

Stress Appraisal and Coping in Siblings of Children with Special Needs

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Abstract

Self-reports from siblings of children with special needs are considered important additions to the disability literature. Twelve sibling dyads from the greater Montreal area were interviewed. Participating siblings of children with special needs were between the ages of 8 and 12, with a mean age of 9.5 years. Siblings with special needs were a mean age of 10.08 years. Sibling daily hassles, uplifts, and coping strategies were examined and analyzed using descriptive statistics. Family coping strategies and parental assessments of sibling relationship quality was also assessed. Children reported that most frequent daily events were when their siblings with special needs cry, scream or yell when they do not want to do something, and when they give hugs or kisses. Siblings reported being most stressed when embarrassed by their siblings with special needs in front of friends, and happiest when playing together with their sibling with special needs. Wishful thinking was reportedly commonly used by all children as a coping strategy during stressful times. Sibling results were also assessed by age and gender. In addition, families reported using acceptance of stressful events to cope, whereas family support was minimally used. Parent perceptions of their children's sibling relationship were generally positive, with loyalty, sharing, and controlling behaviour reported occurring most commonly.

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Stress Appraisal and Coping in Siblings of Children with Special Needs

When a child is diagnosed with a disability, the family is thrown into a state of crisis (Fortier & Wanlass, 1984; Molsa & Ikonen-Molsa, 1985). With new and unexpected issues facing them, family members must adapt and cope. Even years following the initial diagnosis, families with a child with special needs may experience additional stress as compared with families without a child with special needs. Because children with disabilities are exceptional in their functioning, they are likely to affect the psychological status and resources of the family (Bubolz & Whiren, 1984; Frey, Greenberg, & Fewell, 1989). Issues such as additional caregiving demands and parental stress differentiate these families from the norm (Cuskelly, Chant, & Hayes, 1998).

Studies assessing adult issues such as parental adjustment (Duis & Summer, 1997; Hodapp, Ricci, Ly, & Fidler, 2003) and marital satisfaction (Kazak & Marvin, 1984) are ubiquitous in the disability literature. But a family systems orientation dictates that the family is an interactional system, implying that changes in an individual affect the other members and the group as a whole (Walsh, 1982). Healthy siblings in the family may be overlooked during these stressful times, and their role in the family can become unstable and confusing. Acceptable family behaviour, treatment and rules can suddenly become unacceptable, and siblings are expected to adapt, often without attention or explanation. But consistent with the above theory, research on the siblings of children with special needs has been increasingly included in the literature. Because children's psychological adjustment is influenced by their siblings (Dunn, 2002) and with

siblings spending more time with each other than their parents (Larson & Richards, 1994), it is clear that this unique type of sibling bond can have an immense impact on their lives. In addition, healthy family development depends upon the emotional health of all its members (Walsh, 1982), therefore an overlooked sibling perspective can have a detrimental impact.

Studies on the effects of disability on siblings have expanded our view of these exceptional families (see Damiani, 1999 or Moore, Howard, & McLaughlin, 2002 for a review). However, much of the sibling literature asks parents, specifically mothers, to assess their typical child's behaviour and adjustment (Cuskelly & Gunn, 1993). While these studies have revealed valuable insights, leading us to conclude that these children are affected both positively and negatively by the presence of a child with disabilities in the family, siblings need to be given the chance to participate in the dialogue.

Considerable information still needs to be collected about siblings of children with disabilities, particularly information that uses the sibling him or herself as the source.

Self-reports from siblings of a child with disability are rare, but can be found (McHale & Gamble, 1989; Pit-Ten Cate & Loots, 2000; Stoneman, Brody, Davis, & Crapps, 1988). These studies have focused upon the childcare responsibilities of typical siblings, peer and family relations, and sibling conflict. However the scope of research on siblings of children with disabilities is limited, often ignoring sibling perspectives of family and personal stress. For example, one recent study reported that siblings who are sensitive to everyday family stress demonstrated increased externalized problems (Nixon & Cummings, 1999). In addition, physical and psychological well-being has been linked

to one's appraisal of daily stress (Lazarus & Folkman, 1984), confirming the importance of an investigation into sibling perceptions of the stress in their lives.

Psychological theorists who apply adult stress appraisal theories to children do so under the assumption that stress is dependent on the individual's appraisal of the event (Bossert, 1994; Robson, 1999). Assessing children's appraisal of stress therefore can benefit from the adult literature by using it as a foundation, as long as the child's perception is considered foremost. Appraisal is divided into two domains (Lazarus, 1966). Primary appraisal describes the individual's assessment of the personal relevance of the event in terms of well-being, while secondary appraisal involves the assessment of the resources accessible for coping. Lazarus (1966) asserts that as with our psychological structures, our ability to appraise stress progresses and develops over time. Therefore due to emotional and cognitive differences, a child and an adult even from the same family might perceive, react, and cope with stress in very different ways.

From a sociological point of view, a symbolic interactionism model outlines that families, particularly those under stress, will develop a reality based on shared meanings (Boss, 2002). Reiss (1981) calls this shared reality a family paradigm, a collection of the family's shared experiences, expectations, and constructs that guide the patterns of functioning in the family. Until recently, parents have been relied upon to evaluate the stresses of their children (Cuskelly & Gunn, 1993). However because the literature on families experiencing disability demonstrates a discord between parent and sibling assessments of feelings and adjustment (Taylor, Fuggle, & Charman, 2001), it has yet to be explored if the family's shared meanings and experiences impact upon children's interpretation and appraisal of stressful events. This gap in the literature must be

addressed so that an understanding of the sibling appraisal of personal stress in families experiencing childhood disability can be revealed.

The purpose of this study was to reveal the appraisal of stress of school-age siblings of children with special needs. It was anticipated that an assessment of the child's daily hassles and how they cope with them will complement existing literature by including siblings themselves in the dialogue. Consistent with a family paradigm philosophy, the family's adaptation and coping style concerning the disability was also investigated. This systemic view of a family experiencing childhood disability provides insight into how children and their parents perceive and cope with their unique circumstances.

Theoretical Orientation

Families are unique in two ways (Vangelisti, 1993). First, their relationships are involuntary. People, especially siblings, cannot pick and choose their family members, and cannot easily end their associations. Second, the relationships in families are ongoing and take place over extended periods of time. These two factors result in a highly complex, historical, and emotional system that is increasingly emphasized as an important forum for all aspects of development. With these points in mind, it is inevitable that families will experience stress at several points in their life cycle. When investigating families under stress, several theoretical models of family functioning can be useful in understanding the various influences that can impact the family's adjustment.

Family systems. A family systems orientation is often adopted when studying families, both under normal circumstances and duress. This theoretical model describes the family as a system that functions under circular causality, meaning that any individual

change affects the other members and the group as a whole (Buckley, 1967). Members of a family are interdependent and each member's behaviour contributes to the family's patterns of daily living (Minuchin, 1988). As a working system, the family strives to maintain a homeostatic state but is constantly threatened by various challenges. The family's patterns must then be revised so the family can return to a stable state (Minuchin, 1988).

The diagnosis of a disability in the family will inevitably change the family's regular patterns, affecting each member and the family as a whole. For example, it is suggested that the presence of a child with a disability in the family disrupts communication (Featherstone, 1980). The challenges in parental communication stemming from the stress associated with rearing a child with a disability can result in isolation from each other, their children and their social support systems (Burr, 1985). Topics may become taboo and feelings may be encouraged to remain hidden (Seligman, 1983). Because of this break in communication, siblings can experience loneliness, isolation and a sense of detachment from those one is closest to, such as parents (Featherstone, 1980). In response to this disconnection, a child might distance him or herself or act out in response to feeling excluded from family interactions. Boss (2002) describes this type of behavior as "the ripple effect," an individual's acting out in response to the family's increased focus on the problem, or in the present study, the focus on the child with the disability. While many professionals examine only the individual who is acting out, the behaviour is often symptomatic of stress in the entire family system (Boss, 2002). In a longitudinal study of families with an intellectually disabled member, the authors concluded that stress attributed to any specific child within the family may be

an indicator of more general family stress (Baxter, Cummins, & Yiolitis, 2000). Distress in the marriage and conflict between parents has also been linked to depression (Gold, 1993), lower self-esteem, and more behavioural problems (Dyson, Edgar, & Crnic, 1989) in siblings of children with disabilities. McHale and Gamble (1989) have also shown that maternal anger has been connected to conflict between the sibling without a disability and the sibling with a disability. These examples are consistent with the circular causality notion of family systems theory. However families do not exist detached from the outside and therefore their perception and management of stress is also affected by their external contexts that may influence family functioning.

Social ecology. Every family has an ecosystem, a system formed by the interaction of the family with their physical environment (Bubolz & Whiren, 1984). As with systems theory, any change in one part of the ecosystem affects it as a whole. Bronfenbrenner's social ecology model (1979) has the child as its focus, asserting that several layers of interacting influences surround him or her. These layers represent many types of environmental effects that can potentially impact the child's development. The microsystem describes the child's face-to-face interactions, activities, relations, and social roles, such as their family, school or peer group (Bronfenbrenner, 1994). The exosystem expands this influence by including the settings that do not directly contain the child, such as a parent's workplace, their extended family and the community, but which still exert an influence upon the individual. The macrosystem consists of the individual's belief systems, body of knowledge, customs and lifestyle. In the context of disability, Duis and Summers (1997) found that child-related stress was linked to outside influences, such as general and physical resources, and parent-related stress was linked to the level of

external support. These authors also found that external supports helped decrease family stress more than internal family variables.

The external and internal contexts within a family's ecosystem undoubtedly have an impact on adjustment. A family's external context is that over which the family has limited control (Boss, 2002). This includes factors such as genetics, economics, history, and culture. While these entities may be beyond their command, the family can use its internal context to cope with any external stressors. The internal context describes factors the family can change and control, the most relevant of which here are the family's psychological and philosophical contexts. The psychological refers to the family's perception, appraisal, definition or assessment of a stressful event, whereas the philosophical covers the family's values and beliefs. Other studies have demonstrated the positive effects that family and community cohesion can have on a child's adjustment. Duis and Summers (1997) report that higher levels of family cohesion can act as a buffer against stress in families with a child with disabilities. Because these families have experienced considerable hardship together, it is possible that their coping strategies are linked and strengthened by their family unity. A study by Milgram (1982) reported that children reared on a kibbutz, a collective settlement in Israel, developed increased resistance to stress through strong community cohesiveness. Cohesion may be developed through shared family experiences, leading into the final theoretical orientation of symbolic interaction.

Symbolic interaction. The family's internal context also includes any meaning attached to an event. Symbolic interaction theory asserts that the family interacts with various symbols, such as language or rituals, which construct the family's shared

symbolic reality (LaRossa & Reitzes, 1993). These collective meanings are also influenced by the family's ecosystem, for example community, religious, and cultural messages may act as the family's conscience, defining its norms and rules. These theories lead to the question of whether a family's perceptions are collective or individual. While shared experiences of family life can shape the family's perceptions of the world, individual experience certainly has its impact as well.

Reiss (1981) introduced the concept of family paradigms, an organized collection of the family's shared experiences, expectations, and constructs that guide the patterns of functioning in the family. In a crisis, the family's existing paradigm is shattered, replaced by a new paradigm, the crisis construct. He asserts that the family reorganizes itself during a state of crisis, and part of its coping mechanism is to develop a shared understanding of the crisis. During the diagnosis of a disability in a child for example, the family must regenerate itself in a way that will encourage recognition of the problem and growth in response. Hornby and Seligman (1991) assert that several shifts in thinking and behaviour must take place within the family to help them make sense of the disability's cause and implications. It is important to realize that the family may go through severe disorganization before emerging with its fresh family paradigm. Families may dissolve as each member focuses on their own reactions and feelings. But Reiss (1981) asserts that the accumulation of stress is too much for any one member to deal with alone. In time, each member will discover and assume their contributing role in the family, bringing with them their own individual experiences that will contribute to the family's overall conception of the crisis. While personal stressors may still remain individual (e.g., a father's problems at work), the family will unite under shared perceptions, recognizing

the meaningful links between each other's burdens. In the case of disability, the family may cope by recognizing the crisis as external and therefore beyond their control (Reiss, 1981). However because families often disagree or fight over various issues, some people find the concept of a family paradigm difficult to understand. In fact, Reiss and Oliveri (1980) argue that family conflict does not denote the presence of a family paradigm. While conflict may arise, underlying these arguments is a shared belief of the issue's importance and the necessity to find a resolution. In decoding the symbolic meaning of the crisis, the family can emerge with a cohesive sense of solidarity. They can collectively find significance in their reality through the consolidated meaning the family has attributed to the experience.

The above theoretical orientations are reflected in the disability literature. Gold (1993) found that the most powerful predictor of sibling acceptance of disability was parental attitude, particularly their mother's. The literature discussed below on the sibling experience in a family with a child with special needs continues to emphasize the systemic influence of one family member's experience.

Siblings

Typical sibling exchanges are uninhibited, charged with emotional power and can vary intensely between positive and negative expressions (Dunn, 2002). Larson and Richards (1994) report that siblings spend more time with each other than their parents, therefore their shared intimacy can create a strong supportive bond or intense conflict. Siblings exert an enormous amount of influence on each other, impacting such things as development (Stoneman, Brody, Davis, & Crapps, 1987) and adjustment (Dunn, 2002). Dunn (1983) is careful however to cite behaviour geneticists who emphasize that even

though typical siblings share genetic material and family environments, they can differ from each other in terms of personality, intellectual development, and psychopathology. This is most true when one sibling has special needs. While sibling relationship quality can be impacted by both structural and situational variables, the dynamics are even more affected by a sibling's special needs.

Both parents and professionals may overlook a healthy sibling's needs when there is a child with a disability in the family (Vadasy, Fewell, Meyer, & Schell, 1984). Several studies report that siblings of children with disabilities are at risk for deviancy (Trevino, 1979), lower self-concept (Harvey & Greenway, 1984) and behaviour problems (Cuskelly & Gunn, 1993; Dunn, 1992). However while the literature reports that siblings of children with special needs develop more emotional problems than controls (Dunn, 1992), additional research demonstrates that the effects may not be as detrimental as first assumed. Some studies show no significant differences between these siblings and controls in self-concept, social competence and behavior adjustment (Dyson, 1999; Ferrari, 1983). Other studies report positive effects of having a sibling with special needs (Pit-Ten Cate & Loots, 2000). For example, in an early landmark study by Grossman (1972), college-age siblings reported that 45% of these students believed they had benefited from having sibling with cognitive disabilities. They reported increased understanding of other people, more tolerance and compassion and a greater appreciation of their own good health and intelligence. However 45% of these siblings also reported negative experiences such as guilt, shame, a sense of being neglected and negative feelings toward their sibling. Other studies have since confirmed these results, demonstrating that there are both positive (Pit-Ten Cate & Loots, 2000) and negative

aspects (Fisman, Wolf, & Freeman, 2000; Vadasy, Fewell, Meyer, & Schell, 1984) to having a sibling with special needs. It is likely that because the dynamics in these families may be different from the norm, children with siblings with special needs do experience additional stress, including pressure to make up for the inabilities of their sibling with special needs (Grossman, 1972). Siblings also may also be forced to accept any family changes that might restrict normal development (Dyson, 1996). Additional caregiving responsibilities (Cuskelly & Gunn, 2003; Gath, 1973; Nixon & Cummings, 1999; Stoneman et al., 1987) as well as parental differential treatment (Pit-Ten Cate & Loots, 2000) have been reported in the literature.

The interactions of siblings of children with special needs have also been shown to be unique. While typical sibling relationships offer a forum for viewing both reciprocal and complementary interactions (Dunn, 1983), the presence of a sibling with special needs may reduce this variability (Miller, 1974). A reciprocal interaction describes one usually seen between peers, and is characterized by equality and joint exchanges. A complementary interaction is more often seen when there is a difference in power between two individuals, such as in the parent-child relationship. Miller (1974) reported that siblings engaged in more expressive activities (mutually satisfying and self-fulfilling) with their sibling without a cognitive disability, while activities with their sibling with a cognitive disability were more instrumental (helping or teaching). Such differences in interaction quality may add additional stress for a healthy sibling, and can impact personal development as well as the quality of family relationships. However encouraging effects have been found as well. Dunn (1983) cites Doise and Mugny (1981) who examined teaching between siblings of different cognitive abilities. Performance on a

cognitive task improved for the sibling of lesser cognitive ability, and advanced children made cognitive gains as well.

Another issue that siblings of children with special needs must contend with is inevitable differential treatment from parents. This is when more affection, attention and less discipline and control are perceived in a parent's relationship with one sibling than with another, often resulting in more hostile sibling relationships (Dunn, 2002). If a child is ill or has disabilities, the patterns of differential treatment can be exacerbated (Dunn, 2002). It is important however to realize that because of inherent differences in age, gender, personality and in some cases, condition, differential treatment is a complex issue that is almost inevitable due to variations in individual circumstances (McHale & Harris, 1992).

Finally, families with child with a disability are shown to experience greater stress than similar families without a child with a disability (Hastings, 1984). Both parents (Cuskelly, Chant, & Hayes, 1998; Dyson, 1996; Reddon, McDonald, & Kysela, 1992) and siblings (Nixon & Cummings, 1999) report extra sensitivity to additional stress when a child in the family has special needs. In their 1999 study, Nixon and Cummings concluded that having a sibling with a disability and their associated coping responses were related to poorer adjustment. Having controlled for other issues that may impact on family functioning, the authors suggest that sibling adjustment may be related to coping with everyday family stresses. They additionally affirm that their data confirms the results of others (Cummings & Davies, 1994) showing that children exposed to higher levels of stress are more reactive to it and less able to cope with it. However Hastings (1984) demonstrated that while the stress in these families was high, their coping

strategies and adaptation was quite functional. However it is unclear whether a shared family paradigm of stress exists in response to disability in the family. Boss (2002) asserts that understanding a family's view should not preclude understanding each individual's perceptions, affirming the importance of the sibling perspective. Therefore, the existing individual and family literature on stress is described next.

