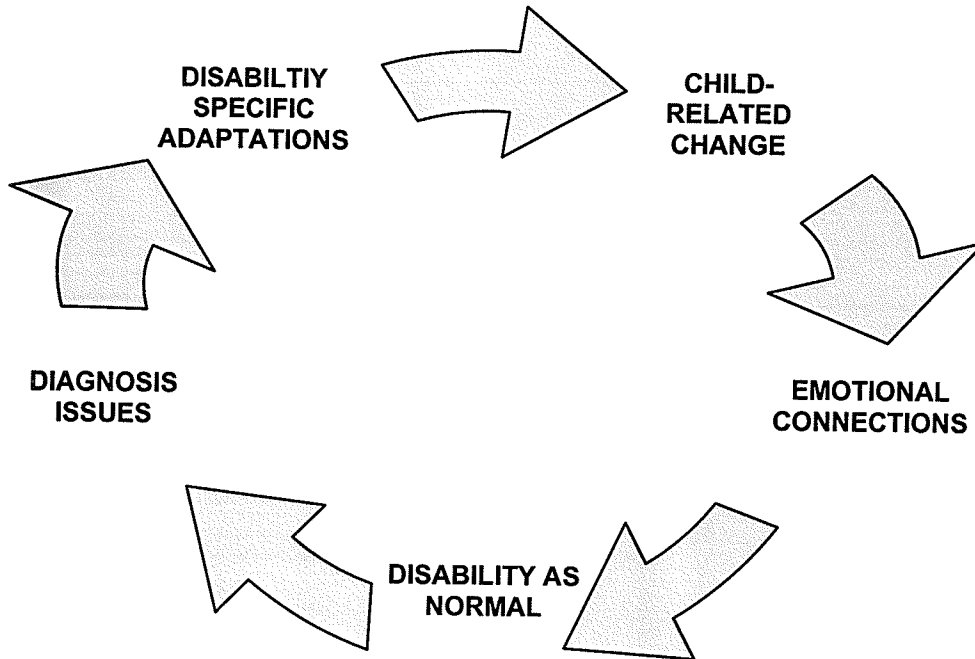
In this study of single mothers of children with disabilities, it became apparent that resilience was manifest through four key processes. First, mothers demonstrated their capacities to "bounce forward" by transforming the "stigma of the single mother" into the position that they were in fact "chosen mothers". Although the mothers may have initially accepted the societal belief that single-mother families are less healthy compared to the normative two-parent structure, they adopted positions wherein mother-presence replaced father-absence, and their single status was preferred over remaining in unhealthy relationships. When faced with the stress of single parenting children with special needs, mothers concentrated on emphasizing the positives in their situation, including the freedom and independence that accompanies being a single parent, in addition to the opportunity to develop emotionally close relationships with their children. Diagram 1 represents this process.

DIAGRAM 1



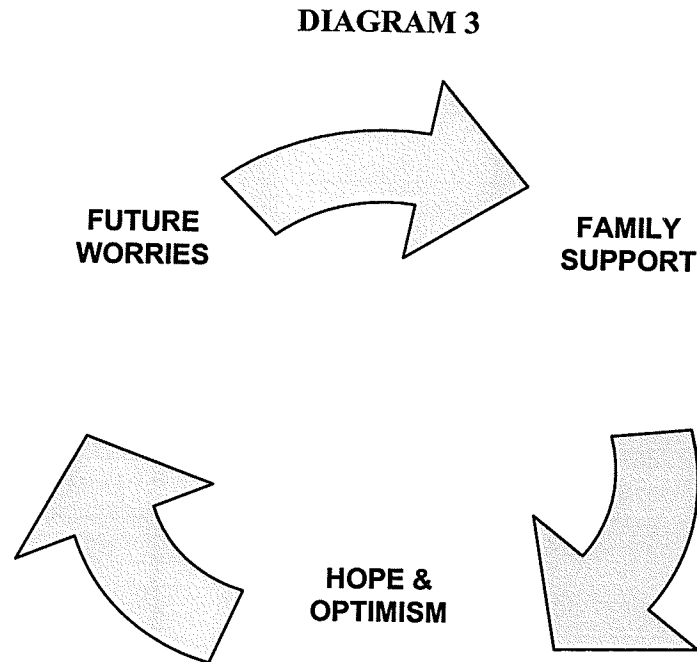
The second process involved transforming the position of “child as disabled” to “disability as normal” involved undertaking disability-specific accommodations in parenting and the recognition of children’s potential. Initially, mothers focused on understanding their children’s behaviour within the parameters of the diagnosis, with the intention of educating themselves about the disability. Paradoxically, when mothers consciously re-evaluated their expectations of their children to align with the diagnosis, they became increasingly aware of their children’s capacities for change, growth, and development. This in turn nurtured the emotional bonds between mothers and children, and through these experiences, mothers moved to the position of ‘disability as normal’. Diagram 2 represents this process.