Stress

Stress has been described and defined in various ways in the literature. Lazarus (1966) and Sorenson (1993) both acknowledge the multiple interpretations the term stress carries, making it difficult to have a generally accepted definition of the term. Lazarus (1966) contends the term elicits thoughts surrounding disturbances in adaptation, the production of bodily disease and psychopathology. He defines stress from a homeostatic point of view. It is a "stimulus condition that results in disequilibrium in the system and produces a dynamic kind of strain" (Lazarus, 1966, p. 12). Other ambiguities surrounding the term's definition question whether stress refers to the stimulus or to the resulting psychological and physiological discomfort. Rutter (1983) describes stress as applying equally to "a form of stimulus (or stressor), a force requiring change of adaptation (strain), a mental state (distress), and a form of bodily reaction in response." For the purposes of this study, stress is defined by the person's individual appraisal of the stimulus or stressor. Therefore the following definition of stress by Lazarus and Folkman (1984) is appropriate: "Psychological stress is a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being" (p. 12).

There are evolutionary reasons for studying one's appraisal of stress. In order to survive, people must learn how to distinguish harmful situations from innocuous ones. It is logical therefore that different or developing levels of cognition will result in variations in individual stress levels. The literature argues that these variations depend upon two important processes that help us evaluate our potential stress events.

Individual stress appraisal. Lazarus and Folkman (1984) have done extensive research on the appraisal of stress and developed what they call the transactional theory of coping. While their research is adult-based, their conclusions may be relevant for children if the proper cognitive and emotional differences are taken into account. Because children's perceptions of life events can significantly influence their behaviour and adjustment (Sheets, Sandler, & West, 1996), it is important to ascertain the child's perspective, as this study does. However existing literature on stress appraisal in adults will be used to clarify the study's theoretical basis.

Lazarus and Folkman (1984) argue that there is an interaction between one's cognitive appraisal and coping resources that ultimately results in the individual's stress. Cognitive appraisal is described as an evaluative process, an individual judgment that determines whether or not the particular interaction between the person and the environment is stressful. Coping describes the individual management of the situational demands and the resulting emotions. Each personal evaluation will determine whether or not a particular situation is stressful. Lazarus (1966) first labeled these processes as primary and secondary appraisal. Primary appraisal is an evaluation of the danger the situation carries. Secondary appraisal determines what resources are available for coping with the situation. While the terms may suggest that one appraisal is more important or

precedes the other, Lazarus and Folkman (1984) caution that neither has any precedence over the other.

Primary appraisal can determine one of three things: the event is irrelevant, benign-positive, or stressful (Lazarus & Folkman, 1984). An irrelevant situation may appear uninteresting theoretically, but what is important is the cognitive process that has appraised the situation as such. A benign-positive appraisal results if the person has determined the situation to be either beneficial or enhancing to well-being. While emotions linked to this type of appraisal are usually positive, such as joy or happiness, the authors assert that it is also usually accompanied by apprehension. Appraisals are complex and while the end result may be positive, a fear that a desirable situation might malfunction can bring about anxiety too. Finally, a stressful appraisal can involve one or several of three facets, none of which are necessarily mutually exclusive. A harm/loss appraisal has determined a situation to cause damage, such as injury or illness. A threat appraisal perceives that harm or loss might be anticipated. This anticipation of harm or loss permits anticipatory coping in that the individual may plan for any difficulties ahead. The final stress appraisal of challenge also considers the coping resources available, but as opposed to the negative emotions such as fear and anxiety that characterize a threat appraisal, a challenge appraisal has the potential for gain and involves emotions such as excitement and eagerness. These categories can occur simultaneously. Lazarus and Folkman (1984) use the example of a job promotion that has the potential for advantage, but also includes increased responsibility and demands.

But what ultimately distinguish primary stress appraisals from one another are their cognitive and affective components. The cognitive component involves the

assessment of the situation as either harmful or beneficial, whereas the affective component involves either positive or negative emotions. Lazarus and Folkman (1987) offer strategies in measuring these two components. To measure one's cognitive appraisal of stress, it must be determined what the person thinks is at stake during the stressful encounter. They describe it as a hierarchy of one's goals and commitments. For example, a situation might be deemed stressful if there is a risk of loss of self-esteem or jeopardy to a loved one's health. The emotional component involves establishing which emotions are reported during stress. Lazarus and Folkman (1987) assert that these feelings reflect the person's appraisal of a situation as harmful, threatening or challenging.

The outcome of a stressful situation is also dependent upon one's secondary appraisal, their perception of their coping resources. Secondary appraisal involves evaluating what can be done about the stressful situation. It includes evaluating strategies and their consequences and the existence of resources, which will eventually interact with the primary appraisal to form the level of stress and the intensity and character of the emotional reaction. Because harm, threat, and challenges depend upon how much influence we think we have over events, secondary appraisal is an essential component in stress appraisal.

Coping is often distinguished as having one, or both of the following functions (Lazarus & Folkman, 1987). It can be either problem-focused, aimed at altering the situation, and/or emotion-focused, aimed at managing the accompanying emotional distress. These authors found that people used both functions in a variety of stressful encounters, however problem-focused coping was used more in situations perceived as

changeable, and emotion-focused was used more in situations that required acceptance (Folkman & Lazarus, 1980).

Lazarus and Folkman (1984) also assert that individuals differ in their sensitivity and vulnerability to events. Children's developmental differences become relevant here. Vulnerability is described as the adequacy of the individual's resources. For example, children's physical, psychological, and social resources are not as developed as adults' are, and as such, their increased vulnerability may transform into increased threat. Also influencing appraisal are personal factors, such as commitments and beliefs. The former describes what the individual holds dear and values, while the latter are one's pre-existing notions about reality. Beliefs about personal control for example are particularly important in terms of appraisal, the extent to which the person feels confident about their influence upon the stressful environment. Termed *situational control appraisal*, Lazarus and Folkman (1984) link this to Bandura's idea of self-efficacy (1982), which is an individual's perception of their ability to deal with challenging situations. Because self-efficacy is dependent upon one's experiences with cause and effect situations, children might be at a disadvantage in terms of their secondary appraisal. Children have had fewer experiences than adults, which might lead them to experience increased stress due to lower levels of self-efficacy or a lesser cognitive ability to appraise their resources realistically. Situational factors will also influence personal appraisal (Lazarus & Folkman, 1984). The situation's novelty, predictability, imminence, duration and other temporal factors will either render an event more or less threatening. Silver and Wortman (1980) identify several variables that influence one's coping with stress, one of which is any prior experience with other stressors. For children, the likelihood of encountering

new stressors is higher than for adults who likely have had experience with stress.

Novelty alone therefore might lead one to believe that children's appraisal of stress will differ from adults'. Appraisal of stress may also be affected by a child's gender. Honig (1986) asserts that male children are more vulnerable to stress than female children, as indicated by higher rates of bed wetting, dyslexia and delinquency.

Children's secondary appraisal, an assessment of one's coping mechanisms, may also differ from adults'. While innate coping begins as soon as a child is born, Brenner (1984) asserts that children will inevitably develop some of their coping mechanisms from their parents, peers, teachers and relatives. The author further believes that coping cannot be classified neatly into an age-stage list, as numerous effective coping strategies have been seen across the lifespan. Children rarely will use only one strategy at a time, and it is possible that children may not even be conscious of their coping patterns. However distinguishing whether a child is avoiding or facing stress can be useful (Brenner, 1984). Avoidance can be displayed through denial (acting as though the stress does not exist), regression (acting younger than their age), withdrawal (removing themselves physically or mentally from the situation), or impulsive acting out. In contrast, altruism (forgetting their trouble by helping others), humour (joking about their stress), suppression (setting aside their stress temporarily), anticipation (foreseeing and planning for next stressful episode) and sublimation (becoming absorbed in activities) are ways children cope while facing the reality of their stress. All these types of coping may bring both positive and/or negative effects for the child, depending on the extremity of their behaviour (Brenner, 1984). Other authors distinguish coping in children in terms of internalizing or externalizing behaviours (Honig, 1986). Children who cope by

internalizing are more likely to accept responsibility and remorse for their actions, whereas those who externalize tend to attribute control or fate to others.

Despite the difficulty, researchers have attempted to reveal developmental differences in coping. Spirito, Stark, and Tyc (1994) suggest that younger children (aged 7 through 12) use more behavioural strategies, such as distracting themselves by watching TV, whereas children aged 13 years and older used more cognitive strategies, such as problem solving. Gender differences in coping have been found as well. Sorensen (1991) reports in her study of school-age children that girls used coping mechanisms that involve social support and intrapsychic comfort (i.e., internally focused, emotionally and intellectually satisfying situations, such as free play, school subjects, etc.), whereas boys used physical-social activities (e.g., sports) and physical comforts (e.g., being at home, getting something new, etc.) to relieve their stress.

Therefore the literature begs the question: do developmental differences between adults and children render it impossible to apply stress appraisal theories to children? Lazarus (1966) asserts that as with our psychological structures, our ability to appraise stress progresses and develops over time. Hetherington (1984) asserts that younger children's appraisals will naturally differ from an older child's due to their limited social and cognitive capacities, their dependence on parents, and their restriction to the home. It is possible therefore that because the above theory emphasizes appraisal as linked to cognition, its foundations may be transferred to children if differences in cognitive levels are accounted for. However research into children's appraisal of stress is, with a few exceptions, missing from the literature. Some studies with children have discovered that negative appraisals of life events correspond to more maladjustment. For example, Sheets

et al. (1996) linked children's negative appraisals of their parent's divorce to higher levels of anxiety (above those effects of the divorce itself). A study by Yamamoto and Felsenthal (1982) demonstrated discord between adult judgments of what they had anticipated to be appraised as stressful by children and actual ratings from the children themselves. Adults "considerably" underestimated those events labeled very upsetting by children, but tended to overestimate items of lower stress. Several authors have attempted to rectify this discrepancy by questioning children themselves about their stressors and coping resources (Elwood, 1987; Sorenson, 1991). Thies and Walsh (1999) attempted to evaluate the cognitive appraisal of stress in children and adolescents with chronic illness. Using Piaget's work (1953) as a basis for their study, the authors revealed that the organization of cognitive appraisal changes as children age. Primary appraisal followed a predictable order from youngest to oldest, from concrete to abstract thinking. Secondary appraisal showed a developmental trend of external to internal rationalization. Younger children based their responses to stress by considering rules and authority figures, whereas the older children considered their own personal standards. These developmental differences were also demonstrated through the emotions children cited. Although the entire sample of children (between 8-16 years old) reported being moderately angry, the younger children were moderately sad while the older adolescents were upset and frustrated. The authors explain that anger and sadness reflect less mature appraisals. Carroll and Steward (1984) have also shown that younger children's use of affective words reflect a simpler structure and meaning than those used by older children. Frustration is a more complex emotion, linked rather to the differences between personal and situational loci of control. Because adolescents were able to think more abstractly

about their stress, they were able to link their emotions to a perceived loss in personal control.

As the differing emotions in the above studies demonstrate, emotional development may also be influential in stress appraisal. Frijda (1993) asserts that there is a strong correlation between one's pattern of appraisal and corresponding emotions. Lusk (as cited in Kagan, 1983) reports younger children will likely become fearful of stressors, while older children are more likely to become angry. She asserts that even 4-year-olds can appreciate this emotional difference in developmental levels. When shown pictures of stressful events occurring to children of different ages, these children labeled infants as frightened and labeled older children and adults as angry. Similarly, children who understand the cause of their emotions therefore may be able to understand the cause of their stress. Harris (1989) contends that by the age of four, children understand that emotions are evoked from situations. As the child develops, their conception of emotions becomes more complex. School-age children understand an emotional experience to be contingent upon what is happening to the individual at the present time, but also upon the person's thoughts, feelings, and expectations (Thompson, 1987).

Therefore, both the child's emotional and cognitive levels can influence their perception of stress. However children are part of a larger family unit, which in turn develops its own perspectives on stressful situations based on its shared experiences and beliefs. It is unclear if children are influenced by their family's paradigms, or if their cognitive and emotional differences limit their ability to be influenced by their family's shared constructs on stress and coping. Families make use of their shared meanings and resources to adapt and cope with their stress as a unit. While functioning similarly to

individual appraisal, family stress appraisal also involves the complex interaction of the system and its members, rendering it a slightly different process. The family stress literature is described next.

Family stress appraisal. Family stress research is defined as the study into how various life events and stressors affect the family (Huang, 1992), as opposed to the individual. Patterson (2002a) describes this as a process: “Specifically, family stress theory...emphasizes the active processes families engage in to balance *family demands* with *family capabilities* as these interact with *family meanings* to arrive at a level of *family adjustment or adaptation*” (emphasis in original) (p236). While family life can be relatively stable, there are times when family demands exceed their capabilities. What can result is a state of family disorganization, a family crisis (Patterson, 2002a). The literature emphasizes the difference between family stress and family crisis. Stress is used to define something that happens *to* the family, changing its usual patterns, whereas the crisis is what results and happens *within* the family (Reiss, 1981). A family stressor is something more specific, an internal or external event “which produces or has the potential of producing, change in the family social system” (McCubbin & Patterson, 1983, p7). As earlier discussed, a family crisis can force the family to change its functioning as it attempts to return to an adaptive state. The family’s ability to regenerate itself is termed ‘family resilience’, and is an ongoing process within the family’s life cycle (Patterson, 2002a).

Research cites several potential effects that can elicit stress in families. Life events, such as divorce or death, are described as events of trauma that potentially cause tension and anxiety (Sorenson, 1993). Others include a more detailed conception. For

example, Pearlin (1991) described life strains as existing within one of three categories. First are the daily, enduring “slow-to-change” problems. Second are the predictable, regular events of the life cycle such as marriage, childbirth, or retirement. Finally, there are the unscheduled, undesirable events, such as divorce or illness. Others emphasize the more common daily hassles of life, defined by Lazarus and Folkman (1984). These authors assert that such stressors are in fact more predictive of psychological and physiological responses than life events. These daily stressors are things such as family arguments, loneliness, or getting a bad grade (Sorenson, 1993). The distinction between stressful life events and daily hassles of life is important. The diagnosis of a disability in a child is an example of a stressful life event. However even years beyond the initial crisis phase of diagnosis, the many enduring, daily disturbances in routine may unfold with which a family must contend. Lazarus and Folkman (1984) have confirmed that one’s appraisal of such daily hassles influence both physical and psychological well-being.

Other authors have developed models that attempt to explain the dynamics involved in family stress. Hill (as cited in Walsh, 1982) developed his famous ABCX model of family adaptation to stress that explains the interaction of the variables. “A”, the stressor and its concomitants (such as severity of a disability) interacts with “B”, the family’s resources and with “C”, the family’s definition of the event. What results is “X”, the crisis. Each of these categories has been expanded over the years to include several influences. Family resources (B) refers to factors such as family flexibility and quality of relationships prior to the crisis (Seligman & Darling, 1989). The definition of the event (C) reflects the values and past history of the family. The meaning a family attaches to

the event is vital in the coping process. Stress does not have to result in family crisis if the stressors are defined as manageable and the family relies on its resources to pull through (Seligman & Darling, 1989). For example, in families with a child with disabilities, Powell and Gallagher (1993) found that an optimistic and accepting parental attitude enhanced the adjustment of normal siblings.

McCubbin and Patterson (1983) expanded Hill's model even further, with their Double ABCX model of family stress. Because these authors believed Hill's model only addressed the short-term disruption a family experiences from the stressor event, an additional level was added to describe the post-crisis phase. For example, when a diagnosis of a disability happens in the family, the above single ABCX model is relevant. After the initial family crisis of diagnosis subsides, the potential for pile-up stressors (aA) emerges and the family continues to evolve in response. Pile-up stressors can include factors such as role changes in the family, ongoing parental conflict, and decreased family finances (Plunkett, Sanchez, Henry, & Robinson, 1997). Therefore in the expanded model, the "bB" factor includes not only the family's initial resources, but also considers the additional resources accumulated through the post-crisis period. The family's definition of the crisis, "cC" also evolves. With time, a family is challenged to redefine their initial meaning attached to the crisis in a way that will encourage adaptation and will benefit everyone. Finally, the xX factor is defined as family adaptation, the outcome of the family after the crisis. The Double ABCX model is particularly relevant to this study, as families will be studied beyond the initial crisis phase of diagnosis. While adjustment has likely developed in these families, pertinent to

this study is the perception of the daily stressors and hassles (aA) with which the members of the family must contend.

Finally, McCubbin, Thompson, Thompson, Elver, and McCubbin (1998) describe a 5-leveled hierarchical ordering of the family stress appraisal process. The first two levels involve situational appraisal and stressor appraisal. The former describes the family's shared assessment of the stressor and its demands on the system, whereas the latter is the family's definition of the stressor. The last three levels of the model describe factors such as the family's values, beliefs, and coherence, asserting that each helps attach meaning to the crisis, aids in coping and guides behavior. McCubbin et al. (1998) emphasize that an event such as the diagnosis of a child with a disability will require drastic changes in family's functioning. As Reiss (1981) previously asserted, family paradigms are challenged in order to respond best to altered family roles and routines. But just as the family system must adapt to a crisis using its pre-existing resources, an individual must as well. Walker (1985) asserts that though Hill's model of family stress is widely used in both the literature and in practice, it neglects the multiple levels of the system. A family's members are interdependent, but are still distinct.

The present study therefore reveals how siblings in families with a child with special needs appraise their stress and coping. Parental coping mechanisms were also examined. The daily hassles of siblings of children with a cognitive disability were investigated, as research demonstrates that these upsets explain more variance in psychological and bodily health outcomes than life events do (Lazarus & Folkman, 1987).

Research Questions

What daily hassles do siblings of children with special needs experience most often and find most stressful? The analysis of frequency of daily hassles may illuminate if there exists any common problems or stressors that siblings of children with disabilities experience. It may also shed some light on any common experiences that consistently elicit stress in the siblings.

How do siblings of children with special needs cope with their daily upsets? Children may use many coping strategies in response to stress. The research hopes to illuminate any commonalities among the siblings in terms of their use of 15 coping strategies. These strategies may also share characteristics with the family's reported coping strategies.

Are there developmental differences in sibling stress appraisal? The research also sought to reveal any developmental differences between the younger (ages 8-9) and older (ages 10-12) children's appraisal of stress. Again, the frequency, intensity, and content of stress were investigated. The literature reports that younger children may think more concretely about stressors, while older children demonstrate more abstract thinking (Sheets et al., 1996; Stattin, 1984).

Are there gender differences in sibling stress appraisal? While sex has been shown not to have an impact on stress levels in children in terms of gender personality traits (Bossert, 1994), female siblings of children with special needs are reported in the literature to be the bearers of more caregiving responsibilities (Stoneman et al., 1988). However Honig (1996) found that males were more vulnerable to stress than females. It

is therefore important to clarify whether or not gender has an impact upon the child's reported levels of stress.

How does the family cope with their difficulties? The family's coping paradigm was also investigated to discover which external and internal resources parents report as most useful. Because the systems literature emphasizes the interdependence and shared meanings of the family structure, this question has relevance for both parents and children. When the family's adaptation paradigm is clear, future investigations may reveal that children are influenced by their family's adaptation to the disability.

How do parents perceive their children's relationship? Parents are often questioned about the nature of a normal sibling relationship, however when one child has special needs, the dynamics inevitably change. Parents' assessments of their children's sibling relationship under these special circumstances may shed some light on what these differences may be and what issues are most prevalent.

Method

Participants

Families with more than one child, including one child with special needs, were recruited from the city of Montreal and its surrounding areas. Participants were found through community centers, special needs schools, word-of-mouth, and through a sibling support group at which the researcher had been volunteering. Information packages (see Appendix H) were distributed to parents after a discussion given by the researcher, or by school or centre employees. A total sample of 12 families participated in the study. The sample size was a direct effect of limited time. Recruitment continued for a period of 5 months, after which point recruitment was suspended in order to begin analyses.

Seven siblings (58%) were younger than their brother or sister with special needs. Gender of the siblings of children with disabilities was evenly distributed, with six boys and six girls. All siblings were between the ages of 8-12 years old at the time of participation. There were three 8-year-olds, four 9-year-olds, three 10-year-olds and two 12-year-olds. The mean age of the children was 9.5 years with a standard deviation of 1.38.

Nine of the 12 children with disabilities were male and three were female. The mean age of these children was 10.08 years, with a range of 3 to 14 years old. All disability types included some type of cognitive disability, and at times included accompanying physical disabilities. Four families described their child's disability as Autism; Three families described their child's disability as Down's Syndrome; Two families described their child's disability as a Chromosomal Abnormality; One family described their child's disability as Pervasive Developmental Disorder, Not Otherwise

Specified; One family described their child's disability as Neurofibromatosis; One family described their child's disability as Cerebral Palsy.

All families except one included a mother and a father, married, and living together with their children. One family was a single-mother family. There were four families with two children (33%), seven families with three children (58%), and one family with four children (8%). Eighty-four percent of fathers, and 33% of mothers were employed. Based on assessment of parent job descriptions and attendance at university, the sample represents a middle class sample. Of the 24 parents (mom's and dad's), 13 have attended some level of university. A sample of job descriptions included chartered accountant, salesman, legal secretary, photographer, lab technician, lawyer and cardiologist. Sixty-seven percent of the families were Christian and 33% were Jewish. Sixty-seven percent of families receive some kind of help with their child with special needs within the home, while 75% receive help outside the home. Thirty-three percent of siblings attended a monthly sibling support group to discuss their experiences of having a sibling with special needs. Finally, 75% of families reported experiencing one or more stressful life events in the past year (such as an extended family member's death), besides the condition of their child with special needs.

Measures

The Daily Events Scale for Siblings of Children with a Disability or Illness. This scale (Giallo & Gavidia-Payne, in press) was used to assess the substance and frequency of daily hassles reported by the sibling, and also provides an overall level of stress for the child. This instrument was developed in Australia and has been used in one study, currently in press. The scale can be seen in Appendix A and includes both hassles and

uplifting factors associated with having a sibling with a disability. The child was asked to rate each item along two dimensions: “how often does the problem happen?” and “how stressed out does the problem make you feel?” The former question was answered along a 5-point likert-type scale, where zero represents “never,” two represents “sometimes,” and four represents “always.” The latter question was also answered along a 5-point scale where zero represented “not at all,” two represented “a bit,” and four represented “very.” Children could also choose numbers 1 or 3, representing a point in between each description. For both the hassles and uplifting subscales, a total score each for both frequency and intensity can be obtained. High scores on the hassle subscale indicate a high frequency of hassles and high intensity of affect associated with hassles. High scores on the uplifting subscale indicate a high frequency of uplifting factors and high intensity of affect associated with these positive events. The instrument has demonstrated good face validity, however no other forms of validity have been investigated. Reliability has also been proven adequate with the original Australian sample. Items in the scale also seem to correspond well with the experiences reported in Pit-ten Cake and Loots’ (2000) study on siblings of children with disabilities in which they divided sibling concerns into one of three categories: the sibling relationship, relationship with peers and external community, and relationship with parents.

KIDCOPE. Secondary appraisal was measured by having the child assess their coping strategies used during stressful events surrounding their sibling by completing the KIDCOPE measure (Spirito, Stark, & Williams, 1988). This instrument asks the child about their coping strategies, both in terms of use of a particular strategy and how much the strategy helped (see Appendix B). For each strategy, the child was asked to answer

either “yes” or “no” depending on whether they used the strategy or not. If they chose yes, they were asked to indicate how much the strategy helped by choosing one of three possible answers: Not at all, a little, or a lot. The younger version of this scale (Spirito et al., 1988) is appropriate for children aged 7 -12-year-olds and uses 15 items to measure the frequency and effectiveness of behavioural and cognitive coping strategies. Children were asked to consider an upsetting event concerning their sibling with special needs when completing the measure. The greatest strength of this instrument is its brevity (Naar-King, Ellis, & Frey, 2004). Although no specific correlations are reported, test-retest reliability is described as adequate. To assess criterion validity, eight items on KIDCOPE were compared with scales in the Coping Strategies Inventory and five correlations were significant.

F-COPES. The family’s coping and adaptation paradigm was measured through the parent’s completion of the Family Crisis-Oriented Personal Evaluation Scale (McCubbin, Olson, & Larsen, 1987). This instrument measures a family’s coping styles in relation to their everyday problems and was based on the family stress literature. The scale includes 30 coping strategies to be rated along a 4-point Likert-type scale and takes about 10 minutes for parents to complete (see Appendix C). Each number represents the degree to which the family uses the listed strategy. An answer of 0 represents “never,” one represents “sometimes,” two represents “often,” and three represents “most of the time.” Items are divided into five sub-scales. Three scales describe the external family coping style, including acquiring social support from relatives, friends, neighbours and extended family, seeking spiritual support, and mobilizing the family to acquire and accept help from community resources. Two subscales assess how the family handles

their problems internally, including reframing, which assesses the family's capacity to redefine stressful situations in order to make them more manageable, and passive appraisal, which measures the inactive or passive behaviours a family might employ. *Alpha* is reported at .86 overall, with subscales ranging from .62 to .84. Test-retest reliability after four weeks for the total scale was .81 (Grotevant & Carlson, 1989).

Disability Index. Parents were also asked to complete a Disability Index (modified from Trute, 1990) to clarify the nature and severity of their child's special needs (see Appendix D). This is a 4-item index that measures the child's level of disability in terms of intellectual impairment, physical disability, need for ongoing medical attention and future need for physical assistance in everyday functions. Each of the four items requires a numerical response of 1 (low), 2 (low to medium), 3 (medium), 4 (medium to high) or 5 (high). Trute and Hiebert-Murphy (2002) report that the item-total correlations in this Likert-type scale ranged from .44 to .64, with *alpha* of .74. They further assessed that the index correlated significantly with disabled children's Developmental Quotient ($r = .59$), but improves upon this measure by including both physical incapacitation as well as mental ability.

Demographic Questionnaire for Parents. This questionnaire was developed specifically for use in this study and asks parents for information on personal and family demographics, such as age, income, etc. (See Appendix E). Several questions on the family's resources concerning their child with special needs were included. A question on any stressful life events the family might have experienced during the last year was included to ascertain the family's recent experience with stress.

Parental Expectations and Perceptions of Children's Sibling Relationships

Questionnaire (PEPC-SRQ). This instrument (Kramer & Baron, 1995) measures parental appraisal of children's sibling relationship quality (see Appendix F). Only the second part of the questionnaire was used, "How I see my children's sibling relationship". This part lists 24 behaviours and asks parents to rate how frequently the behaviour occurs in their children's relationship. They are also asked how much of a problem the behaviour is, how easily they could improve the behaviour, and how much would they like help to improve the behaviour. For the purposes of this study, each of the 24 items was analyzed using only the first two questions. Frequency of the behaviour required a response of 0 (never), 1 (rarely), 2 (sometimes), 3 (usually) or 4 (always). Parents then choose 0 (it's not a problem), 1 (it's a small problem), 2 (it's a big problem), or 3 (it's a very big problem) in response to the listed behaviour. Test-retest reliability was evaluated, and resulted in correlations of .74 and above for the first section of the questionnaire. However lower correlations (between .37 and .71) were found for the second section in which parents are asked to report their perceptions of their children's actual behaviour, suggesting that results should be interpreted carefully. Construct validity is supported by comparisons with other standardized measures of sibling relationships (i.e., the Sibling Relationship Questionnaire), which use similar domains in their evaluation (Kramer & Baron, 1995).

Follow-up Survey. Following the initial phase of data collection, follow-up surveys were mailed to parents in an effort to descriptively clarify some results. These surveys included four questions that evolved from a descriptive statistical analysis of the above instruments. The four questions probed the kinds of coping strategies parents used

and sibling behaviour parents observed in more detail. The questions can be seen in Appendix G. Parent answers supplemented the discussion of the results.

Procedure

Families were all studied in the home setting and were given an initial information page and consent form to participate in the study (see Appendix H). The researcher and the parent arranged a convenient time when the study could take place, mostly during evenings and weekends. When there was more than one sibling without a disability in the family, the sibling closest-in-age to the child with special needs was evaluated. In most cases, parents filled out their instruments while the researcher interviewed the child in a separate room. Most home visits were about a half-hour to an hour in length.

Ten of the 12 children were interviewed alone. In two cases, the child requested that their parent be present. Prior to beginning each interview, the researcher engaged the child in some brief casual discussion in order to put them at ease. After a few minutes, the sibling consent form (see Appendix H) was read aloud to the child and he or she was asked to print their name if they agreed to participate in the study. At this point, information on the first instrument, the Daily Events Scale for Siblings of Children with a Disability or Illness (Giallo and Gavidia-Payne, in press), was read to the child directly from the instrument itself. In developmentally appropriate terms, it was additionally explained that each question required two answers. All the children were presented with the option of using a prepared pictorial scale so they could point to their answers. This representation used increasingly-sized circles to correspond to the increasing levels of the scale. Before beginning, an initial example was demonstrated to the child to assure their

understanding. Each item was then read aloud to the child and their ratings recorded by the researcher. School-age children more easily understand the word *upset* than *stressed*, therefore this word was substituted regularly. Other words or phrases that were found confusing by some of the children were modified as needed throughout the interview. The phrase “how often” was sometimes substituted with “how much”; “Giving in to my sibling” was sometimes substituted with “letting my sibling get what he or she wants”; “Interrupt” was sometimes substituted with “bother”; and “blame” was sometimes substituted “fault or doing.” In general, all children seemed comfortable with the scale and appeared to understand the instructions.

The administration of the KIDCOPE (Spirito et al., 1988) to the sibling was prefaced with the following instructions: “Sometimes children do different things to make themselves feel better when they are upset. While answering these questions, I want you to think about the times when you are upset or bothered about something concerning your (name of brother/sister with special needs). I’m going to read different things that some people do to make themselves feel better and then I will ask if you ever do that thing. If you do, then I will ask you how much it helps you feel better, if at all.” The children were again supplied with the option of pointing to their answers pictorially.

After the interview, children were thanked for their hard work and offered a choice of a toy for themselves. Additional children in the family were also invited to choose a toy. As mentioned, most parents completed their instruments in a separate room during the sibling interview where the researcher was available nearby for questions. Two families were given stamped envelopes so they could return their questionnaires at a later time, which they did.

Results

Due to a small sample size, all instruments were analyzed using descriptive statistics only. Parent instruments are analyzed first, followed by sibling instruments.

Parental Rating of the Child's Disability

Parents were asked to rate the degree of their child's disability along a 5-point scale that included four categories: Intellectual impairment, physical disabilities, need for ongoing medical attention, and future need for physical assistance in everyday functions. Each of the four scores was added together for a total disability rating, with the highest possible rating of 20. Four parents (33%) gave a total rating of 10 or under, while 8 parents (66%) rated their child's disability as 11 or above. Five of these eight gave a rating of 15 or above (42% of the total sample). The mean rating was 12.04, with a standard deviation of 4.07 (range = 6 - 17). Parents were also asked to rate the adjustment of their child without a disability on a 10-point scale, with 10 representing optimal adjustment. Three parents (25%) rated their child's adjustment as a 5 or below, while 9 (75%) of parents rated a 6 or above.

Parental Rating of Family Coping Strategies

The purpose of these analyses was to reveal how the family coped with their daily difficulties; however a larger sample size would have also made possible comparisons with sibling coping strategies. Consistent with family systems theories, family and sibling coping strategies may be linked. Reliability of the 30 items in F-COPES was reasonably high ($\alpha = 0.73$). Results are reported by individual items and can be seen in Table 1. Tables are found at the end of the Results section. The scale is a 4-point likert-type scale, with a range of 0 to 3. The overall mean for the scale was 1.07 with a standard deviation

of 0.64. The most commonly item reported by parents as a problem-solving attitude and behaviour developed by their family in response to problems or difficulties, as displayed by having the highest mean, was “accepting stressful events as a fact of life.” All families reported using this strategy to some degree, whereas 8 of 12 families reported using it “often” or “most of the time.” The second most commonly used strategy was “facing the problem head on and trying to get a solution right away.” Again, all families reported using this strategy to some degree, with 8 of 12 families using it “often” or “most of the time.” The third most commonly used coping strategy was reported as “showing that we are strong.” Again, all families used this strategy to some degree and 8 reported using it “often” or “most of the time.” Each of the above strategies had means over 2. Other strategies reportedly used by all the families to some degree included “knowing we have the power to solve major problem,” and “accepting that difficulties occur unexpectedly.”

As displayed by the lowest means, two coping strategies were reportedly used least often by families, “asking relatives how they feel about problems we face,” and “seeking advice from a religious leader.” Eleven of the 12 families reported never seeking advice from a religious leader, whereas 8 of the 12 families never seek advice from relatives. The third least commonly used strategy by families was reported as “knowing luck plays a big part in how well we are able to solve family problems.” Nine of 12 families reported never using this strategy.

In summary, families indicated that internal coping strategies, such as reframing (accepting stressful events as a fact of life; accepting that difficulties occur unexpectedly; knowing we have the power to solve major problems; showing that we are strong) were used most often. An active problem-solving strategy was also commonly used (facing the

problem head on and trying to get a solution right away). Spiritual and family supports were the less popular strategies.

Parental Ratings of Sibling Relationship Quality

The sibling relationship questionnaire was intended to answer the research question of how parents perceived their children's sibling relationship. The *PEPC-SRQ* (48 items) demonstrated high internal reliability with a reported *alpha* of 0.93. Only the first and second questions on each of the 24 behaviours was evaluated, "how frequently would you say each of the following occurs in your children's relationship?" and "how much would you say this is a problem?" The scale for the first question ranged from 0 - 4, and 0 - 3 for the second question. Results can be seen in Table 2 (positive items) and Table 3 (negative items). Overall means for positive items were the following for the first and second questions respectively: $M = 1.98$, $SD = .049$; $M = 0.44$, $SD = 0.41$. Overall means for negative items were the following for the first and second questions respectively: $M = 1.58$, $SD = .052$; $M = 0.70$, $SD = 0.25$.

Two positive items were reported most commonly, "loyalty or sticking up for one another" (item 1 in Table 2) and "sharing" (item 2). Ten of 12 parents reported seeing loyalty between their special needs child and their sibling "sometimes or more" and the same number reported this behaviour as "not a problem." Six of 12 parents reported seeing sharing "sometimes or more," however 5/12 reported this behaviour as a "small problem." Next most commonly reported characteristic was "kindness" (item 3), followed by "protectiveness – looking out for the other's welfare" (item 4). Kindness was observed in 5 of 12 families "sometimes or more" and 3/12 reported it as "a small problem." Protective behaviour was observed in 9/12 families "sometimes or more" and

11/12 reported this as “not a problem.” The positive characteristic reported as the biggest problem between their children was “talking to each other, conversations” (item 12).

Seven of 12 families reported this as a “small problem or more.” The least reported positive characteristics seen between siblings was “sharing worries or concerns” (item 13). This was never reported in 7/12 families. The two positive characteristics reported as least problematic in their children’s sibling relationship were “protectiveness – looking out for the other’s welfare” (item 4) and “feeling proud of one another” (item 6). In both cases, 11/12 families reported these as “not a problem.”

“Trying to control each other’s behaviour” (item 1 in Table 3) was the negative item reported as seen most commonly between siblings. Eleven of 12 parents reported seeing controlling between their special needs child and their sibling “sometimes or more,” although 6/12 reported the behaviour as “not a problem.” Three characteristics were most commonly reported next: Anger or hostility (item 2), fighting over objects (item 3), and fighting over territory or space (item 4). “Fighting over objects” and “anger or hostility” was observed in 9/12 families “sometimes or more.” Nine of 12 families reported “fighting over objects” as a “small problem” or more. Eleven out of 12 families reported “anger or hostility” as a “small problem” or more. “Fighting over territory or space” was observed in 8 of 12 families “sometimes or more” and 7/12 consider the behaviour a “small problem” or more. The negative characteristic reported as the biggest problem between their children was “anger or hostility” (item 2), again with 11 of 12 families reporting this as a “small problem” or more. The two least reported negative characteristics seen between siblings were “threats” (item 11) and “competition” (item 10). “Threats” were never reported in 6 out of 12 families, and “competition” was

seen “rarely or never” in 9 of 12 families. The negative characteristic reported by parents as least problematic in their children’s sibling relationship was “competition.” Nine of 12 families reported this characteristic as “not a problem.”

When parents were asked to rate the relationship between their child without special needs and their child with special needs on a scale of 1-7, one representing “extremely poor” and seven representing “extremely well,” 8 of 12 parents rated the relationship as a five or above. A mean of 5 resulted, with a standard deviation of 1.71. The range was 2 - 7.

In summary, controlling, loyalty, and sharing behaviours were reported as most commonly seen between children and their sibling with a disability. The most problematic behaviours were anger or hostility and talking to each other. The least problematic behaviours in the sibling relationship were competition, pride and protectiveness.