DIAGRAM 2



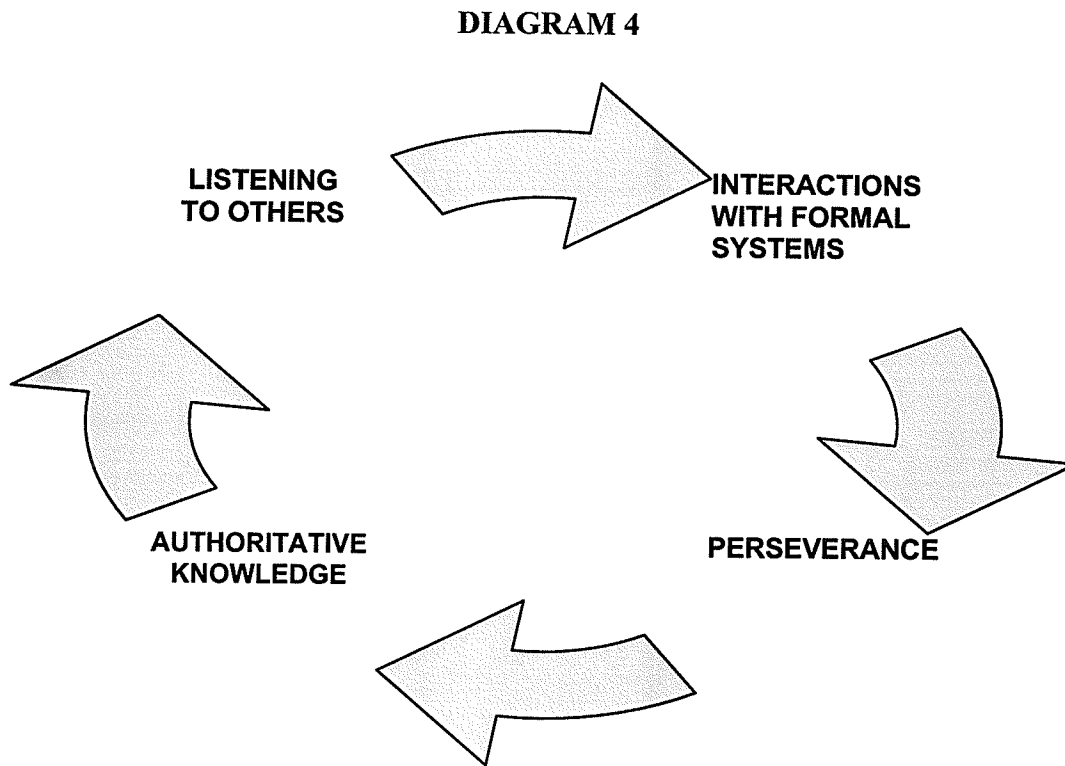
The third process through which mothers developed resilience occurred by drawing upon their available resources and/or developing new resources to assist them in managing the immediate and long-term needs of their children. This was most clearly demonstrated by mothers' conscious development of relational connections with their families of origin and expressing hope and optimism about the future. Mothers relied upon their families for instrumental and emotional and support. Practical support provided mothers with emergency groceries or money, child-care and respite. Emotional support provided mothers with the knowledge that they were cared about. Family support became most critical however when planning for the future needs of their children. Resilience became an expression of mothers' making plans with their family members to act as guardians/caregivers for their children, at the point they were no longer available to

provide care. Diagram 3 represents mothers' movement from worry to hope through family support.



The fourth resilience-building process occurred when mothers moved from the position of “listening to others” to one in which their personal and subjective knowledge regarding their children and their view of self was valued. Many of the mothers indicated that when their children were first diagnosed, others’ voices dominated their experiences of how to parent their children and influenced their parenting practices. Family members, friends, and professionals voices’ were typically negative, and highly critical of mothers’ choices, knowledge, and parenting practices. This was particularly evident in mothers’ interactions with the formal service delivery system. However, when mothers encountered situations in which their knowledge was challenged, they became actively engaged in the situation, developed action plans to address the problematic aspects of the

situation, and followed through based on their beliefs that they were the experts on their children. Through this process, they arrived at a position wherein their experiential knowledge was perceived as the more accurate reflection of reality. Diagram 4 represents this process.



Summary

Many single mothers encounter a range of social, psychological, financial, educational, physical and vocational challenges. Participants in this study were not exempt from these issues. They too described struggles with financial stress, time poverty, and health-related concerns. However, in addition to these challenges, participants were also the mothers of children with special needs. Using a resilience framework that encompassed the general categories of family belief systems and

resources/ protective processes, this study provided evidence for understanding how single mothers successfully manage the challenges of parenting children with disabilities. The qualitative analysis resulted in clear descriptions of the experienced stressors and resources drawn upon by single mothers of children with disabilities. These results are supported by analysis of the quantitative data that indicated positive adaptation to stressors occurs over time.

Mothers identified the stigma of the single mother as a key stressor, independent of their children's disability status. In contrast to previous research with single mothers where dis-empowerment has frequently been a key theme, participants revealed that strategies of reframing single parenthood as the superior and empowering choice assisted them in managing others' negative perceptions. Mothers also used the strategy of positive appraisal to re-define the strengths and limitations of their children and drew upon their practices of faith and spirituality to create meaning for themselves. They defined their children's realities of father-absence as mother-presence by prioritizing their children's needs over their own, developing strong emotional connections with their children, and demonstrating flexibility in their parenting practices. Although mothers frequently encountered numerous barriers in their interactions with the service system, they persevered, and continued to advocate for the best interests of their children. Mothers also demonstrated responsibility in ensuring that their children would be well taken care of in the future, by fostering relationships with their extended family members. Four years later, mothers described their situations in positive terms. In contrast to their initial experiences of stress, mothers perceived that their children had made significant improvements, and they themselves acknowledged that against all odds, they experienced

a general absence of adverse effects. In contrast to the ideas about the inevitable negative prognoses for single mothers and their children with disabilities, participants described their families as healthy, happy, and hopeful about the future.

CHAPTER SIX

Discussion

As diagnoses of developmental disability continue to escalate in conjunction with an increase in lone parent families, a growing number of women will find themselves in the role of single-parent of a child with a disability. Therefore, understanding the needs and resources of this population is a critical area of social work research and practice, as it is important to understand the factors and processes that are associated with successful adaptation. Using concepts derived from family stress and coping theory, the Family Adjustment and Adaptation Response (FAAR) model (Patterson, 2002), and the family resilience framework (Walsh, 1998) the purpose of this study was to explore the experiences of single mothers of children with disabilities within a longitudinal timeframe.