Sibling Daily Events Ratings

Results from the Daily Events Scale for Siblings of Children with a Disability or Illness can be seen in Table 4 for overall means and Table 5 and 6 for individual items. These ratings will shed light on the research question that asks what daily hassles do siblings of children with special needs experience most often and find most stressful. Daily uplifts for these siblings will also be revealed. Organization of these ratings into gender and age categories may also reveal any developmental and gender differences in stress appraisal. Reliability for the entire scale and its 128 items was high with an *alpha* of 0.94. An *alpha* of 0.91 resulted for the Hassle scale (80 items), and an *alpha* of 0.93

resulted for the uplift scale (48 items). The range of the scale is from 0 - 4 for both questions (frequency and intensity).

Hassles. Disability specific hassles (22 items) and uplifts (10 items) were extracted from the scale and are analyzed by frequency and intensity (see Tables 4 and 5). Analysis of daily hassles resulted in an overall frequency mean of 1.69 ($SD = 0.63$) and an intensity mean of 2.05 ($SD = 0.64$). The most frequently reported daily hassle (see Table 4) was “when my sibling with a disability cries, screams or yells when they don’t want to do something” (item 11 in Table 5). Seven of 12 siblings reported this behaviour as occurring “always.” The most stressful item based on the intensity rating was reported as “when my brother/sister with a disability embarrasses me when I have friends over” (item 21). Of the 5/12 sibling that reported this behaviour as occurring, three found this behaviour “very stressful.”

Results are further categorized by age (younger children were 8 or 9; older children were 10, 11, or 12) and by gender. Overall means comparing these categories are displayed in Table 4. Disability specific hassle results will be reported first.

For siblings aged 8 or 9, a frequency mean of 1.76 ($SD = 0.73$), and intensity mean of 2.13 ($SD = 0.73$) was found (see Table 5). Compared to the overall average, and to the older children, both ratings for this younger age group were higher. The most frequently reported daily hassles for this age (see Table 5) were “when my brother/sister with a disability cries, screams or yells when he/she doesn’t want to do something” (item 11), “when my brother/sister with a disability cries or gets upset” (item 1), and “when my brother/sister with a disability hurts, hits, pushes, scratches or kicks me or others” (item 3). The most stressful items for this age based on the intensity ratings were “when my

brother/sister with a disability embarrasses me when I have friends over” (item 21) and “not being able to do what I want because my brother/sister with a disability interrupts me” (item 15).

For children aged 10 - 12, the frequency mean was reported as 1.59 ($SD = 0.74$) and the intensity mean as 1.79 ($SD = 1.01$), both below the overall and younger children’s averages (see Table 5). Most frequently reported hassles for this age group were “when my brother/sister with a disability cries or gets upset” (item 1), “when my brother/sister with a disability cries, screams or yells when he/she doesn’t want to do something,” (item 11) and “having to give in to my brother/sister with a disability so he/she does not get upset” (item 10). The most stressful items for this age group based on the intensity ratings were reported as “when my brother/sister with a disability cries, screams or yells when he/she doesn’t want to do something” (item 11), “when my brother/sister with a disability is sick or hurt” (item 2), and “when people don’t understand about my brother/sister’s disability” (item 20).

For females, the overall frequency mean was reported as 2.03 ($SD = 0.81$) and the intensity mean as 1.95 ($SD = 1.04$). This frequency mean is above the overall and male average; however the intensity means are below both the overall and male averages. Most frequently occurring hassles for females were “when my brother/sister with a disability cries or gets upset” (item 1) and “when my brother/sister with a disability cries, screams or yells when he/she doesn’t want to do something” (item 11). Based on the intensity ratings, the latter was also found most stressful by females, followed by “when my brother/sister with a disability takes my things without asking” (item 4).

For males, the overall frequency mean was reported as 1.34 ($SD = 0.66$) and the intensity mean as 1.98 ($SD = 0.77$) (see Table 4). These scores were below the overall averages. The frequency mean was below the female mean; however the intensity mean was slightly above. In terms of frequency, males reported the same two items as most frequently occurring as the females: “When my brother/sister with a disability cries, screams or yells when he/she doesn’t want to do something” (item 11) and “when my brother/sister with a disability cries or gets upset” (item 1). As indicated by the intensity rating, the item found most stressful by males was “when my brother/sister embarrasses me when I have friends over” (item 21) and “when my brother/sister with a disability cries or gets upset” (item 1).

In summary, these results suggest that younger children may be more sensitive to their sibling’s disability, reporting more negative daily hassles and more stress associated with them than the overall sample and older children’s ratings. Both ages reported that crying or yelling was most often displayed by their sibling with a disability. However the issues that each age group found most stressful differed. Younger children reported being more stressed by being embarrassed or interrupted by their sibling, whereas older children were more stressed by their sibling’s crying and sickness. This older group was also stressed when others did not understand about their sibling’s condition. In addition, females reported higher incidences of daily hassles; however males reported being more stressed by these hassles. Both genders agreed on what hassles occurred most frequently (sibling crying or upset). Females were most stressed when their sibling cried when they did not want to do something, whereas males were most stressed when their sibling embarrassed them when they had friends over.

Uplifts. Analysis of daily uplifts resulted in a frequency mean of 2.13 ($SD = 0.50$), and an intensity mean of 3.38 ($SD = 0.19$) (see Tables 4 and 6). Both of these means were higher than the overall hassle ratings. The most frequently occurring uplifting behaviour, as indicated by the highest mean was “when my brother/sister with a disability gives me hugs or kisses” (item 4 in Table 6). This behaviour occurred “sometimes” or more for 10/12 siblings. The two behaviours that elicited the most happiness based on the intensity ratings from siblings were reported as “playing together with my brother/sister with a disability” (item 6) and “spending time with my brother/sister with a disability” (item 7). Of the 11 siblings who reported the two items as occurring, eight described feeling “very” happy when the former occurred, and six described the same for the latter.

Disability specific uplifts were also categorized as above. For siblings aged 8 or 9, an overall frequency mean of 2.03 ($SD = 0.58$), and an intensity mean of 3.10 ($SD = 0.46$) was found. Compared to the overall and older children’s means, the younger children’s means are lower. The most frequently reported daily uplifts for this age were “playing together with my brother/sister with a disability” (item 6), and “spending time with my brother/sister with a disability” (item 7). Happiest items based on the highest mean intensity ratings for this age were “spending time with my brother/sister with a disability” (item 7) and “when my brother/sister with a disability tries hard at something” (item 2).

For children aged 10-12, the frequency mean was reported as 2.28 ($SD = 0.56$) and the intensity mean as 3.59 ($SD = 0.15$), both above the overall and younger children’s mean scores. Most frequently reported uplifts for this age group, as indicated by the

highest means, were “when my brother/sister with a disability gives me hugs or kisses” (item 4) and “when my brother/sister with a disability learns something new” (item 1). The items eliciting the most happiness for this age group based on the highest intensity means were reported as “Helping my brother/sister with a disability to learn something new” (item 3), “Playing together with my brother/sister with a disability” (item 6), and “when my brother/sister with a disability shares something with me” (item 8).

For females, the frequency mean was reported as 2.15 ($SD = 0.69$) and the intensity mean as 3.62 ($SD = 0.34$). These means were above the overall and male mean scores. Most frequently occurring uplifts for females were “when my brother/sister with a disability gives me hugs or kisses” (item 4) and “when my brother/sister with a disability does funny things” (item 5). Females reported the following items as eliciting the most happiness based on the highest intensity means: “When my day runs smoothly without interruptions from my brother/sister with a disability” (item 10) and “when my brother/sister with a disability shares something with me” (item 8).

For males, the frequency mean was 2.12 ($SD = 0.54$) and the intensity mean as 3.27 ($SD = 0.27$), both below the overall and female means. Males reported these items as occurring most frequently: “Spending time with my brother/sister with a disability” (item 7), “playing together with my brother/sister with a disability” (item 6), and “when my brother/sister with a disability tries hard at something” (item 2). Based on the highest intensity means, males reported that the following items elicited the most happiness: “Playing together with my brother/sister with a disability” (item 6), “when my brother/sister with a disability shares something with me” (item 8), “spending time with

my brother/sister with a disability” (item 7), and “hearing good news about my brother/sister with a disability” (item 9).

In summary, older children reported higher frequencies of uplifts and higher happiness ratings associated with their daily uplifts. Younger siblings reported that playing and spending time with their sibling with special needs occurred most frequently, while older children reported that affection from their sibling occurred most frequently. Age also resulted in different reports of items that elicited the most happiness. Younger children reported the most happiness associated with spending time with their sibling and when their siblings tried hard at something. Older children reported being most happy when they helped their sibling learn something new, playing together, and when their sibling shared something with them.

Males reported less frequent daily uplifts, and less happiness associated with them than females. Females reported that kisses, hugs, and funny behaviour from their sibling occurred most frequently, while males reported they spent time or played with their sibling most frequently. Both genders reported high levels of happiness when their sibling with a disability shared something with them. Females reported being most happy when their day ran smoothly without interruptions from their sibling, whereas males reported that spending time or playing with their sibling made them happiest.

Sibling KIDCOPE Ratings

Results from the KIDCOPE are displayed by individual coping items and can be seen in Table 7. These results provide information on how siblings of children with special needs report coping with their daily upsets. In terms of strategy use, the range of scores was 0 – 1, with an overall mean of 0.68 and a standard deviation of 0.13. Strategy

utility had a range of 0 – 2, with an overall mean of 1.14 and a standard deviation of 0.42. Items that are most and least commonly used and that helped the most and least are reported.

The most commonly used coping item based on strategy use means reported by all the children was “I wish the problem had never happened” (item 12 in Table 7). Eleven of 12 children (92%) used this strategy, and 6 of these 11 reported that it helped “a little” or “a lot.” Other commonly reported strategies were (a) “I wish I could make things different” (item 13), (b) “I try to fix the problem by thinking of answers” (item 8), and (c) “I try to fix the problem by doing something or talking to someone” (item 9). In all cases, these strategies were used by 10/12 children (83%). The two least commonly used items were “I just try to forget it” (item 1) and “I do something like watch TV or played a game to forget it” (item 2). In each case, 50% of the children had used the item and 50% had not. For those who used the item, all reported that it helped either “a bit” or “a lot.” Two coping items were reported as helping the most: “I try to feel better by spending time with others, like family, grownups or friends” (item 14) and “I try to fix the problem by doing something or talking to someone” (item 9). For the former, the nine children who used the technique reported that it helped a little ($n = 2$) or a lot ($n = 7$). For the latter, of the 10 children who used the technique, one reported that it did not help at all; two reported it helped a little, and seven reported it helped a lot.

Coping was further analyzed by age and gender. Analysis of 8-and-9-year olds resulted in an overall strategy use mean of 0.70 ($SD = 0.21$), and a utility mean of 1.09 ($SD = 0.46$). The coping item used the most by 8- and 9-year olds was “I wish the problem had never happened” (item 12) and “I try to fix the problem by doing something

or talking to someone” (item 9). The strategy used the least by this age group was “I keep quiet about the problem” (item 4). The coping item reported as helping the most was “I do something like watch TV or played a game to forget it” (item 2). The item reported as helping the least was “I don’t do anything because the problem can’t be fixed” (item 15).

The strategy-use mean for children aged 10 years old and up was 0.65 ($SD = 0.19$), and the utility mean was 1.20 ($SD = 0.52$). This strategy-use mean was lower than the younger children’s mean; however their utility mean was higher. Children aged 10 years old and up reported using the strategy “I keep quiet about the problem” (item 4) most often. Used least often were “I just try to forget it,” (item 1), “I do something like watch TV or played a game to forget it” (item 2), “I blame myself for causing the problem” (item 6), and “I try to calm myself down” (item 11). The items reported as helping the most for this age group were “I try to calm myself down” (item 11) and “I try to feel better by spending time with others, like family, grownups or friends” (item 14). The item reported as helping the least was “I blame someone else for causing the problem” (item 7).

For females, the strategy-use mean was 0.73 ($SD = 0.15$), and the utility mean was 1.34 ($SD = 0.43$), both higher than the male means. Two items were reportedly used most often by females: “I try to fix the problem by thinking of answers” (item 8) and “I try to feel better by spending time with others, like family, grownups, or friends” (item 14). Two items were reportedly used least often: “I blame myself for causing the problem” (item 6) and “I blamed someone else for causing the problem” (item 7). Females reported

“I stay by myself” (item 3) as helping the most. Helping the least for females was “I wish the problem had never happened” (item 12).

For males, the strategy-use mean was 0.63 ($SD = 0.19$), and the utility mean was 0.92 ($SD = 0.54$). Both these means were below the female means. The item reported by males as used most often was “I wish the problem had never happened” (item 12).

Reportedly used least often by males were “I just try to forget it” (item 1) and “I do something like watch TV or played a game to forget it” (item 2). The item reported as helping the most for this group was “I try to feel better by spending time with others, like family, grownups, or friends” (item 14). The item reported as helping the least was “I yelled, screamed or got mad” (item 10).

In summary, younger children reported using wishful thinking, as well as active problem solving to feel better, whereas older children were more likely to internalize the problem by staying quiet (younger children reported using this last technique the least). Younger children also reported that distracting activities helped the most, whereas older children reported that calming down and seeking social support was most helpful. Younger children reported using more strategies than older children; however older children reported that their strategies were more helpful. Similar to the younger children, males also reported using wishful thinking most often. Females reported using active problem solving and social support most often. Males and females reported opposing techniques as most helpful, with females reportedly helped the most by staying by themselves, and males reportedly helped the most by seeking social support. Females used more strategies, and reported being helped more by these strategies than males.

Table 1

Mean Scores of F-COPES Results (in descending order)

When we face problems or difficulties in our family, we respond by:	Mean (Standard Deviation)	When we face problems or difficulties in our family, we respond by:	Mean (Standard Deviation)
1. Accepting stressful events as a fact of life.	2.17 (0.94)	16. Doing things with relatives (get-togethers, dinner, etc.).	1.17 (1.11)
2. Facing the problems “head-on” and trying to get a solution right away.	2.08 (0.90)	17. Seeking information and advice from persons in other families who have faced the same or similar problems.	0.83 (0.72)
3. Showing that we are strong.	2.00 (0.85)	18. Having faith in God.	0.83 (0.94)
4. Knowing we have the power to solve major problems.	1.84 (0.83)	19. Exercising with friends to stay fit and reduce tension.	0.83 (1.19)
5. Accepting that difficulties occur unexpectedly.	1.67 (0.89)	20. Watching television.	0.67 (0.78)
6. Believing we can handle our own problems.	1.58 (0.79)	21. Asking neighbours for favours and assistance.	0.58 (0.67)
7. Knowing that we have the strength within our own family to solve our problems.	1.58 (0.90)	22. Attending religious services.	0.42 (0.51)
8. Seeking information and advice from the family doctor.	1.50 (0.80)	23. Sharing problems with neighbours.	0.42 (0.67)
9. Seeking information and advice from the family doctor.	1.50 (0.80)	24. Receiving gifts and favours from neighbours (e.g. food, taking in mail, etc.).	0.42 (0.67)
10. Defining the family problem in a more positive way so that we don't become too discouraged.	1.50 (0.91)	25. Seeking advice from relatives (grandparents, etc.).	0.33 (0.49)
11. Sharing concerns with close friends.	1.33 (0.49)	26. Believing if we wait long enough, the problem will go away.	0.33 (0.49)
12. Seeking encouragement and support from friends.	1.25 (0.87)	27. Participating in religious activities.	0.33 (0.65)
13. Feeling that no matter what we do to prepare, we will have difficulty handling problems.	1.17 (0.58)	28. Knowing luck plays a big part in how well we are able to solve family problems.	0.25 (0.45)
14. Sharing our difficulties with relatives.	1.17 (1.03)	29. Asking relatives how they feel about problems we face.	0.08 (0.29)
15. Seeking professional counseling and help for our family difficulties.	1.17 (1.03)	30. Seeking advice from a religious leader.	0.08 (0.29)

Table 2

Mean Scores of Sibling Relationship Questionnaire Results (Positive behaviours).

Positive Behaviours	How frequently would you say each of the following occurs in your children's relationship?	How much would you say this is a problem?
	<i>Mean (Standard Deviation) (Rank)</i>	<i>Mean (Standard Deviation) (Rank)</i>
1. Loyalty or sticking up for one another	2.58 (1.38) (1)	0.17 (0.39) (9)
2. Sharing	2.58 (1.68) (2)	0.42 (0.51) (4)
3. Kindness	2.42 (1.08) (3)	0.25 (0.45) (7)
4. Protectiveness – looking out for the other's welfare.	2.42 (1.31) (4)	0.08 (0.29) (10)
5. Comforting one another.	2.25 (1.22) (5)	0.33 (0.65) (5)
6. Feeling proud of one another.	2.17 (1.34) (6)	0.08 (0.29) (11)
7. Affection (hug, kiss, saying "I love you" etc.)	2.00 (1.28) (7)	0.25 (0.62) (8)
8. Respecting each other's property	1.92 (1.24) (8)	1.17 (1.03) (2)
9. Helping one another.	1.83 (0.83) (9)	0.25 (0.45) (7)
10. Playing together in single activity	1.67 (0.78) (10)	0.83 (0.94) (3)
11. Teaching (how to play a game, how to read, etc.)	1.58 (1.24) (11)	0.33 (0.79) (6)
12. Talking to each other, conversations.	1.33 (1.61) (12)	1.33 (1.37) (1)
13. Sharing worries or concerns	1.00 (1.35) (13)	0.25 (0.45) (7)

Table 3

Mean Scores of Sibling Relationship Questionnaire Results (Negative Behaviours).