This study was conducted by first reviewing the literature on family stress and coping theory, the Family Adjustment and Adaptation Response model (FAAR) (Patterson, 2002), and the family resilience framework (Walsh, 1998), in the context of childhood disability. The results of this literature review identified four key categories that are shared by these models. The study explored factors related to (a) family stressors/demands, (b) family belief systems, (c) family resources and protective processes, and (d) family outcomes and adaptation.

Using qualitative and quantitative research methods, 15 single mothers of children with disabilities who had previously participated in the Family Strengths in Childhood Disability project (Trute et al., 1999) were interviewed. Participants also completed a set of standardized measures. Qualitative analysis of the interview data resulted in the

formation of 17 themes. Analysis of the quantitative data provided support for selected qualitative themes.

Participant Demographics

The dominant discourse on lone motherhood continues to position young single mothers, never-married mothers, and separated, divorced or widowed mothers within the same category. Even within the relatively small sample of this study, the demographics of the participants challenged the myth of homogeneity and reinforced the reality that lone mothers are an exceedingly diverse group in terms of age, social class, ethnicity, income, educational level, and pathway to single-parent status. Participants ranged in age, occupational status, educational level and country of origin. Some were single-parents by choice, some as a result of separation or divorce, some were never married and one mother was widowed.

This study supports previous research that concludes economics are a major influence on maternal well-being (Jackson, Brooks-Gunn, Huang, & Glassman, 2000; Olsson & Hwang, 2001). Disadvantages experienced by single mother families are strongly linked to their income, which was evident as different stressors were described by participants based on their income and socioeconomic status. Mothers from low to poverty-level income brackets reported issues related to financial strain, food security and housing issues. Mothers from middle to upper-middle class income brackets described stressors related to balancing work and child care issues. However, they also reported that having access to private resources including psychologists, occupational therapists, and funding for extra-curricular activities for their children provided them with additional support.

Secondly, the majority of the children were males who had been diagnosed within the Pervasive Developmental Disorder (PDD) spectrum. This reflects general trends (partially attributed to improved clarity within the diagnostic concept) that indicate “prevalence rates for ASD appear to have increased over the past 25 years, from about 0.5/1000 in the seventies to more recent estimates that are generally about 1/100.” (Missiuna et al., 2001, p. 15). Given that there are an increasing number of single mothers, and increasing numbers of children being diagnosed with PDD, it is important for service providers to develop resources that are targeted toward addressing the specific needs of single mothers of children with developmental disorders.

Caring for children with disabilities exposed participants to a range of stressors that tested their abilities to “bounce back”. Most families did not experience a single stressor, but managed multiple demands at different points in time. A pile-up of stressors occurs when the demands of daily living coupled with the efforts required in caregiving multiply. Participants identified financial hardship, worries about one’s personal health, developmental challenges, such as parenting adolescents, time poverty, role strain from caregiving and household tasks, transportation and housing, environmental safety and potential job loss due to child care issues. These stressors have been previously identified as endemic to single-parents, and thus the participants’ experiences are representative of stressors experienced by many single mothers (Heath & Orthner, 2003; Richards & Schmiede, 1993). Single mother families operate in a different reality and function differently than two-parent families. They do not have the luxury of taking a day off from

their child care responsibilities, secure in the knowledge that a second parent is available to step in and assume the myriad of parenting responsibilities.

Participants experienced the “stigma of the single mother” as their initial stressor. The majority of participants reported experiences of being criticized or judged for becoming a single-parent, and expressed concerns about how this would impact their children. This is congruent with other studies that concluded negative reactions from significant others remain powerful influences for single mothers, even for those who have been sole parents for a long time (Webber & Boromeo, 2005). These patriarchal attitudes were identified by the participants as barriers to the development of a positive view of self and family and constrained their abilities to access educational, employment and social engagement opportunities.

Individuals play an active role in constructing the meaning that experiences hold for themselves, and the participants demonstrated that an essential component of resilience was their ability to create positive meaning from difficult circumstances. Participants’ capacities to reframe the “stigma of the single mother” to a more constructive perspective that defined their single-parent status as safer, emotionally healthier, less stressful, or in some situations, indistinguishable, from their former two-parent structures, emerged as a key process. Even when confronted with a multitude of negative and forceful messages that reinforce stereotypes of single mothers as poor, welfare-dependent, and educationally disadvantaged, mothers in this study were less likely to internalize the social problem perspective of their family structure. Many made the conscious decision to become single-parents, and even mothers who did not initiate the separation from children’s fathers noted that a turning point occurred in their own

perspectives when they found themselves in the position of being the sole responsible parent.

Aveling (2002) suggests that feminist post-structuralism is a useful theoretical lens for understanding women's unique social and cultural contexts and the choices they make within them. This analysis appears to be especially applicable to single mothers. In contrast to dominant images that single mothers are victims of their own choices, a feminist lens reveals that the participants represented themselves as socially situated agents who made intentional choices and effected positive change for their children.

A second theme to emerge in this study was how mothers negotiated the tension between definitions of disability and normal, and how these were represented within their personal experiences. This is consistent with the theoretical position which suggests that a search for meaning is triggered when the stress and trauma associated with a negative life event is of sufficient magnitude that a person's assumptions and sense of purpose are challenged (Tedeschi, Park, & Calhoun, 1998). Although the diagnosis itself may have been ambiguous, the time of diagnosis functioned as a precise point of reference for the mothers. The literature suggests that a number of factors (i.e., parental grief, parents' perception of the seriousness of the diagnosis, the child's age, concurrent stressful events, inadequate information, and professional support) may influence how parents cope with their changed situation (Baker et al., 2003). Clearly, mothers may begin from a position of understandably high stress at the time of their children's diagnoses when they confront the fact that they will be raising a child with a disability. It is only with the passage of time that mothers are able to undertake shifts in their appraisals.