Negative Behaviours	How frequently would you say each of the following occurs in your children's relationship?	How much would you say this is a problem?
	<i>Mean (Standard Deviation) (Rank)</i>	<i>Mean (Standard Deviation) (Rank)</i>
1. Trying to control each other's behaviour using phrases like "Don't do that," "Stop it," or "Leave me alone."	2.67 (1.15) (1)	0.67 (0.78) (5)
2. Anger or Hostility	1.92 (0.90) (2)	1.17 (0.58) (1)
3. Fighting over objects.	1.92 (1.08) (3)	0.83 (0.58) (3)
4. Fighting over territory or space	1.92 (1.16) (4)	0.67 (0.65) (4)
5. Physical Aggression (hitting, pushing, etc.)	1.58 (0.90) (5)	0.92 (0.79) (2)
6. Arguments	1.58 (1.08) (6)	0.92 (0.79) (2)
7. Jealousy	1.50 (1.09) (7)	0.67 (0.89) (6)
8. Rivalry	1.42 (1.31) (8)	0.42 (0.67) (9)
9. Conflicts where the problem never gets worked out.	1.08 (0.99) (9)	0.58 (0.67) (7)
10. Competition	0.92 (0.99) (10)	0.33 (0.65) (10)
11. Threats	0.92 (0.99) (11)	0.50 (0.52) (8)

Table 4

Overall Mean Scores of Daily Events Scale Results

Daily Hassles						
		Total	Male	Female	8-9 years	10-12 years
		<i>Mean (Standard Deviation)</i>	<i>Mean (SD)</i>	<i>Mean (SD)</i>	<i>Mean (SD)</i>	<i>Mean (SD)</i>
Overall Ratings	How often does the problem happen?	1.69 (0.63)	1.34 (0.66)	2.03 (0.81)	1.76 (0.73)	1.59 (0.74)
	How stressed out does the problem make you feel?	2.05 (0.64)	1.98 (0.77)	1.95 (1.04)	2.13 (0.73)	1.79 (1.01)
Daily Uplifts						
		Total	Male	Female	8-9 years	10-12 years
		<i>Mean (Standard Deviation)</i>	<i>Mean (SD)</i>	<i>Mean (SD)</i>	<i>Mean (SD)</i>	<i>Mean (SD)</i>
Overall Ratings	How often does the good thing happen?	2.13 (0.50)	2.12 (0.54)	2.15 (0.69)	2.03 (0.58)	2.28 (0.56)
	How happy does the good thing make you feel?	3.38 (0.19)	3.27 (0.27)	3.62 (0.34)	3.10 (0.46)	3.59 (0.15)

Table 5

Mean Scores of Daily Hassles Results

Daily Hassles						
		Overall	Male	Female	8 – 9 years	10 -12 years
		<i>Mean (Standard Deviation) (Rank)</i>	<i>Mean (SD) (Rank)</i>	<i>Mean (SD) (Rank)</i>	<i>Mean (SD) (Rank)</i>	<i>Mean (SD) (Rank)</i>
1. When my brother/sister with a disability cries or gets upset.	How often does the problem happen?	2.92 (1.12) (2)	2.50 (0.55) (2)	3.33 (0.82) (1)	3.00 (0.82) (2)	2.80 (0.84) (1)
	How stressed out does the problem make you feel?	2.75 (1.20) (4)	3.17 (1.17) (2)	2.33 (1.63) (10)	2.85 (1.35) (4)	2.60 (1.67) (6)
2. When my brother/sister with a disability is sick or hurt.	How often does the problem happen?	1.92 (1.18) (7)	1.50 (0.55) (6)	2.33 (0.82) (7)	1.71 (0.76) (11)	2.20 (0.84) (4)
	How stressed out does the problem make you feel?	2.58 (1.57) (7)	2.50 (1.76) (4)	2.67 (1.21) (6)	2.29 (1.70) (9)	3.00 (1.00) (2)
3. When my brother/sister with a disability hurts, hits, pushes, scratches or kicks me or others.	How often does the problem happen?	1.92 (1.71) (10)	1.67 (1.63) (5)	2.17 (1.83) (10)	2.71 (1.11) (3)	0.80 (1.79) (19)
	How stressed out does the problem make you feel?	2.00 (1.73) (13)	2.25 (2.06) (7)	1.50 (1.91) (15)	2.14 (1.86) (11)	0.00 (0.00) (20)
4. When my brother/sister with a disability takes my things without asking.	How often does the problem happen?	1.83 (1.68) (11)	1.00 (1.26) (15)	2.67 (1.75) (5)	2.57 (1.62) (4)	0.80 (1.30) (18)
	How stressed out does the problem make you feel?	2.88 (1.57) (2)	2.00 (1.73) (10)	3.40 (1.34) (2)	3.00 (1.55) (3)	2.50 (2.12) (7)

		Overall <i>Mean (Standard Deviation) (Rank)</i>	Male <i>Mean (SD) (Rank)</i>	Female <i>Mean (SD) (Rank)</i>	8 – 9 years <i>Mean (SD) (Rank)</i>	10 -12 years <i>Mean (SD) (Rank)</i>
5. When my brother/sister with a disability goes into my room.	How often does the problem happen?	2.25 (1.60) (3)	1.50 (1.38) (9)	3.00 (1.55) (4)	2.43 (1.51) (3)	2.00 (1.87) (7)
	How stressed out does the problem make you feel?	2.11 (1.64) (9)	1.50 (1.29) (15)	2.60 (1.95) (7)	2.67 (1.75) (6)	1.00 (1.00) (16)
6. When my brother/sister with a disability messes up my room.	How often does the problem happen?	1.75 (1.66) (12)	0.50 (0.84) (16)	3.00 (1.26) (3)	1.71 (1.49) (12)	1.80 (2.05) (12)
	How stressed out does the problem make you feel?	2.75 (1.66) (5)	2.00 (1.41) (9)	3.00 (1.67) (3)	2.80 (1.30) (5)	2.67 (2.31) (4)
7. When my brother/sister with a disability teases me.	How often does the problem happen?	0.08 (0.59) (22)	0.17 (0.41) (18)	0.00 (0.00) (20)	0.14 (0.38) (20)	0.00 (0.00) (21)
	How stressed out does the problem make you feel?	2.00 (1.50) (11)	2.00 (0.00) (8)	0.00 (0.00) (21)	2.00 (0.00) (12)	0.00 (0.00) (20)
8. Arguing with my brother/sister with a disability.	How often does the problem happen?	1.33 (1.46) (17)	1.67 (1.63) (5)	1.00 (1.55) (19)	1.43 (1.51) (15)	1.20 (1.79) (16)
	How stressed out does the problem make you feel?	1.57 (1.29) (17)	2.25 (1.50) (6)	0.67 (0.58) (20)	1.40 (0.89) (17)	2.00 (2.83) (10)
9. Stopping what I'm doing so my brother/sister with a disability does not get upset.	How often does the problem happen?	2.08 (1.28) (5)	2.17 (1.17) (3)	2.00 (1.41) (12)	2.29 (0.95) (6)	1.80 (1.64) (11)
	How stressed out does the problem make you feel?	1.73 (1.04) (16)	1.33 (1.63) (16)	2.20 (0.84) (11)	1.71 (1.25) (14)	1.75 (1.71) (12)
10. Having to give in to my brother/sister with a disability so they do not get upset.	How often does the problem happen?	2.08 (0.97) (4)	2.17 (0.41) (2)	2.00 (0.89) (11)	1.71 (0.49) (10)	2.60 (0.55) (3)
	How stressed out does the problem make you feel?	2.08 (1.35) (10)	2.33 (1.37) (5)	1.83 (1.17) (12)	1.71 (1.38) (15)	2.60 (0.89) (5)

		Overall <i>Mean (Standard Deviation) (Rank)</i>	Male <i>Mean (SD) (Rank)</i>	Female <i>Mean (SD) (Rank)</i>	8 – 9 years <i>Mean (SD) (Rank)</i>	10 -12 years <i>Mean (SD) (Rank)</i>
11. When my brother/sister with a disability cries, screams or yells when they do not want to do something.	How often does the problem happen?	3.00 (1.46) (1)	2.67 (1.03) (1)	3.33 (1.63) (2)	3.14 (1.07) (1)	2.80 (1.79) (2)
	How stressed out does the problem make you feel?	2.72 (1.49) (6)	1.67 (1.50) (13)	4.00 (0.00) (1)	2.43 (1.72) (7)	3.25 (1.50) (1)
12. When my brother/sister with a disability does not do what he/she is asked to do.	How often does the problem happen?	2.00 (1.45) (6)	1.67 (1.37) (4)	2.33 (1.37) (8)	2.14 (1.57) (7)	1.80 (1.10) (9)
	How stressed out does the problem make you feel?	2.00 (1.53) (12)	1.60 (1.67) (14)	2.40 (1.67) (8)	2.33 (1.50) (8)	1.50 (1.91) (14)
13. When my brother/sister with a disability does not do what I ask them to do.	How often does the problem happen?	1.00 (1.26) (20)	0.33 (0.52) (17)	1.67 (1.63) (14)	1.14 (1.68) (16)	0.80 (0.84) (17)
	How stressed out does the problem make you feel?	1.16 (1.33) (20)	1.00 (0.00) (17)	1.25 (1.50) (18)	2.00 (1.00) (13)	0.33 (0.58) (19)
14. When my brother/sister with a disability interrupts me when I'm trying to do something.	How often does the problem happen?	1.92 (1.28) (8)	1.50 (1.05) (8)	2.33 (1.63) (9)	1.86 (1.57) (8)	2.00 (1.22) (5)
	How stressed out does the problem make you feel?	1.8 (1.29) (14)	2.00 (1.41) (9)	1.60 (1.14) (14)	1.80 (1.09) (13)	1.80 (1.48) (11)
15. Not being able to do what I want because my brother/sister with a disability interrupts me.	How often does the problem happen?	1.42 (1.54) (15)	1.00 (1.09) (14)	1.83 (1.60) (13)	1.43 (1.51) (15)	1.40 (1.34) (14)
	How stressed out does the problem make you feel?	2.86 (1.58) (3)	3.00 (1.00) (3)	2.75 (1.89) (5)	3.00 (0.82) (2)	2.67 (2.31) (4)
16. Having to remind my brother/sister with a disability to do things.	How often does the problem happen?	1.25 (1.33) (18)	1.00 (0.89) (13)	1.50 (1.76) (16)	1.00 (1.15) (17)	1.60 (1.67) (13)
	How stressed out does the problem make you feel?	1.29 (1.26) (19)	1.50 (1.29) (15)	1.00 (1.73) (19)	1.00 (1.41) (21)	1.67 (1.53) (13)

		Overall <i>Mean (Standard Deviation) (Rank)</i>	Male <i>Mean (SD) (Rank)</i>	Female <i>Mean (SD) (Rank)</i>	8 – 9 years <i>Mean (SD) (Rank)</i>	10 -12 years <i>Mean (SD) (Rank)</i>
17. Having to do things for my brother/sister with a disability.	How often does the problem happen?	1.50 (1.54) (14)	1.00 (0.89) (13)	2.00 (1.41) (12)	1.57 (0.98) (13)	1.40 (1.67) (15)
	How stressed out does the problem make you feel?	1.44 (1.48) (18)	1.00 (2.00) (18)	1.80 (2.05) (13)	1.50 (1.97) (16)	1.33 (2.31) (15)
18. When my brother/sister with a disability does not share with me.	How often does the problem happen?	1.08 (1.19) (19)	1.17 (1.17) (11)	1.00 (1.09) (18)	1.43 (1.13) (14)	0.60 (0.89) (20)
	How stressed out does the problem make you feel?	1.14 (1.43) (21)	2.00 (1.41) (9)	0.00 (0.00) (21)	1.40 (1.67) (18)	0.50 (0.71) (18)
19. When people ask questions about my brother/sister's disability.	How often does the problem happen?	1.59 (1.59) (13)	1.50 (0.84) (7)	1.67 (1.97) (15)	1.43 (1.51) (15)	1.80 (1.48) (10)
	How stressed out does the problem make you feel?	1.75 (1.59) (15)	2.00 (1.87) (12)	1.33 (2.31) (16)	1.25 (1.89) (20)	2.25 (2.06) (9)
20. When people don't understand about my brother/sister's disability.	How often does the problem happen?	1.92 (1.57) (9)	1.33 (1.21) (10)	2.50 (1.52) (6)	1.86 (1.46) (9)	2.00 (1.58) (6)
	How stressed out does the problem make you feel?	2.56 (1.84) (8)	2.00 (1.83) (11)	3.00 (1.73) (4)	2.20 (1.64) (10)	3.00 (2.00) (3)
21. When my brother/sister with a disability embarrasses me when I have friends over.	How often does the problem happen?	1.42 (1.83) (16)	1.17 (1.83) (12)	1.67 (1.97) (15)	1.00 (1.73) (19)	2.00 (2.00) (8)
	How stressed out does the problem make you feel?	3.00 (1.50) (1)	4.00 (0.00) (1)	2.33 (1.53) (9)	4.00 (0.00) (1)	2.33 (1.53) (8)
22. When my brother/sister with a disability bothers me when I have friends over.	How often does the problem happen?	0.92 (0.99) (21)	0.50 (0.84) (16)	1.33 (1.21) (17)	1.00 (1.29) (18)	0.80 (0.84) (17)
	How stressed out does the problem make you feel?	1.00 (0.89) (22)	0.50 (0.71) (19)	1.25 (0.96) (17)	1.33 (0.58) (19)	0.67 (1.15) (17)

Table 6

Mean Scores of Daily Uplift Results

Daily Uplifts						
		Overall	Male	Female	8 – 9 years	10 -12 years
		Mean (Standard Deviation) (Rank)	Mean (SD) (Rank)	Mean (SD) (Rank)	Mean (SD) (Rank)	Mean (SD) (Rank)
1. When my brother/sister with a disability learns something new.	How often does the good thing happen?	2.50 (1.09) (2)	2.33 (0.82) (4)	2.67 (1.37) (3)	2.14 (0.69) (5)	3.00 (1.41) (2)
	How happy does the good thing make you feel?	3.42 (0.99) (4)	3.00 (1.26) (7)	3.83 (0.41) (2)	3.28 (1.25) (4)	3.60 (0.55) (3)
2. When my brother/sister with a disability tries hard at something.	How often does the good thing happen?	2.33 (1.44) (6)	2.50 (1.38) (3)	2.17 (1.60) (6)	2.14 (1.35) (6)	2.60 (1.67) (4)
	How happy does the good thing make you feel?	3.50 (0.97) (3)	3.20 (1.30) (5)	3.80 (0.45) (3)	3.67 (0.52) (2)	3.25 (1.50) (6)
3. Helping my brother/sister with a disability to learn new things.	How often does the good thing happen?	2.00 (1.21) (8)	2.00 (1.41) (7)	2.00 (1.09) (7)	2.14 (1.35) (6)	1.80 (1.10) (8)
	How happy does the good thing make you feel?	3.10 (1.45) (8)	3.20 (1.79) (6)	3.00 (1.22) (8)	2.67 (1.75) (8)	3.75 (0.50) (1)
4. When my brother/sister with a disability gives me hugs or kisses.	How often does the good thing happen?	2.59 (1.08) (1)	2.17 (0.75) (6)	3.00 (1.26) (1)	2.29 (1.11) (4)	3.00 (1.00) (1)
	How happy does the good thing make you feel?	3.33 (1.07) (6)	3.00 (1.26) (7)	3.67 (0.82) (4)	3.14 (1.21) (6)	3.60 (0.89) (4)
5. When my brother/sister with a disability does funny things.	How often does the good thing happen?	2.33 (1.37) (5)	1.67 (0.52) (8)	3.00 (1.67) (2)	2.29 (1.25) (3)	2.40 (1.67) (5)
	How happy does the good thing make you feel?	3.09 (1.14) (9)	2.83 (0.98) (8)	3.40 (1.34) (6)	2.86 (1.21) (7)	3.50 (1.00) (5)
6. Playing together with my brother/sister with a disability.	How often does the good thing happen?	2.42 (1.16) (4)	2.50 (1.05) (2)	2.33 (1.37) (4)	2.71 (0.76) (1)	2.00 (1.58) (7)
	How happy does the good thing make you feel?	3.64 (0.67) (1)	3.67 (0.52) (1)	3.60 (0.89) (5)	3.57 (0.79) (3)	3.75 (0.50) (1)

		Overall <i>Mean (Standard Deviation) (Rank)</i>	Male <i>Mean (SD) (Rank)</i>	Female <i>Mean (SD) (Rank)</i>	8 – 9 years <i>Mean (SD) (Rank)</i>	10 -12 years <i>Mean (SD) (Rank)</i>
7. Spending time with my brother/sister with a disability.	How often does the good thing happen?	2.42 (0.99) (3)	3.00 (0.00) (1)	1.83 (1.17) (8)	2.57 (0.79) (2)	2.20 (1.30) (6)
	How happy does the good thing make you feel?	3.64 (0.67) (1)	3.50 (0.84) (3)	3.80 (0.45) (3)	3.71 (0.49) (1)	3.50 (1.00) (5)
8. When my brother/sister with a disability shares something with me.	How often does the good thing happen?	1.42 (1.31) (9)	1.17 (0.98) (10)	1.67 (1.63) (9)	1.00 (1.00) (8)	2.00 (1.58) (7)
	How happy does the good thing make you feel?	3.33 (1.32) (7)	3.50 (0.58) (2)	4.00 (0.00) (1)	2.50 (1.97) (10)	3.75 (0.50) (1)
9. Hearing good news about my brother/sister with a disability.	How often does the good thing happen?	2.25 (1.14) (7)	2.33 (1.21) (5)	2.17 (1.17) (5)	2.00 (1.29) (7)	2.60 (0.89) (3)
	How happy does the good thing make you feel?	3.33 (0.89) (5)	3.50 (0.84) (3)	3.17 (0.98) (7)	3.14 (0.90) (5)	3.60 (0.89) (4)
10. When my day runs smoothly, without interruptions from my brother/sister with a disability.	How often does the good thing happen?	1.08 (1.31) (10)	1.50 (1.52) (9)	0.67 (1.03) (10)	1.00 (1.53) (9)	1.20 (1.10) (9)
	How happy does the good thing make you feel?	3.5 (0.84) (2)	3.25 (0.96) (4)	4.00 (0.00) (1)	2.50 (1.91) (9)	3.67 (0.57) (2)