It is clear from past research that parents of children with disabilities report high levels of stress (Beckman, 1983), and mothers of children with pervasive developmental disorders consistently display significantly elevated stress scores (Tomanik, Harris, & Hawkins, 2004). This was evident from the results of the Parenting Stress Index at Time 1 that indicated elevated stress scores for the majority of the participants. However, four years after entry into the service system, the children's developmental disabilities were not identified by participants as an overarching stressor. This is in contrast to families' experiences wherein their children's disabilities remain the primary stressor (Green, 2004; Landsman, 2003). Mothers whose children had behavioural problems perceived these as a source of stress; however, this was not interpreted as a function of the disability or their marital status. This finding is strongly supported by previous research that concludes parenting stress associated with behavioural problems is universal (Baker, McIntyre, Blacher, Crnic, Edelbrok, & Low, 2003; Florsheim, Tolan, & Gorman-Smith, 2004; Lipman, Boyle, Dooley & Offord, 2002).

Mothers described how they had created their own meanings, through redefining, accommodating, encouraging, negotiating and interpreting their children's behaviours in ways that extended well beyond parameters of normalcy. Participants' capacities to transform their positions of "child as disabled", to "child as different", and for some, "child as normal", emerged as a key process in resilience-building. This is congruent with recent research that notes raising a child with a disability can be a life-altering experience that invites parents to examine their beliefs about children, their parental roles, and their families (King et al., 2006).

Historically, studies of maternal response to the diagnosis of childhood disability suggest that acceptance is associated with psychological well-being and denial associated with increased distress (Ferguson, 2002; Glidden & Schoolcraft, 2003). This highlights the conflict that is created when acceptance and denial are viewed as binary opposites and are therefore mutually exclusive. The findings from this study challenge these ideas. Resilience-building was enhanced when mothers created meanings about their children's disabilities in a way that concurrently acknowledged and resisted the externally-applied labels. Larson (1998) referred to this emotional compromise as "the embrace of paradox" (p. 870), a position located somewhere between acceptance and denial. She further notes that the conscious embrace of paradox energizes mothers, and is therefore essential to their well-being.

The majority of mothers affirmed that faith in a higher power and spirituality was also an important aspect of how they made sense of their lives. Participants broadly defined spirituality as their beliefs and experiences that reflected faith in God or other higher power, connections with self, others, and nature, and the integration of mind, body and spirit. Mothers clearly experienced spiritual ways of dealing with stress as supportive and strengthening. For several participants, their convictions that they had been chosen by God to be mothers of children with disabilities contributed to their capacities to successfully manage disability-related challenges and their overall well-being. Other participants found social support through the congregation that also helped them to cope with stress.

The inclusion of a spiritual dimension in coping is emerging as a key consideration in family resilience, and seeking spiritual support has been identified as an

active coping strategy (Bacchus & Holley, 2004; Mactavish & Iwasaki, 2005; Nolte, 2000). Additionally, the use of prayer is noted to be an important aspect of maternal coping with serious childhood illness (Wilson & Miles, 2001) and resilient single mothers (Brodsky, 2000). This study confirmed that expressions of spirituality by connecting to a spiritual path or tradition created the context in which the participants found meaning in life and valuable social support. However, it is important to recognize that spirituality is individually defined. Although several participants identified affiliation with formal religious institutions, the findings indicate that the spiritual dimension cannot be limited to expressions of religiosity. Mothers described a range of self-care activities that contributed to their sense of emotional well-being including journaling, physical exercise, and “alone-time”. Evidence for the importance of self-care activities including meditation and yoga has been noted to be particularly effective for family caregivers, and may improve overall affect, coping, and physical well being (Waelde, Thompson, & Gallagher-Thompson, 2004). These findings further highlight the need for attention to the spiritual dimension by service providers, and as such invites professionals to find ways in which to discuss issues of faith and spirituality with families.

Family resources or protective processes are described as the patterns of relational functioning that serve to protect the family when exposed to risk, and include family cohesion and flexibility (Patterson, 2002; Walsh, 1998). The FAAR model views family stress as a process in which families draw upon existing assets, and develop new resources in response to the identified stressors. This category reflected mothers’ abilities to develop new ways of interacting with their children, in addition to utilizing social and environmental resources. Family cohesion was most evident in mothers’ transformations

of “father-absence” into “mother-presence” through the development of powerful emotional bonds with their children and determination to foster close relational connections to extended family members. Mothers’ relationships with their children were a key source of personal happiness and pleasure. Despite the challenges of disability-related issues and significant time pressures, the participants demonstrated how resilience was facilitated through their thoughtful and intentional actions directed toward strengthening and prioritizing their relationships with their children. This was accomplished through undertaking disability-specific adaptations in order to access information, social support, and ensure that their children were able to participate in recreational activities. This is consistent with other literature that suggests maternal perceptions of children as sources of happiness are associated with greater well-being (Hastings, Allen, McDermott, & Still, 2002; Little, 2006; Pruchno, Patrick & Burant, 1997).

This study further highlights the importance of optimism as a psychological resource in family resilience. Prior research has indicated that the quality of the relationship between mothers and adult children with autism and psychological well-being is mediated by optimism (Greenberg, Seltzer, Krauss, Chou & Hong, 2004). Optimism has also been associated with long-term positive outcomes in parents of children with brain injury (Ylvisaker & Feeney, 2002). Mothers’ capacities to remain optimistic despite dealing with the stressors associated with single parenthood and children with disabilities provide substantial support for the importance of optimism as a coping resource.

Secondly, the social and environmental resources potentially available in the connections that individuals have to their families and communities were central to navigating the challenges of single-parenting children with disabilities. The majority of participants identified that their extended family members were a critical source of both instrumental and emotional social support. Previous studies in families with children with disabilities and lone mother families conclude that there is a positive relationship between the availability of informal social support and reduction of parenting stress (Ben-Zur, Duvdevany & Lury, 2005; Boyd, 2002; Gottlieb, 1998; Kotchick, Dorsey, & Heller, 2005; Weinraub & Wolf, 1983; White & Hastings, 2004).

However, beyond providing immediate help, it became evident that mothers intentionally foster strong relationships with their families as the primary means of alleviating their worries about their children's futures. Findings from this study suggest that single mothers consciously nurture and promote their children's relationships with extended family in order to mitigate the worry they experience when confronting their own mortality. This is a critical issue for single mothers who do not have access to the children's father or paternal family as potential supports. However, Lazarus and Folkman (1984, p. 250) state that social support is a resource that must be cultivated and used in order to be effective. Findings from this study suggest that resilient mothers deliberately call upon their support networks in order to assist them in planning for their children. Mothers' efforts to ensure that their children had strong relationships with family members who would be responsible for their future care suggests that these opportunities should be further explored. Bigby and Ozanne (2004, p. 284) have suggested that a "proactive pathway" that focuses on future, non-crisis oriented planning, results in more

positive outcomes for older carers of adults with disabilities. Therefore, the ability to proactively engage in future care planning for their children may be pivotal to resilience-building in single-parent families.

Social relations and contexts shape the experiences of the mothers caring for their children, and these were reflected in their experiences of negotiating access to and use of formal support services. Analyses of the data indicate that mothers identified a decrease in the availability of the formal disability service system and did not identify their children's disability service coordinator as a critical source of current formal support. Furthermore, this was not experienced as stressful. There are several possible explanations for this finding. First, it may be interpreted as an indicator of personal self-efficacy with regard to managing the challenges of parenting special needs children. Four years after entry into the system, mothers described themselves as more confident and capable in managing the challenges of parenting. Secondly, mothers report greater emotional and instrumental support from informal systems compared to formal systems. Informal support sources are more effective at reducing stress than formal support, and the most useful source of formal support for mothers seems to be parent support groups (Boyd, 2002, p. 213). Therefore, the need for formal support may decrease in the presence of a strong informal network and the ability to access parent to parent support.

However, a third explanation may be located within the continuing patriarchal nature of the formal service delivery system. As Rice notes (2001, p. 356), "if we blame the poor mother for her lack of incentive, the proposed solutions are likely to be personal and individual." This was particularly true for women who were in receipt of income assistance. They chose to live on poverty-level incomes in order to remain physically and

emotionally available to their children, and in the case of one participant, with the explicit recognition that her family's income would be further reduced if she were required to obtain employment. These findings support Scarbrough's contention (2001) that frequently, the most responsible decision for a single mother is welfare, rather than a paying job and unstable employment.

Participants' decisions regarding the best interests of their families were frequently challenged by professionals. The findings indicate that professionals who work in the education, income, employment assistance, disability and other social service systems continue to judge mothers' actions and decisions. Valuing mothers' knowledge regarding their families challenges a legacy of professional helping beliefs that have served to dis-empower single mothers and their children. Making the 'right' choice continues to distinguish the 'civilized' (i.e., the good mother who accepts the expert advice) from the marginalized (Dean, 1995, p. 561). In many ways, the public service system that is tasked with the mandate to assist families often magnifies mothers' feelings of powerlessness and shame. Kissane (2003) points out that the public sector is beginning to replicate the paternalistic and discretionary dynamics of the traditional non-profit sector in terms of defining needs based on altruism and not as a fundamental civil right. The experiences of the participants provide minimal evidence that an understanding of the different needs of single mother families are either known or acknowledged by service systems.

The critical component of family-centred services is family empowerment. Family-centred services endeavor to enhance self-efficacy, value families' knowledge about their children, promote family choice in decision-making, and develop families'

abilities to meet self-defined needs and achieve aspirations in ways that promote a clear sense of control over the important aspects of family functioning (Dunst, Trivette, & Deal, 1994). Although there is increasing recognition of the importance of family-centred principles within childhood disability services, it does not appear that their application has extended toward single mother families. This has particular relevance for social work educators as Parish and Lutwick (2005, p. 345) note the critical role of the social work profession in training social workers in family-centred approaches, developing new interventions, and creating new organizational supports. Feminist insights have made major contributions to social work theory, research and knowledge (Nes & Iadicola, 1989). The findings from this study suggest there is a need for the inclusion of a feminist analysis in the family-centred literature that extends the basic principles to explicitly acknowledge the different social and economic contexts of single mothers.

In this study, the dire outcomes predicted by the convergence of single-parent family structure and presence of childhood disability did not emerge. Longitudinal, qualitative family systems studies provide researchers with opportunities to document families' coping and adaptation over time. A core component in the concept of resilience is significant risk exposure, and it is generally accepted that families headed by single-parents and those that include children with developmental disabilities are at a statistically higher risk of poor outcomes. Coping processes are dynamic and changes are not necessarily reflected from snapshots provided at particular points in time, but from an overview of family functioning at different developmental stages. This is congruent with Patterson's (2002, p. 237) perspective that family resilience is an "ongoing, emergent

process” and thus longitudinal analysis is necessary in order to fully understand how families successfully adapt. At Time 1, children had only recently been diagnosed, which facilitated the referral to the disability service system. Stress at this time may be a function of not knowing what to expect from their children or the service system, the need to incorporate additional meetings and appointments into an already full schedule, as well as learning about the nature of the disability itself. Clearly, the passage of time resulted in a decrease of stress, as mothers developed confidence in their abilities to manage the challenges of their children’s disabilities, and enhanced existing or developed new coping abilities and resources. Time further allowed for mothers to undertake positive appraisals of their situations which in turn have a significant effect on the quality of life.