Table 7

Mean Scores for KIDCOPE Results

KIDCOPE						
		Overall Mean (Standard Deviation) (Rank)	Male Mean (SD) (Rank)	Female Mean (SD) (Rank)	8 – 9 years Mean (SD) (Rank)	10 -12 years Mean (SD) (Rank)
1. I just try to forget it.	Do you do this?	0.50 (0.52) (7)	0.33 (0.52) (5)	0.67 (0.52) (3)	0.57 (0.53) (5)	0.40 (0.55) (4)
	How much does it help?	1.33 (0.52) (6)	1.00 (0.00) (6)	1.50 (0.58) (6)	1.25 (0.50) (6)	1.50 (0.71) (3)
2. I do something like watch TV or play a game to forget it.	Do you do this?	0.50 (0.52) (7)	0.33 (0.52) (5)	0.67 (0.52) (3)	0.57 (0.53) (5)	0.40 (0.55) (4)
	How much does it help?	1.50 (0.55) (4)	1.50 (0.71) (4)	1.50 (0.58) (6)	1.75 (0.50) (1)	1.00 (0.00) (8)
3. I stay by myself.	Do you do this?	0.67 (0.49) (5)	0.67 (0.52) (3)	0.67 (0.52) (3)	0.57 (0.53) (5)	0.80 (0.45) (2)
	How much does it help?	1.38 (0.92) (5)	0.75 (0.96) (8)	2.00 (0.00) (1)	1.25 (0.96) (7)	1.50 (1.00) (4)
4. I keep quiet about the problem.	Do you do this?	0.58 (0.51) (6)	0.50 (0.55) (4)	0.67 (0.52) (3)	0.29 (0.49) (7)	1.00 (0.00) (1)
	How much does it help?	0.88 (0.83) (9)	1.00 (1.00) (8)	1.00 (0.82) (9)	0.50 (0.71) (13)	1.20 (0.84) (7)
5. I try to see the good side of things.	Do you do this?	0.67 (0.49) (5)	0.67 (0.52) (3)	0.67 (0.52) (3)	0.71 (0.49) (4)	0.60 (0.55) (3)
	How much does it help?	1.50 (0.53) (3)	1.50 (0.58) (3)	1.50 (0.58) (6)	1.60 (0.55) (3)	1.33 (0.58) (5)
6. I blame myself for causing the problem.	Do you do this?	0.67 (0.49) (5)	0.83 (0.41) (2)	0.50 (0.55) (4)	0.86 (0.38) (2)	0.40 (0.55) (4)
	How much does it help?	0.50 (0.76) (13)	0.20 (0.45) (12)	1.00 (1.00) (10)	0.50 (0.84) (14)	0.50 (0.71) (11)
7. I blame someone else for causing the problem.	Do you do this?	0.58 (0.51) (6)	0.67 (0.52) (3)	0.50 (0.55) (4)	0.57 (0.53) (5)	0.60 (0.55) (3)
	How much does it help?	0.43 (0.79) (14)	0.25 (0.50) (11)	0.67 (1.15) (11)	0.75 (0.96) (11)	0.00 (0.00) (12)
8. I try to fix the problem by thinking of answers.	Do you do this?	0.83 (0.39) (3)	0.67 (0.52) (3)	1.00 (0.00) (1)	0.86 (0.38) (2)	0.80 (0.45) (2)
	How much does it help?	1.20 (0.63) (7)	1.25 (0.50) (5)	1.16 (0.75) (8)	1.17 (0.75) (8)	1.25 (0.50) (6)
9. I try to fix the problem by doing something or talking to someone.	Do you do this?	0.83 (0.39) (3)	0.83 (0.41) (2)	0.83 (0.41) (2)	1.00 (0.00) (1)	0.60 (0.55) (3)
	How much does it help?	1.60 (0.70) (2)	1.60 (0.55) (2)	1.60 (0.89) (5)	1.57 (0.79) (4)	1.67 (0.58) (2)

		Overall <i>Mean (Standard Deviation) (Rank)</i>	Male <i>Mean (SD) (Rank)</i>	Female <i>Mean (SD) (Rank)</i>	8 – 9 years <i>Mean (SD) (Rank)</i>	10 -12 years <i>Mean (SD) (Rank)</i>
10. I yell, scream, or get mad.	Do you do this?	0.67 (0.49) (5)	0.67 (0.52) (3)	0.67 (0.52) (3)	0.57 (0.53) (3)	0.80 (0.45) (2)
	How much does it help?	0.88 (0.99) (10)	0.00 (0.00) (13)	1.75 (0.50) (4)	0.75 (0.95) (10)	1.00 (1.15) (10)
11. I try to calm myself down.	Do you do this?	0.67 (0.49) (5)	0.50 (0.55) (4)	0.83 (0.41) (2)	0.85 (0.38) (3)	0.40 (0.55) (4)
	How much does it help?	1.50 (0.53) (3)	0.75 (0.50) (9)	1.80 (0.45) (3)	1.33 (0.52) (5)	2.00 (0.00) (1)
12. I wish the problem had never happened.	Do you do this?	0.92 (0.29) (1)	1.00 (0.00) (1)	0.83 (0.41) (2)	1.00 (0.00) (1)	0.80 (0.45) (2)
	How much does it help?	0.82 (0.87) (11)	1.00 (0.89) (7)	0.60 (0.89) (12)	0.71 (0.76) (12)	1.00 (1.15) (10)
13. I wish I could make things different.	Do you do this?	0.83 (0.39) (2)	0.83 (0.41) (2)	0.83 (0.41) (2)	0.85 (0.38) (3)	0.80 (0.45) (2)
	How much does it help?	1.10 (0.88) (8)	1.00 (1.00) (8)	1.20 (0.84) (7)	1.17 (0.98) (9)	1.00 (0.82) (9)
14. I try to feel better by spending time with others, like family, grownups, or friends.	Do you do this?	0.75 (0.45) (4)	0.50 (0.55) (4)	1.00 (0.00) (1)	0.86 (0.38) (2)	0.60 (0.55) (3)
	How much does it help?	1.78 (0.44) (1)	1.67 (0.58) (1)	1.83 (0.41) (2)	1.67 (0.52) (2)	2.00 (0.00) (1)
15. I don't do anything because the problem can't be fixed.	Do you do this?	0.58 (0.51) (6)	0.50 (0.55) (4)	0.67 (0.52) (3)	0.43 (0.53) (6)	0.80 (0.45) (2)
	How much does it help?	0.71 (0.76) (12)	0.33 (0.58) (10)	1.00 (0.82) (9)	0.33 (0.58) (15)	1.00 (0.82) (9)

Discussion

Results yield significant information on sibling stressors, uplifts, and coping style, and family coping style. Also suggested were several possible connections between the core issues, such as between sibling stress/coping style and age, and gender. The study's method was an explanatory mixed method design. Because substantial quantitative connections were hindered by a small sample size, as well as no comparison group, research questions were supported and refined with qualitative follow-up data from parents.

Twelve families, each including a child with and without special needs, participated in the study. Nine of the 12 children with disabilities were male and three were female. The mean age of these children was 10.08 years, with a range of 3 to 14 years old. All disability types included some type of mental disability, and at times included accompanying physical disabilities. Examples of disabilities included Autism, Down syndrome, and Chromosomal Abnormalities. Siblings of the children with disabilities were interviewed. These children were all between the ages of 8 – 12 years old (with a mean age of 9.5 years); six siblings were males and six were females. Four of the 12 siblings attended a monthly support group for siblings of children with special needs.

Descriptive statistics were obtained from parent and sibling interviews and were presented above. The above results shed some light on the original six research questions first discussed on page 27. Each question is discussed and linked to the research. When appropriate, qualitative data obtained through parental surveys was used to support and enrich the results.

What daily hassles do siblings of children with special needs experience most often and find most stressful/?

Based on an analysis of the Daily Event Scale for Siblings of Children with a Disability or Illness measure, 7 of 12 siblings reported that their sibling with special needs “always” cries, screams, or yells when they do not want to do something. This behaviour may be linked to the item reported as most stressful by siblings, being embarrassed by their sibling with special needs when they have friends over. It is possible that the embarrassment may extend from friends to other public situations as well. Qualitative data supplied by parents offers more insight into the topic. One parent described “tantrum” type behaviour and the reactions of their children without special needs:

The girls find it very difficult when (my child with special needs) tantrums in public. One day, we decided to go shopping at Sears before going to a movie. (Child with special needs) was dropping, shrieking, and hitting people as they passed him (on the floor). I could not pick him up and carry him out because he was too heavy...The girls were humiliated and did not want to go to a movie anymore...The remainder of the evening, the girls were quite upset, and embarrassed (Parent 1, Female sibling, age 10).

Another parent specified the embarrassment as being linked to friends, as well as to public situations.

My son is somewhat embarrassed about his handicapped brother amongst some of his friends, especially new friends. One day, a new friend came to call him and (child with special needs) was heading to the door to answer

it. My son saw this and quickly ran to the door, pushed him away, and told him to go upstairs. His way of coping is often to pretend he is not with him if we are out in public (Parent 7, Male sibling, age 10).

This parent noted the same theme. “(Sibling) is very sensitive to (sibling with special needs) making a scene in public” (Family 8, Male sibling, age 9). The literature confirms that embarrassment may be common amongst siblings of children with special needs. The early landmark study by Grossman (1974) reported that 45% of college-aged siblings of children with special needs reported feeling negative feelings, such as shame, towards their sibling. However a more recent study by Pit-ten Cate and Loots (2000) looked at the issues related to peers and the external community in more depth. While they concluded that there were no indications of complications in peer relationships associated with having a sibling with a disability, they did find that some (19.1% of their sample) siblings (10 - 18 years old) chose not to tell some people about their sibling with disabilities. Some children reported that this was due to a fear that others might react in an unpleasant way, for example, by teasing (9.5%). The authors also documented that while it was ‘normal’ to go out with their sibling with a disability, siblings did not always like it. Several reasons were cited, including strange behaviour or incontinence on the part of their sibling with a disability. Siblings also noted that people often stared or looked at them. In addition, Powell and Gallagher (1993) note that school-age children (such as those in the present study) may be conflicted with feelings of wishing to be accepted by their peers, while at the same time wanting to defend their sibling with a disability.

Interestingly, siblings in the study reported experiencing more frequent daily uplifts than hassles, and more intense feelings associated with the uplifts. Qualitative data affirmed that positive daily events were virtually universal among the children without disabilities, no matter what age or gender. Parents described their children displaying love for their sibling with special needs. “Both of our sons love their sister very much. They both encourage her and revel in her accomplishments” (Parent 2, male sibling, age 9). Another parent remarked about her daughter without a disability, “She’s been great. She adapts well to (sibling with special needs)’s issues. She is great with him” (Parent 4, female sibling, age 8).

The findings of the present study are in line with the literature. Numerous researchers have found that the relationship between children with disabilities and their siblings is usually full of joy as well (Gath, 1973; McHale and Gamble, 1989). Pit-ten Cate and Loots (2000) interviewed 43 siblings of children with physical disabilities between the ages of 10 and 18. Siblings described their sibling with a disability mostly as “funny” (41.9%), “cheerful, spontaneous” (32.6%) and “pleasant” (26.9%). The authors also found that siblings could name numerous positive experiences associated with their sibling with a disability. Siblings reportedly enjoyed doing things together with their sibling with a disability (i.e., playing games), and even appreciated their special perspective regarding other people (including those with disabilities). While unpleasant experiences were also cited (including communication problems, as displayed in the current study), children and teens in the study reported having a lot of fun with their siblings with special needs.

Are there developmental differences in sibling stress appraisal?

The ages used in the present study were chosen based on several factors.

Costigan, Floyd, Harter, and McClintock (1997) note in their study that healthy siblings of children with mental disabilities, aged 6 to 12 years, demonstrated the most negative effects as compared with older siblings and controls. They also speculate that this period of middle to late childhood is the most difficult for these siblings, especially if they are chronologically younger than the sibling with the disability. During this age range, a younger sibling's competencies may surpass that of their sibling with a disability, requiring adaptation to the new older sibling role. In addition, this age is often characterized by concrete operational thinking, which may make these children more sensitive to issues about family rules and differential treatment. Children of these ages have also been documented to recognize emotions (Carroll & Steward, 1984; Muris, Hoeve, Meesters, & Mayer, 2003), affirming the child's capability to assess their own stress and coping.

Although a small sample size limits the present study's generalizability, younger children's (age 8-9) ratings of hassle frequency and intensity were higher than the older children's. If we examine the particular issues that the younger children found most stressful, they coincide with Lazarus and Folkman's (1984) primary appraisal theory on the significance of events. When determining the level of stress associated with a stressor, there are three considerations. The first is its goal relevance (should I care?); the second is its goal congruence (is this positive or negative?); and the final and most relevant developmentally is the type of ego involvement (in what way am I involved?) (Sheets et al., 1996). Because younger children reported daily hassles that directly

involved themselves as most stressful (i.e., being embarrassed by their sibling, and not being able to do what they want because they are interrupted by their sibling), these results add to the body of literature that demonstrates existing developmental differences in stress appraisal.

Consider the items the older children found most stressful: “When my brother/sister with a disability cries, screams or yells when he/she doesn’t want to do something”; “when my brother/sister with a disability is sick or hurt”; “when people do not understand about my brother/sister’s disability”. Each of these items includes a consideration of others in the appraisal, while younger children’s items were more personally relevant. These results are confirmed by Sheets et al. (1996), who found similar developmental differences between 8-9-year-olds and 10-12-year-olds in their sample of children experiencing divorce. They reported that children’s concepts of the self became more differentiated with development; older children were more likely to think about events in more abstract ways.

Similarly, Stattin (1984) reported that younger children (8-year-olds) considered concrete, physically salient clues in evaluating stress, whereas older children (12-year-olds) used abstract thinking and anticipated consequences. In the present study, it is possible that the older children were considering future consequences of their sibling’s illness or sickness, and future stigmatization or isolation due to a lack of understanding from others. Vassey (as cited in Sheets et al., 1996) suggests that older children may have an increased ability to think about alternative consequences of events, and therefore are able to think more broadly about a negative event. This may also explain why the older children’s ratings of hassle frequency and intensity were lower than the younger

children's. The older children may have found certain personally relevant hassles as having a smaller impact due to a broader perspective of importance. They may also have considered the positive uplifts associated with their sibling with a disability, and therefore felt less stress associated with their daily hassles. This may be evidenced by the higher frequency and intensity ratings associated with daily uplifts reported by the older children. In addition, the older siblings may be spending more time with peers, and therefore spending less time with the family. This may also be a consideration in their ratings.

Qualitative data supplied by parents support the above interpretation of the results. One parent of a younger sibling described the frustration her daughter felt that was associated with her sibling with special needs. The parent's comments demonstrate the sensitivity this younger age group may have to differential parental treatment.

(Sibling) sometimes expects us to treat her brother the same way we discipline her and when we fail to – for whatever reason – she gets angry and starts to resent him...there is often stress surrounding rules. She often expects all rules to apply to them equally. At times, more energy is devoted to her brother (Parent 6, female sibling, age 8).

Another parent describes the social concern also voiced by the younger siblings. "He adjusted very well to his brother with special needs. The only thing that I'm concerned about is his school environment, his friends, and peer pressure" (Parent 5, male Sibling, age 9). Another parent noted the theme of embarrassment. "The sibling is now 10 ½ and we find that if he could avoid/hide his special needs brother, he would. He seems to be embarrassed about him. The earlier years were easier" (Parent 7, male sibling, Age 10).

Are there gender differences in sibling stress appraisal?

Bossert (1994) states that sex does not have an impact on stress levels in children in terms of gender personality traits. However female siblings of children with special needs are reported in the literature as being the bearers of more caregiving responsibilities (Stoneman et al., 1988), indicating that perhaps their stress levels could be higher. Although it is also possible that taking a caregiving role may be more adaptive, helping the child feel more in control. Although significant results in the present study were hindered by the study's small sample size, the higher male intensity ratings for their daily hassles, coupled with the lower intensity ratings for daily uplifts, may indicate that boys are more sensitive than girls to stress associated with their sibling with special needs. The literature presents conflicting information on the topic. Grossman (1974) found that younger brothers were most affected, in terms of self esteem and social adaptation, by their sibling with special needs. Honig (1986) also found that male children were more vulnerable to stress than female children. One parent in the study described the stress her son experienced.

Often my older son gets upset with his brother with special needs, and because they are so close in age, it is difficult for him to understand that his brother doesn't bug him on purpose. The way he copes is to scream at him, "you are very mean," and go to his room and bang the door. When he was smaller, he understood less, so he used to bite his younger brother (Parent 3, male sibling, age 10).

However Gath (1973) found that older sisters were most affected by their sibling with Down Syndrome, especially first born daughters who were more than three years

older than their sibling. Breslau (1982) reported that in terms of stress, gender of the sibling interacted with birth order. In a population of children with physical handicaps, younger boys and older girls were most affected, as demonstrated by greater psychological difficulties. In a study by Cuskelly and Gunn (1993), mothers reported that female siblings of children with Down syndrome demonstrated more conduct problems than males. The effect of gender concerning the adjustment of siblings without disabilities will continue to be debated, especially considering the increased blurring of gender roles in today's society. However the present study might have yielded more substantial results with a larger sample size, and an investigation into birth order, as well as age.

How do siblings of children with special needs cope with their daily upsets?

Based on the findings of the KIDCOPE measure, wishful thinking emerged as a common coping strategy among siblings of all ages (92% of the sample), a trend demonstrated by other coping studies (Donaldson, Prinstein, Danovsky, & Spirito, 2000; Hunter & Boyle, 2004). Males and younger children also reported using this strategy the most frequently. This method of coping focuses on controlling the emotional aspects of stress appraisal, rather than being a problem-focused method. Sorgen and Manne (2002) demonstrated in their study of coping in children with cancer that emotion-focused coping strategies were linked to lower appraisals of control, while problem-focused strategies were associated with higher appraisals of control. Hunter and Boyle (2004) specifically cite wishful thinking as being associated with a perceived lack of control. Present results demonstrating that younger siblings also used wishful thinking the most corroborate the above study's results. In accordance with Bandura's theory of self-

efficacy (1982), younger children's perception of personal control may be less than older children's or adults. Because the older children in this study did not use wishful thinking predominantly, support is apparent for Bandura's ideas. Honig (1996) also offers the idea that coping techniques chosen by older children may be more effective because of their increased capability to think about problems. Again, this broader perspective by older children may be an indication of why their frequency and intensity ratings of daily hassles were lower than the younger children's. Sheets et al. (1996) noted that a child's perception of major life events can have a considerable impact on their behaviour and adjustment.