A key theme that emerged from this study was mothers’ process of gaining and expressing authoritative knowledge regarding their children. Many of the mothers indicated that four years earlier, others’ voices dominated. Family members’, friends’, and professionals voices were typically negative, and highly critical of mothers’ choices, knowledge, and parenting practices. However, four years later, the participants demonstrated their capacities to take on the risks associated with the dual challenges of single-parenting and childhood disability, and utilize protective factors that contributed to their abilities to take care of themselves and their families. There are some indications that the participants began from a position of positive affect, although they themselves may not have acknowledged their capacities. Gibson (1999) described the process of empowerment for mothers of critically ill children as one in which mothers become aware of their personal strengths, abilities and resources. This may suggest that although

it is important for service providers to acknowledge mothers' strengths, their abilities to do so for themselves is a much stronger influence on their well-being.

These findings further support the need to promote capacity-building as a means of mothers acting on their strengths. In essence, participants' authoritative knowledge became a vehicle for them to exercise control. According to Bandura (2001), the capacity to exercise control over one's life is the essence of human agency. Bandura described agentic individuals as those who are "future-oriented, have the capacity to plan and act with intention and foresight, give shape to the appropriate courses of action, engage in a process of self-examination, and reflect upon personal motivation, values, and meanings of life pursuits" (p. 2). The exploration of the data revealed that single mothers of children with disabilities demonstrate capacity for resilience as strategies of personal agency.

Mothers revealed how they managed the dual burden of lone parenthood and childhood disability as practices of thoughtful, responsive and strategic decision-making within their individual contexts. Mothers committed to acting in ways that would ensure the best interests of their children. In contrast to the socially constructed cultural stories of women who are powerless victims, the expression of personal agency involving both responsibility and choice emerged as the core theme of resilience. This was expressed through participants' abilities to make decisions that truly expressed their own distinct manner of living, without relying upon others to do that for them, interpreting their experiences in ways that were volitional, intentional and self-referencing, and recognizing and responsibly addressing the needs of their families.

Perhaps the key finding of this study is that single mothers of children with disabilities are no different from single mothers with non-disabled children. Single mothers cope with a range of stressors, of which childhood disability is only one, and for many mothers, is the least of their concerns. In view of this, findings support prior research on two-parent families that suggest the long-term outcomes for families with children with disabilities are not fundamentally different from families with non-disabled children (Carr, 2005).

Implications of the Study for Social Work Practice

The findings of this study have relevance for professionals in the field of childhood disability, and support the following policy, practice and research recommendations. First, this study provides strong support for the position that at the outset, what is required is a fundamental transformation of how single mothers and disability are perceived. In conjunction with ideas about the pathology of disability, the patriarchal nature of the service system replicates the social, economic, and structural inequities that single mothers continue to experience. Clearly, professionals need to recognize that family-centred models of service delivery that view the family as a “whole”, emphasize family strengths, and promote family empowerment within a context of normalization may not be sufficiently relevant for single mother families. This study provides support for the idea that there is clearly another side to images of single mothers that prevail within service systems and society at large. Rather than erecting attitudinal and institutional barriers that require mothers to utilize a significant amount of energy to dismantle, professionals should assist parents in developing services that support them in caring for their children, in a collaborative context that acknowledges their economic and

social realities. The authoritative knowledge that women who are single parents have about their lives and their families should form the basis for collaboration between themselves and social work practitioners. Family resilience will therefore be enhanced when professionals work toward ensuring that there are adequate resources within the system to facilitate the development of family capabilities and consequently, family resilience. Personal agency should not function as a replacement for the absence of resources to support families. Moreover, professionals need to acknowledge that mothers of children with disabilities experience pleasure from their children, regardless of their children's perceived limitations.

Mothers' capacities for perseverance were strongly associated with well-being. This study provides some direction for professionals in which they can better understand the coping strategies of single mother families and can provide services in a manner that helps promote family strengths. Perseverance may also be critical for families of children with disabilities given the chronicity of these conditions. Moreover, because single mother families have been stigmatized within society, their ability to persevere has depended, in part, on developing coping strategies that have allowed them to develop self-reliance and to garner support from family members or other informal support systems. However, professionals also need to be aware that the availability of informal social support does not automatically result in the utilization of this support, and create opportunities for parents to discuss how they may choose to nurture these relationships, particularly with respect to the future care needs of their children. Additionally, given the importance of optimism as a resource, the emerging literature on cognitive-behavioural

interventions and learned optimism (Seligman, 1991) may assist professionals to facilitate the development of optimism in parents.

Second, it is suggested that the disability service system may not be meeting the needs of parents of older children. The finding that formal social support was not relevant for the participants does not undermine the potentially beneficial outcomes that could result from appropriate professional intervention. Although families with younger children may have increased needs for diagnostic information, availability of community services and family support, mothers identified issues related to the interpersonal relationships, employment needs, and sexuality issues of their children that arise as they mature. Families may not have decreased needs for formal support but rather different needs which consequently may indicate a gap in child and adolescent disability services. Although participants noted that the educational system is for the most part, meeting the social and therapeutic needs of their children, it is not designed to provide the parents with the information and support they require as their children mature. Family needs are dynamic, and it does not appear that the service system is keeping pace with the needs of parents of older children. Therefore, it may be helpful for professionals to increase their knowledge of disability throughout the family life cycle, and enact the appropriate accommodations within service provision models. As Walsh notes (1998) family stress typically coincides with developmental transitions within the family. Professionals can assist mothers to ameliorate stress by providing anticipatory guidance for developmental changes within the family.

Third, the importance of cognitive appraisal for single mothers of children with disabilities cannot be overstated. The results from this study provide further support for

this importance of cognitive appraisal and point to several implications for interventions to attenuate negative affective states. In light of the relationship between cognitive appraisal and resilience, it is clear that professionals and other service providers need to create an emotional and psychological context in which parents may undertake the process of cognitive appraisal that shifts from an emphasis on the negative aspects of the situation, to one in which the positives may be emphasized.

As family resilience theory suggests, professionals need to be aware of the variety of belief systems held by parents, acknowledging that negative appraisal is associated with maternal stress and depression (Hassall, Rose, & McDonald, 2005). The context-oriented framework provided by Lazarus (1993) may assist professionals in understanding how mothers' belief systems influence coping and adaptation. Not only is it important to help mothers modify or reframe the objective demands of their role, it is also important to help modify their interpretations of these demands and their abilities to respond to them. If professionals are able to encourage mothers to utilize positive appraisal in their interactions with their children, (i.e., by helping caregivers to modify their appraisals), interventions may be able to reduce psychological distress and contribute to maternal well-being. King et al. (2006) found that positive family adaptation occurs in the context of a changed world view. If social workers can facilitate discussions regarding the meaning of disability within families' worldview, i.e., through reframing single parent families as healthy and disability as difference, this may contribute to families' abilities to adapt. Additionally, social workers and other professionals need to be comfortable in discussing the spiritual dimensions of coping and adaptation as they clearly facilitate resilience in mothers. Although some post-secondary programs in social

work or psychology may include elective courses on spirituality, it has not yet become an integral component of the standard course offerings.

Implications for Future Research

The finding that mothers who maintain optimistic mood states positively adapt over time requires further exploration. Surprisingly, however, few studies have yet to explore specifically why positive emotions are useful: Are positive emotions a result of resilient modes of thinking, or do they serve some function in the ability of resilient individuals to cope effectively in the face of stress? Moreover, if as these findings suggest, resilience in single mothers is a function of agency, then the question arises as to how professionals may facilitate the enhancement of agency within parents: Further research on self-efficacy and agency in a theoretical context of women's self-development may provide further insight as to how mothers raising children with disabilities may best be supported. Additionally, further research may explore how the resilient-enhancing factors suggested by this study may be helpful to mothers who would be considered less resilient. Does a negative orientation have a negative impact on resources, support utilization as well as maternal behaviour and appraisals? How may professionals assist mothers in developing their personal strategies of agency?

A second area for consideration is the examination of the contributions of children with disabilities to the family system. The perspective that children are limited to passive recipients of family care, and are not mutually responsive to the needs of family members, nor active participants in the family system, requires reconsideration.

Third, the indication that mothers are able to demonstrate resilience over time suggests that there is a need for additional longitudinal research to more fully explore the

factors that impede or facilitate this process. Are there other mediating or moderating factors that account for varying degrees of resilience? These questions merit further investigation. Grant (2002) highlights how families and service providers perceive family coping differently. In keeping with the findings regarding parental appraisal, the expression of negative emotions does not preclude the absence of positive affect. Although there may be times when parenting stress is high, it is important for professionals to assess this within a developmental or time-specific perspective, and to not assume a direct relationship between parenting stress and ineffective or distressed family functioning.

Finally, this study highlighted the importance of “mother-presence” as a key factor in family resilience. However, this raises an important question. Why are fathers not taking responsibility for their children? What are the reasons for father-absence? Moreover, this study focused on the needs and experiences of single mother families. Although there are a smaller proportion of single parent fathers of children with disabilities, the question is raised as to whether the needs and experiences of these families are similar or different from those identified by the participants in this study.

Strengths of the Study

The literature on resilience suggests that professional understandings can be deepened by studying individuals for whom the statistical prognoses of negative outcomes do not hold. This has translated into research that is directed toward exploring the experiences of individuals who have been identified as exemplary in their functioning. What was unique about this study is that participants were drawn from a prior research project, and not chosen on the basis of their perceived exceptionality. They

were in essence a convenience sample, and were not previously identified as “resilient”. Through exploration of their narratives however, similar themes of resilience were illuminated, providing information about a population that has not typically been the focus of salutogenic research. Although the data was obtained from a heterogeneous sample, as single mothers of children with disabilities, they clearly travelled similar journeys and reported comparable experiences. Despite the demographic diversity, participants’ expressions of resilience as strategies of personal agency were strikingly similar.

A second strength was the inclusion of quantitative assessment within a longitudinal framework. Quantitative data analyses revealed consistencies and change between the time that participants first entered the child disability service systems, and again, four years later. Findings from the analysis of the quantitative results data served to support selected themes in the analyses of the qualitative data.

Limitations of the Study

Although qualitative methods yield a richness of data and an opportunity to explore the numerous factors that influence the lives of mothers of children with disabilities, findings from this study cannot be generalized to the whole population of single mothers. The sample size was small, and the findings were descriptive in nature. They can however be considered an exploratory beginning, and used to develop models for understanding how resilience is manifest in various individual contexts.

Secondly, although retrospective narratives can provide meaning to experience, they do not necessarily allow for the comprehensiveness of the experience to emerge. It is of critical importance to respect experience and explore meanings, recognizing that

meanings are not static and unchanging, and have likely shifted over time, and that aspects of the experience will remain invisible. Clearly, retrospective accounts of becoming a single-parent in the context of caring for a child with disabilities will change over time, and each mother will experience a range of emotions associated with these dynamics, affect which may not be represented in its entirety. Prospective, qualitative studies that capture mothers' experiences at different points in time may produce data that holds greater validity.

Conclusion

Grant and Ramcharan (2000) have suggested that there is a need for an improved theoretical and empirical understanding of resilience in families supporting a member with a disability. This study employed an integrative theoretical framework derived from family stress and coping theory, the Family Adjustment and Adaptation Response (FAAR) (Patterson, 2002) and the family resilience framework (Walsh, 1998) to identify the specific components of family resilience as perceived by single mothers of children with disabilities.