It is important to note however that all children commonly reported using problem-solving and social support strategies to cope with their daily hassles, which supports another trend also found in the literature (Hunter & Boyle, 2004). This finding reveals that they are facing, rather than avoiding, their stress. Social support strategies were cited as helping the most, indicating that children may be considering the effectiveness of their coping when choosing a technique. Lazarus and Folkman (1984) emphasize however that the selection of a coping strategy is situation-specific, indicating that children may use a variety of techniques, depending on the situation. In the present study, siblings were asked to consider an upsetting situation concerning their sibling with special needs. Because least commonly-used strategies were distraction or trying to forget about the problem, this may indicate that siblings of children with special needs find it difficult to ignore their situation. One parent offered some insight into this possibility. "The problem is that (child with special needs) wakes up generally at 4 a.m. and proceeds to wake up the whole family. He also tends to be very loud, which does distract (sibling)

sometimes” (Parent 2, female sibling, age 8). Another parent made a similar remark, “(Siblings) have grown so used to (child with special needs)’s noise that not even a fire alarm at night wakes them up” (Parent 11, female sibling, age 12).

However an interesting difference was noted between the younger and older children’s coping strategies. The strategy used the least by younger children was keeping quiet about the problem, whereas older children reported using this strategy the most. Older children may have chosen to keep quiet about their problem in an effort to save their parents from additional stress. Older children may also feel an increased responsibility to deal with their problems themselves. It is also possible that the older children’s additional experience with stress may have resulted in the realization that their problem could not be fixed. Older children did use this technique (“I didn’t do anything because the problem can’t be fixed”) second most frequently (tied with 5 other techniques). Older children also used this technique more than younger children ($M = 0.80$ vs. $M = 0.43$). This may be due in part to their increased cognitive ability. While all children were generally in Piaget’s (1953) concrete operational stage (8-12 years), the older children are nearing the formal operational stage (age 12 and up) and may be developing the ability to think logically and abstractly about their problems. In addition a lack of egocentrism in this new stage of development broadens their perspectives and ability to consider an effect on another person (i.e., their parents). Consider another coping strategy such as “I blame myself for causing the problem.” Interestingly, 8-9 year-olds ranked this strategy second in terms of its frequency of use, and was used considerably more by the younger children than older.

Gender differences emerged in the present study. Females reported using active problem solving and social support techniques the most frequently, whereas males reported using wishful thinking most often. Pit-ten Cate and Loots (2000) also found that sisters of children with physical disabilities actively tried to solve their problems, rather than tolerating them. Hunter and Boyle (2004) and Sorenson (1991) also found that girls used more social support strategies than males. Interestingly, males reported that social support techniques helped the most, whereas females reported that staying alone helped the most. The contradictions between coping strategies used the most and those that help the most between genders are clear, however the motivation is not. Further investigation into why siblings use their particular strategies is warranted to obtain a greater understanding of the thought processes associated with their choices.

How does the family cope with their difficulties?

Based on parental reports, results of the F-COPES suggest that families may rely on their internal capacities to cope with the stress of having a child with special needs. The most often used strategy of “accepting stressful events as a fact of life,” reportedly used by all families, reflects a direct, realistic way of approaching stress. Parents may realize that the inevitability of their stress leaves no room for avoidance or rejection of their issues. One parent commented, “It is very hard to accept what life throws at us. Nevertheless, we still have to accept. There is no other way” (Parent 3). Another parent affirmed, “We have come to the conclusion that stress will always be a part of our life. We always try to solve one problem and to be ready to incur the next problem that should arise” (Family 5). Gold (1993) argues that this kind of attitude, especially when displayed by the mother, will positively impact a typical sibling’s acceptance of their

sibling with special needs (Gold, 1993). One parent's remarks also indicated that acceptance may be a crucial beginning to the family coping and functioning:

Accepting that stressful events are a fact of life helps us on an almost daily basis. It gives us perspective when something is not going right. It helps us take a deep breath, take a minute, and assess the best way to resolve a situation. In other words, it keeps us from being paralyzed by fear, by the enormity of the challenges we face. It allows us to move forward, not to get stuck, and not to feel sorry for ourselves for too long a period - an evening or two at the most! (Family 2).

The above comment may indicate that acceptance of the disability and its accompanying stressors must precede any practical problem solving. An active problem solving strategy was the second most commonly used strategy, and was reportedly used by all parents (facing the problem head on and trying to get a solution right away). This may indicate that family acceptance influences the family's ability to practically and realistically attack their problems.

Another acceptance strategy was reportedly used by all parents to some degree (accepting that difficulties occur unexpectedly). This element of surprise is illustrated by one parent:

When you have a handicapped child, there are always surprises that come up. If I were to have been told of everything that lay ahead of me when my son was born, I would have given him up. It would have been too much to take in at one given time. I think that it is just easier to deal with the

present problems and stresses and try to solve and accept each difficulty as it comes along (Family 7).

In addition to the level of acceptance, previous research has emphasized the effect that a family's outlook on disability can have on their adjustment. Frey et al., (1989) found that parental stress and family adjustment were most influenced by parental beliefs, such as self-ratings of coping efficacy and personal control. Patterson (2002b) considers such family attitudes in his model of family resiliency, derived from Hill (as cited in Walsh, 1982) and McCubbin and Patterson's 1983 model of family stress and coping (described earlier in the literature review). An integral component of each of these models is family meaning, which interacts with family demands and capabilities to arrive at a level of family adjustment or adaptation. Patterson (2002b) describes three levels of family meaning in his Family Adjustment and Adaptation Response model (FAAR): the family's definition of their demands and capabilities (linked to Lazarus and Folkman's 1984 concepts of primary and secondary appraisal), their internal identity as a family unit, and their world view. Also linked to Reiss' (1981) concept of the family paradigm, Patterson (2002b) contends that these shared beliefs impact on how the family responds to stress. Consistent with family system's theory, a parent who accepts and deals appropriately with the stress associated with their child's disability is likely to influence the entire family's adjustment in positive ways.

The present findings support the idea that family cohesion may be used to cope with stress. Commenting on families with a child with a disability, Duis and Summers (1997) reported that higher levels of family cohesion can act as a buffer against stress. Two such coping strategies were used by all families to some degree in the present study,

including “showing that we are strong” and “knowing we have the power to solve major problems.” One parent commented:

As a team, we have worked together sometimes making decisions contrary to medical advice. But staying together and backing our decision with the belief that we have the power to get through our problems helps (Family 2).

Antonovsky and Sourani (1988) affirm through their study of married Israeli males who were disabled that strong levels of family coherence, as defined by the perception by spouses that life is manageable and meaningful, lead to better adaptation following a crisis.

Families, therefore, seem to demonstrate positive coping strategies when dealing with their family stress, as Hastings (1984) previously asserted. Frey et al., (1989) reported that parents who used more problem-focused coping strategies had lower levels of psychological distress. Higher levels of distress were related to avoidance and wishful thinking strategies. Even with children in the present study reportedly using wishful thinking strategies frequently, it is hoped that parents are modeling positive strategies, which may in turn lead to more positive coping as their children develop.

Interestingly, family support strategies were not commonly used by families. Parent comments shed some light into this result and reveal that a lack of understanding may be at the root.

Learning that our child was autistic was a big family problem and we had to turn to professional support. Family members didn't understand. The comments were 'don't worry, he will talk soon, maybe that is something

you ate when you were pregnant'. Comments like this, we did not need, so we went to professional. (Parent 3).

Another parent echoed these thoughts:

My support system is my husband. We support each other when one needs it. I chose him because he is the only one that truly understands. Friends and family have not been in any way helpful. They can't understand what our life is like. (Family 7).

It is possible however that making use of various support systems may be problem-specific. For example, one parent described using family to provide practical assistance, rather than advice or comfort.

When (child with special needs) was hospitalized for 10 weeks, (sibling) was a newborn. We turned to my parents to watch her during the day. I would sleep at their house during the night and care for her and (husband) slept in the hospital. Then I would return to the hospital in the morning (Parent 1).

This type of support may require little or no understanding, and may therefore be easier for parents to utilize. Another parent illustrated why they chose one family member's support over another, indicating that perhaps personality is a factor as well.

We usually use (child's) maternal grandmother as a sounding board. She is able to be very supportive without involving her own fears, concerns. She trusts us and may voice her opinion, but would never make a situation about her views, feelings. Unfortunately, (child's) paternal grandparents

are unable to do this and as a result we never consult with them when difficulties arise (Family 2).

Research indicates that in terms of support, parents of children with special needs report having less social support than parents with children without special needs (Friedrich & Friedrich, 1981). Another study of 330 families of children with intellectual disabilities revealed that parents of younger children used more support systems than those with older children (Suelzle & Keenan, 1981). Parents of older children were also more isolated and perceived a greater need for expanded services. While age was not directly considered in this study in terms of parental support, the mean age of the child with special needs was 10.08 years. Compared with the above study, these children would be considered “older” children with special needs. It is possible that as their children age, parents may encounter more frustration and dissatisfaction with their social support systems, and consequently reduce or abandon their support networks. Further investigation into this issue is warranted.

The present study adopted a family systems perspective; therefore comparisons between family and child responses are warranted. Both siblings and family’s reported facing and accepting their stressors, rather than avoiding them. The two least commonly used coping strategies reported by siblings were “I just try to forget it” (item 1) and “I do something like watch TV or played a game to forget it” (item 2). With all parents using the strategy of “Facing the problem head on and trying to get a solution right away” to some degree, it is possible that some children avoid using distraction and forgetting about their problems in response to their parent’s direct approaches. As Reiss (1981) suggested, the family may share the viewpoint that the stressor is beyond their control and therefore

unavoidable. Whether or not an influential connection exists between parent and child coping strategies, one parent's comments demonstrate an active attempt to impart knowledge: "That's what we teach our kids – be prepared because things happen unexpectedly and we can't let it drag us down" (Family 3).

All children also utilized problem solving strategies, similar to parental reports. However it is also noted that children seemed to use more support strategies than their parents. Some parents avoided spiritual and external family supports, whereas children reported that spending time with others, such as family, grownups, or friends was the most helpful strategy.

It is also important to note that these families demonstrated high levels of adaptation in response to their family stress. Because of the sample's small size and limited variability in terms of religion and social economic status, results may not be generalized to the greater population. It is also possible however that because these families have been dealing with the stress of childhood disability for several years (range of 3-14 years), their adaptation is a reflection of having the time to develop positive coping responses and finding appropriate resources.

How do parents perceive their children's relationship?

Findings reported here are based on results from the Sibling Relationship Questionnaire. Loyalty (sticking up for one another) was the positive characteristic most commonly perceived by parents between their child with a disability and their sibling without a disability. These actions witnessed by parents may be examples of the sibling demonstrating family cohesiveness cohesion and unity. "Sharing," "kindness," and "protectiveness – looking out for the other's welfare" were noted next frequently by

parents. One parents shared, “(Sibling) will not accept anyone making fun of his brother. And he will take his time to explain that his brother does not understand everything” (Family 3). Another parent described how her children stood up for their brother with special needs at school.

When both girls had discussions in class about handicapped people, they discussed (sibling with special needs). When other children would say ridiculous things like “He’s a retard,” or “he’s a midget,” both girls answered back to the other children...(Sibling) answered, “my brother is not a midget. He has an extra chromosome that makes him shorter. The extra chromosome also gives him extra needs but I love him just the way he is. (Family 1).

All the above positive characteristics noted by parents may reflect the under-workings of systems theory at work. By protecting, and being loyal and kind to their brother or sister with special needs, the child may be modeling positive parental behaviour, or perhaps even working to keep their family together and strong.

In addition, overall parent mean ratings of positive sibling relationship characteristics were higher than the overall mean for negative ratings (1.98 versus 1.27). As earlier mentioned, when one child in the sibling dyad has special needs, the typical sibling relationship rules may not apply. The positive sibling relationship ratings by parents may affirm this. Kramer and Baron (1995) suggest that stereotypical views in American society about siblings may negatively influence parental ratings of their children’s relationship. In the case of families with a child with a disability, no such stereotype exists as of yet. Kramer and Baron (1995) suggest an investigation of parent’s

daily hassles to see whether or not sibling relationship concerns are less important than other concerns. The authors also note that their study had a white, middle-class, and highly educated sample. Such demographics may impact parent's perspectives. Because this area of study is unclear in siblings who are developing in normal ways, further investigation into this phenomenon is needed for families with a child with special needs.

Not surprisingly, the positive characteristics reported as the biggest problem between their children was "talking to each other, conversations." This appears to connect with the characteristic reported as observed the least frequently between siblings, "sharing worries or concerns." Because of the intellectual capacity of the child with special needs, these issues may be inevitable. This inability to communicate with the child with special needs seems to be an issue recognized by both parents and siblings. The most frequent daily hassle cited by siblings was when their sibling with special needs cried, screamed, or yelled when they did not want to do something. This behaviour may reflect an inability to communicate what they want or need with other people. Both parents and siblings seem to recognize that communication with the child with special needs may be difficult.

The negative behaviours perceived most often by parents between siblings are consistent with behaviour found in typical sibling relationships. Kramer and Baron (1995) found that agonistic behaviour, such as conflict, anger, and attempts to control the sibling, were primary concerns for parents. Parents in the present study reported that trying to control each other's behaviour, anger, and fighting were observed most commonly between their two children. While some universalities may exist between siblings of all types, again, the sibling relationships observed in the present study seem to

defy these rules. Threats and competition were the least reported negative characteristics reported by parents in the study, with competition cited as the least problematic. Kramer and Baron (1995) reported that competition was perceived as the second-most problematic item for parents of typically developing children. This lack of competition between siblings in the present study may demonstrate that normally developing siblings are very aware of the abilities of their sibling with special needs. Previous research has emphasized that this awareness might lead to a sense of pressure to make up for a lack of abilities (Grossman, 1972). This stressor was not specifically investigated in the present study, however further investigation into the issue is warranted to determine how a lack of competition may affect a child whose sibling has a disability.

Finally, parents in the present study rated their children's sibling relationship as being fairly positive. This optimistic perspective was also displayed in the Kramer and Baron (1995) study of developmentally normal siblings. While dynamics and stressors are unique to each individual family, parents seem to possess an optimistic view of their children's relationship. Further research might investigate how siblings themselves would rate their relationship with their brother or sister with a disability, in terms of both individual characteristics and overall.

Limitations

Several limitations to the present study require discussion. A small sample size was an unfortunate consequence of limited time, and is the major drawback to the study. This, as well as the lack of a control group, hinders any meaningful conclusions and generalizations. As well, statistical analyses were limited and no meaningful relationships between variables could be tested. The sample also cannot be considered representative

of the general population, as a range of ages and disabilities was not obtained. Additionally, families may not reflect the broader population in terms religion, race, and social economic status. Families were also 2-parent families (with the exception of one), therefore an analyses of several different family types would be especially useful, especially when considering issues of stress and coping as different issues may arise in divorced or separated families. In addition, several siblings were participants in a support group for siblings of children with special needs. While this effect was not measured, it may have had an impact on sibling assessments, as well as parental reports of coping and support. Because both quantitative and qualitative results reflect a fairly high level of family adaptation and coping, the study's generalizability may be additionally limited.

In terms of analyses, birth order, in addition to age, might have been considered, as research often demonstrates the significance of this factor. Effects of several other interesting factors were also not assessed, including disability type, participation in sibling support group, and impact of family coping on sibling coping. As well, parental reports demonstrated many gaps in their support systems, another practical research area to be explored.

Throughout the course of data collection, several limitations were found with the instruments. For the *Kidcope* and *F-Copes* instruments, more examples of each coping strategy might have useful. The instruments were originally chosen for their brevity; however reliability could have been enhanced with additional strategies. Also, parents and children might have been given the opportunity to add their own coping choices, should any have been missing from the instruments. This same issue applies for the *Daily Events Scale*. Children should have been given the opportunity to expand on the list of

daily hassles and uplifts, revealing perhaps items that were not considered. Parents themselves recognized and voiced an important limitation of the *Sibling Relationship Questionnaire*. While many relationship characteristics were considered, parents were unable to specify in which direction the characteristic was displayed between siblings. For example, when considering loyalty, parents often commented that the item was only demonstrated by their sibling who was normally developing towards their child with special needs, while the opposite relationship was never observed.

Parents were the ones assessing the sibling relationship quality; however siblings themselves might have been questioned as well to remain consistent with the goal of allowing siblings their own voice in the literature. While the self-report method is certainly valuable, it might also be important to replicate these results using other methods, such as observation.

Future Research

Several new directions for the siblings of children with disabilities literature have been noted above. Research should continue to focus on what stressors are particular to each age group. An investigation into the impact of gender and birth order on sibling adjustment is also warranted as well. The disability type and the cognitive and physical limitations of the child with special needs is another branch of the literature that could be expanded. Examining this issue could reveal any disability-specific issues that may arise between these siblings (such as a lack of competition or communication).

Children's motivations for choosing their coping strategies should also be explored. Their thought processes will yield further insight into children's perspective on stress and coping, and may help shed some light on any age and gender differences. The

same suggestion may be made for a family's motivation for their collective coping strategies. Clarifying such details help us understand such things as a family's functioning and belief systems, and may reveal similarities between parent and children perspectives. Furthermore, siblings often demonstrated excitement and pride when given the opportunity to discuss their experiences, and many expressed pleasure at being the focus of the interview. Further inclusion of this self-report method will not only yield more accurate information, but also improves children's self-esteem and confidence.

As well, a family system perspective asserts that all individual members are critical to family health. Children therefore should continue to be personally asked about their experiences as a sibling of a child with special needs. Their perspectives on their sibling relationship, their fears, or even their parent's adjustment, should all be investigated. As well, the siblings-of-children-with-disabilities literature should continue to be expanded by linking it with other areas of study. The current study integrated the family stress and coping literature. Other studies have, and should continue to consider involving such areas as family functioning (Costigan et al., 1997) or parenting style. Longitudinal studies are especially valuable, for example an investigation of the school success of siblings without disabilities.

Conclusion

Even with a small sample size, the study offers some valuable insights into the daily lives of 12 siblings of children with special needs. Their self-reported concerns should be considered when designing support and resources for these children. Sibling and family coping strategies also offer important insight into family functioning. This

information could be used to improve family environments, especially in a therapeutic capacity where more effective strategies could be encouraged.

In conclusion, the author was genuinely honoured to have spoken to so many articulate, sensitive, and loving siblings of children with disabilities, and to have been welcomed into so many loving homes. It was clear that all parents in the study had the best interest their children at heart. Because time and resources are concerns for typical families, the family with a child with special needs knows these and other issues intimately. Parents with special situations today can take comfort in the growing body of literature on a variety of family situations, continuing to improve treatment and support for these families. Reassuring and inspiring are the many families that thrive and find strength from their unique situations.