Through the analysis of qualitative and quantitative data, the finding that resilience is manifest as agency may not otherwise have been revealed. This analysis has thereby contributed to the previous research linking maladaptive family functioning to single-parent status and childhood disability, a finding that has previously been considered unequivocal. The value of this study is that it provides an introduction to the factors that are associated with resilience in single mothers of children with disabilities and suggests possible avenues of intervention. This study indicates that defining single parent status and disability in positive ways, maintaining an optimistic outlook,

advocating for their families when encountering barriers, utilizing informal support networks in a pro-active manner, and adapting parenting practices to accommodate to the uniqueness of their children's developmental challenges, are all associated with positive outcomes.

These findings create opportunities for social work research, practice and policy development. The dominant view that single mother families are an inherently problematic family form continues to prevail. Perhaps the salient contribution of this study has been to reveal alternative stories of women's explicit and at times, transformative adaptation, amidst the complexities and particularities of their experiences as single mothers of children with disabilities.

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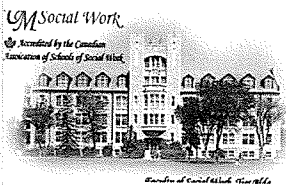
Resilience in Single Parent Mothers of Children with Disabilities

CONSENT FORM

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, please feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

I, _____, consent to participate in this research project on resilience in single mother families with children with disabilities. This dissertation research is being conducted by Kathryn A. Levine, of the Faculty of Social Work, at the University of Manitoba, (Telephone: 474-7461) under the supervision of Dr. Barry Trute, of the Faculty of Social Work, at the University of Calgary, (Telephone: (403) 220-5239) in partial fulfillment of the requirements for the degree Doctor of Philosophy. The research project is part of The Family Strengths in Childhood Disability study that is being conducted by Dr. Barry Trute, and Diane Hiebert-Murphy and Dr. Alex Wright of the Faculty of Social Work at the University of Manitoba..

I understand that this project is intended to understand how single mother families are affected by parenting children with disabilities. I understand that I will be asked to participate in an interview about my experiences raising a child with disability. I understand that this interview will be audio taped, and the tapes will be transcribed for analysis. I understand that the transcripts will not contain any identifying information, and that neither my name nor personal comments will allow anyone to identify me. In addition, I will be asked to complete a set of questionnaires as part of this process. I may have completed some of the questionnaires in the course of my participation in the Family Strengths Study, and if so, I agree to allow the researcher access to this information. I further understand that I will be asked to participate in a second interview with the researcher in order to verify the accuracy of the researcher's interpretation of the information I provided. The information gained from this study will assist in identifying the specific needs of single parent families who have children with disabilities.



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Appendix C
Resilience in Single Parent Mothers of Children with Disabilities
Interview Guide

A. Family History

1. Who are the members of your family?
2. How did you come to be a single-parent?

B. Impact of the diagnosis and entrance into the service system (Time 1 measures)

When we first interviewed you in 2001, you completed a series of measures that looked at issues of parental stress, family needs, demands, and supports, and the impact of having a child with disability on your family. Looking back at this time, it seems these areas (to be determined) were points of difficulty and/or strength for you. Looking back, can you tell me about your perception/ explanation of your experience at that time. How do you make sense of these results? What other events may have contributed to these results? How do you feel being a single-parent may influence these results?

Possible areas for probes:

1. How did you react to the diagnosis of your child's disability?
2. With whom did you speak after receiving the diagnosis? How did they react?
3. How has it affected the life and functioning of your family? (stress-related issues)
4. Siblings?
5. Work life?
6. Leisure time?
7. Social life?

C. Time 2 measures

When we met with you approximately 18 months later, and you completed a similar set of measures, we noted that there were changes that occurred in these areas. (Researcher can share where there was difference) Can you share with me your explanation and perception of why these change occurred? What other events may have influenced these

changes? Can you share with me why some areas did not change? What is the meaning of these changes in the context of being a single-parent?

224

Possible areas for probes:

1. Other events that occurred,
2. Changes in family, work, friendship networks
3. Changes in child functioning,

D. Current Circumstances

We are now 3 years later, and would like to hear about your current circumstances. Can you please describe to me your current life and family circumstances?

Possible areas for probes:

1. Can you describe your feelings about your daily involvement raising your child?
2. What do you identify as being stressful events for your family?
3. What do you perceive to be the demands/challenges on your family?
4. What are your daily concerns in raising your child?
5. What do you identify as some of the struggles for your family? For you as a mother? For your child? For your other children?
6. What do you see as the important needs for your family? For your child? For your other children? For yourself?

E. Identification of Family Capabilities

Looking back, what do you see as the strengths and resources of your family? What factors helped you in the past three years, and what do you feel hindered your family?

Possible areas for probes:

1. How does your family adapt to new challenges?
2. How would you describe your family functioning?
Emotional connectedness, flexibility, roles, etc.
3. How do you solve problems?
4. What are the coping strategies that you use?

5. Who do you identify as being an important source of informal support?
Formal support?
6. What has your experience been with support services and case management?

F. Family Meaning

Looking back at the last three years, what is meaning for you, as a single-parent, of having a child with a disability?

Possible areas for probes:

1. Can you describe your feelings about your daily involvement in raising a child with a disability?
2. Can you describe your main expectations that you anticipate regarding your child's future?
3. Can you describe any difficulties that you anticipate regarding your child's future?
4. Can you describe what helps you manage on a day to day basis?
5. Making meaning from adversity?
6. Positive outlook?
7. Spirituality?

G. Personal Reflections

What do you feel are important factors for people to learn about your experience? What is it important for researchers and practitioners to know about being a single mother of a child with a disability?

Other comments?