References

- Antonovsky, A., & Sourani, T. (1988). Family sense of coherence and family adaptation. *Journal of Marriage and the Family*, 50, 79-92.
- Bandura, A. (1977). Self-efficacy: Toward a unifying theory of behavioral change. *Psychological Review*, 84, 191-215.
- Baxter, C., Cummins, R.A., & Yiolitis, L. (2000). Parental stress attributed to family members with and without disability: A longitudinal study. *Journal of Intellectual & Developmental Disability*, 25 (2), 105-118.
- Boss, P. (2002). *Family stress management: A contextual approach*. Thousand Oaks, CA: Sage.
- Bossert, E. (1994). Stress appraisals of hospitalized school-age children. *Children's Health Care*, 23 (1), 33-49.
- Brenner, A. (1984). *Helping children cope with stress*. Lexington, MA: Lexington Books.
- Breslau, N. (1982) Siblings of disabled children: Birth order and age-spacing effects. *Journal of Abnormal Child Psychology*, 10, 85-95.
- Bronfenbrenner, U. (1979). *The ecology of human development: Experiments by nature and design*. Cambridge: Harvard University Press.
- Bronfenbrenner, U. (1994). Ecological models of human development. In T. Husen & T. N. Postlethwaite (Eds.), *International Encyclopedia of Education*. Oxford: Pergamon.
- Bubolz, M.M. & Whiren, A.P. (1984). The family of the handicapped: An ecological model for policy and practice. *Family Relations*, 33, 5-12.

- Buckley, W. (1967). *Sociology and modern systems theory*. Englewood Cliffs, NJ: Prentice Hall.
- Burr, C. K. (1985). Impact on the family of a chronically ill child. In N. Hobbs & J. Perrin (Ed.), *Issues in the care of children with chronic illness* (pp. 24-40). San Francisco: Jossey-Bass.
- Carroll, J.J. & Steward, M.S. (1984). The role of cognitive development in children's understanding of their own feelings. *Child Development*, 55, 1486-1492.
- Costigan, C.L., Floyd, F.J., Harter, K.S.M. & McClintock, J.C. (1997). Family process and adaptation to children with mental retardation: Disruption and resilience in family problem-solving interactions. *Journal of Family Psychology*, 11, 515-529.
- Cummings, E.M. & Davies, P.T. (1994). Maternal depression and child development. *Journal of Child Psychology and Psychiatry*, 35, 73-112.
- Cuskelly, M. & Gunn, P. (2003). Sibling relationships of children with Down syndrome: Perspectives of mothers, fathers, and siblings. *American Journal on Mental Retardation*, 108, 234-244.
- Cuskelly, M., Chant, D., & Hayes, A. (1998). Behaviour problems in the siblings of children with Down syndrome: Associations with family responsibilities and parental stress. *International Journal of Disability, Development and Education*, 45, 295-311.
- Damiani, V.B. (1999). Responsibility and adjustment in siblings of children with disabilities: Update and review. *Families in Society*, 80, 34-40.

- Daniels, D., Moos, R. H., Billings, A.G., & Miller, J. J. (1987). Psychological risk and resistance factors among children with chronic illness, healthy siblings and healthy controls. *Journal of Abnormal Child Psychology*, 15, 295-308.
- Donaldson, D., Prinstein, M.J., Danovsky, M., Spirito, A. (2000) Patterns of children's coping with life stress: Implications for clinicians. *American Journal of Orthopsychiatry*, 70 (30), 351-359.
- Duis, S.S. & Summers, M. (1997). Parent versus child stress in diverse family types: An ecological approach. *Topics in Early Childhood Special Education*, 17, 53-74.
- Dunn, J. (1983). Sibling relationships in early childhood. *Child Development*, 54, 787-811.
- Dunn, J. (1992). Sisters and brothers: Current issues in developmental research. In F. Boer & J. Dunn (Eds.), *Children's sibling relationships: Developmental and clinical issues* (pp. 1-17). Hillsdale, NJ: Lawrence Erlbaum.
- Dunn, J. (2002). Sibling relationships. In P.K. Smith & C.H. Hart (Ed.), *Blackwell handbook of childhood social development*. (pp. 223-237). Oxford: Blackwell.
- Dyson, L.L. (1996). The experiences of families of children with learning disabilities: Parental stress, family functioning, and sibling self-concept. *Journal of Learning Disabilities*, 29, 280-286.
- Dyson, L.L. (1999). The psychosocial functioning of school-age children who have siblings with developmental disabilities: Change and stability over time. *Journal of Applied Developmental Psychology*, 20, 253-271.

- Dyson, L.L., Edgar, E., & Crnic, K. (1989). Psychological predictors of adjustment of siblings of developmentally disabled children. *American Journal of Mental Retardation*, 94, 292-302.
- Elwood, S.W. (1987). Stressor and coping response inventories for children. *Psychological Reports*, 60, 931-947.
- Featherstone, H. (1980). *A difference in the family*. NY: Basic Books.
- Ferrari, M. (1983). Chronic illness: Psychosocial effects on siblings. *Journal of Child Psychology and Psychiatry*, 25, 459-476.
- Fisman, S., Wolf, L., & Freeman, T. (2000). A longitudinal study of siblings of children with chronic disabilities. *Canadian Journal of Psychiatry*, 45, 369-376.
- Fortier, L.M. & Wanlass, R.L. (1984). Family crisis following the diagnosis of a handicapped child. *Family Relations*, 33, 13-24.
- Frey, K.S., Greenberg, M.T., & Fewell, R.R. (1989). Stress and coping among parents of handicapped children: A multidimensional approach. *American Journal on Mental Retardation*, 94, 240-249.
- Friedrich, W.N., & Friedrich, W.L. (1981). Comparison of psychosocial assets of parents with a handicapped child and their normal controls. *American Journal of Mental Deficiency*, 85, 551-553.
- Friedrich, W.N., Greenberg, M.T., & Crnic, K. (1983). A short-form of the Questionnaire on Resources and Stress. *American Journal of Mental Deficiency*, 88, 41-48.
- Frijda, N.H. (1993). The place of appraisal in emotion. *Cognition and Emotion*, 7(3/4), 357-387.

- Gath, A. (1973). Sibling reactions to mental handicap: A comparison of the brothers and sisters of Mongol children. *Journal of Child Psychology and Psychiatry*, 15, 187-198.
- Giallo, R., & Gavidia-Payne, S. *The development of a daily events scale for siblings of children with a disability or chronic illness*. Unpublished manuscript, RMIT University, Melbourne.
- Gold, N. (1993). Depression and social adjustment in siblings of boys with autism. *Journal of Autism and Developmental Disorders*, 23, 147-163.
- Grossman, F.K. (1972). *Brothers and sisters of retarded children: An exploratory study*. Syracuse: Syracuse University Press.
- Grotevant, H.D., & Carlson, C.I. (1989). *Family assessment: A guide to methods and measures*. NY: Guilford Press.
- Harris, P. L. (1989). *Children and emotion: The development of psychological understanding*. NY: Blackwell.
- Harvey, D. H., & Greenway, A.P. (1984). The self-concept of physically handicapped children and their nonhandicapped siblings: An empirical investigation. *Journal of Child Psychology and Psychiatry*, 25, 273-284.
- Hastings, R.P. (2003). Brief Report: Behavioural adjustment of siblings of children with autism. *Journal of Autism and Developmental Disorders*, 33 (1), 99-104.
- Hetherington, E.M. (1984). Stress and coping in children and families. In A.B. Doyle, D, Gold, & D.S. Moskowitz (Eds.), *Children in families under stress*. San Francisco: Jossey-Bass.

- Hodapp, R.M., Ricci, L.A., Ly, T.M., & Fidler, D.J. (2003). The effects of the child with Down syndrome on maternal stress. *British Journal of Developmental Psychology*, 21, 137-151.
- Honig, A.S. (1986). Stress and coping in Children (Part 1). *Young Children*, 47-59.
- Hornby, G., Seligman, M. (1991). Disability and the family: Current status and future developments. *Counselling Psychology Quarterly*, 4, 267-272.
- Huang, I. (1992). Family stress and coping. In S.J. Bahr (Ed.), *Family Research: A sixty-year review, 1930-1990* (pp. 289-334). Lexington: Lexington Books.
- Kagan, J. (1983). Stress and coping in early development. In N. Garnezy & M. Rutter (Ed.), *Stress, coping, and development in children* (pp. 191-216). NY: McGraw Hill.
- Kazak, A.E. & Marvin, R.S. (1984). Differences, difficulties and adaptation: Stress and social networks in families with a handicapped child. *Family Relations*, 33, 67-77.
- Kramer, L., & Baron, L.A. (1995). Parental perceptions of children's sibling relationships. *Family Relations*, 44, 95-103.
- LaRossa, R., & Reitzes, D. C. (1993). Symbolic interactionism and family studies. In P. G. Boss, W. J. Doherty, R. LaRossa, W. R. Schumm, & E. S. K. Steinmetz (Eds.), *Source book of family theories and methods: A contextual approach* (pp. 135-166). NY: Plenum.
- Larson, R. & Richards, M.H. (1994). *The emotional lives of mothers, fathers and adolescents*. NY: Basic Books.
- Lazarus, R. (1966). *Psychological stress and the coping process*. NY: McGraw Hill.

- Lazarus, R.S. & Folkman, S. (1980). An analysis of coping in a middle-aged community sample. *Journal of Health and Social Behavior*, 21, 219-239.
- Lazarus, R.S. & Folkman, S. (1984). *Stress, appraisal and coping*. NY: Springer.
- Lazarus, R.S. & Folkman, S. (1987). Transactional theory and research on emotions and coping. *European Journal of Personality*, 1, 141-169.
- McCubbin, H. I., Thompson, A. I., Thompson, E. A., Elver, K. M., & McCubbin, M. A. (1998). Ethnicity, Schema, and Coherence: Appraisal processes for families in crisis. In H. I. McCubbin, E. A. Thompson, A. I. Thompson & J. E. Fromer (Eds.). *Stress, coping, and health in families: Sense of coherence and resiliency* (pp. 41-67). CA: Sage.
- McCubbin, H. I., Olson D.H., & Larsen A.S. (1987). Family crisis oriented personal evaluation scales (FCOPES). In N. Fredman & R. Sherman (Eds.), *Handbook of measurements for marriage and family therapy* (pp. 199-203). NY: Brunner Mazel.
- McCubbin, H., & Patterson, M. (1983). The family stress process: The double ABCX model of adjustment and adaptation. In H. McCubbin, M. Sussman, & J. Patterson (Eds.), *Social stress and the family* (pp. 7-38). NY: Haworth.
- McHale, S.M. & Gamble, W.C. (1989). Sibling relationships of children with disabled and nondisabled brothers and sisters. *Developmental Psychology*, 25, 421-429.
- McHale, S. M. & Harris, V.S. (1992). Children's experiences with disabled and non-disabled siblings: Links with personal adjustment and relationship evaluations. In F. Boer & J. Dunn (Ed.), *Children's sibling relationships: Developmental and clinical issues* (pp. 83-101). New Jersey: Lawrence Erlbaum.

- Milgram, N.A. (1982). War related stress in Israeli children and youth. In N. Garmezy & M. Rutter (Eds.). *Stress, coping, and development in children*. New York: McGraw-Hill.
- Miller, S.G. An exploratory study of sibling relationships in families with retarded children. (Doctoral dissertation, Columbia University, 1974) *Dissertations Abstracts International*, 1974, 35, 2994B-2995B.
- Molsa, P.K. & Ikonen-Molsa, S.A. (1985). The mentally handicapped child and family crisis. *Journal of Mental Deficiency Research*, 29, 309-314.
- Moore, M.L., Howard, V.F., & McLaughlin, T.F. (2002). Siblings of children with disabilities: A review and analysis. *International Journal of Special Education*, 17, 49-64.
- Muris, P., Hovee, I., Meesters, C., & Mayer, B. (2004). Children's perception and interpretation of anxiety-related physical symptoms. *Journal of Behavior Therapy and Experimental Psychiatry*, 35, 233-244.
- Naar-King, S., Ellis, D.A., & Frey, M.A. (2004). *Assessing children's well-being: A handbook of measures*. New Jersey: Lawrence Erlbaum.
- Nixon, C.L. & Cummings, E.M. (1999). Sibling disability and children's reactivity to conflicts involving family members. *Journal of Family Psychology*, 13, 274-285.
- Patterson, J.M. (2002a). Understanding family resilience. *Journal of Clinical Psychology*, 58, 233-246.
- Patterson, J.M. (2002b). Integrating family resilience and family stress theory. *Journal of Marriage and Family*, 64, 349-360.

- Pearlin, L.I. (1991). Life strains and psychological distress among adults. In A. Monat & R.S. Lazarus (Eds.), *Stress and coping: An anthology*. (pp. 319-336). NY: Columbia University Press.
- Piaget, J. (1953). *The origins of intelligence in children*. NY: International University Press.
- Pit-Ten Cate, I.M. & Loots, G.M.P. (2000). Experiences of siblings of children with physical disabilities: An empirical investigation. *Disability and Rehabilitation*, 22, 399-408.
- Plunkett, S.W., Sanchez, M.G., Henry, C.S. & Robinson, L.C. (1997). The double ABCX model and children's post-divorce adaptation. *Journal of Divorce and Remarriage*, 27, 17-37.
- Powell, T. H., & Gallagher P. A. (1993). *Brothers & sisters: A special part of exceptional families*. Baltimore: Paul H. Brookes.
- Reddon, J.E., McDonald, L., & Kysela, G.M. (1992). Parental coping and family stress I: Resources for and functioning of families with a preschool child having a developmental disability. *Early Child Development and Care*, 83, 1-26.
- Reiss, D. (1981). *The family's construction of reality*. Cambridge: Harvard University Press.
- Reiss, D. & Oliveri, M.E. (1980). Family paradigm and family coping: A proposal for linking the family's intrinsic adaptive capacities to its responses to stress. *Family Relations*, 29, 431-444.
- Robson, M. (1999). Stress and its perception in childhood. *Counselling Psychology Quarterly*, 12, 217-231.

- Russell, J.A. & Ridgeway, D. (1983). Dimensions underlying children's emotion concepts. *Developmental Psychology*, 19, 795-804.
- Rutter, M. (1983). Stress, aging, and development: some issues and some questions. In N. Garnezy & M. Rutter (Ed.), *Stress, coping, and development in children* (pp. 1-41). NY: McGraw Hill.
- Ryan-Wenger, N .M. (1990). Development and psychometric properties of the Schoolagers' coping strategies inventory. *Nursing Research*, 39, 344-349.
- Seligman, M. (1983). Sources of psychological disturbance among siblings of handicapped children. *The Personnel and Guidance Journal*, 61, 529-531.
- Seligman, M. (1983). Siblings of handicapped persons. In M. Seligman (Ed.), *The family with a handicapped child: Understanding and treatment*. (pp. 147-174). NY: Grune & Stratton.
- Seligman, M. & R.B. Darling. (1989). *Ordinary Families, Special Children*. NY: Guilford Press.
- Sheets, V., Sandler, I. & West, S.G. (1996). Appraisals of negative events by preadolescent children of divorce. *Child Development*, 67, 2166-2182.
- Silver, R.L. & Wortman, C.B. (1980). Coping with undesirable life events. In J. Garber & E.P. Seligman (Eds.), *Human Helplessness*. NY: Academic Press.
- Sorenson, E.S. (1991). Identification of stress buffers in school-age children. *Journal of Community Health Nursing*, 8, 15-24.
- Sorenson, E. S. (1993). *Children's stress and coping: a family perspective*. NY: Guilford Press.

- Sorgen, K. E., & Manne, S.L. (2002) Coping in children with cancer: Examining the goodness-of-fit hypothesis. *Children's Health Care*, 31, (3), 191-207.
- Spirito, A., Stark, L.J., & Tyc, V. (1994). Coping strategies described during hospitalization by chronically ill children. *Journal of Clinical Child Psychology*, 23, 314-322.
- Spirito, A., Stark, L.J., & Williams, C. (1988). Development of a brief coping checklist for use with pediatric populations. *Journal of Pediatric Psychology*, 13, 555-574.
- Stattin, H. (1984). Developmental trends in the appraisal of anxiety-provoking situations. *Journal of Personality*, 52, 46-57.
- Stoneman, Z. (2001). Supporting positive sibling relationships during childhood. *Mental Retardation and Developmental Disabilities*, 7, 134-142.
- Stoneman, Z., Brody, G.H., Davis, C.H., & Crapps, J.M. (1988). Childcare responsibilities, peer relations, and sibling conflict: Older siblings of mentally retarded children. *American Journal on Mental Retardation*, 93, 174-183.
- Suelzle, M., & Keenan, V. (1981). Changes in family support networks over the life cycle of mentally retarded persons. *American Journal of Orthopsychiatry*, 51, 285-296.
- Taylor, V., Fuggle, P. & Charman, T. (2001). Well siblings psychological adjustment to chronic physical disorder in a sibling: How important is maternal awareness of their illness attitudes and perceptions? *Journal of Child Psychology and Psychiatry*, 42, 953-962.
- Thies, K.M. & Walsh, M.E. (1999). A developmental analysis of cognitive appraisal of stress in children and adolescents with chronic illness. *Children's Health Care*, 28, 15-32.

- Thompson, R.A. (1987). Development of children's inferences of the emotions of others. *Developmental Psychology*, 23, 124-131.
- Trevino, F. (1979). Siblings of handicapped children: Identifying those at risk. *The Journal of Contemporary Social Work*, 60, 488-493.
- Trute, B. (1990). Child and parent predictors of family adjustment in households containing young developmentally disabled children. *Family Relations*, 39,
- Trute, B. & Hiebert-Murphy, D. (2002). Family adjustment to childhood developmental disability: A measure of parent appraisal of family impacts. *Journal of Pediatric Psychology*, 27, 271-280.
- Vadasy, P.F., Fewell, R.R., Meyer, D.J., & Schell, G. (1984). Siblings of handicapped children: A developmental perspective on family interactions. *Family Relations*, 33, 155-167.
- Vangelisti, A. L. (1993). Communication in the family: The influence of time, relational prototypes and irrationality. *Communication Monographs*, 60, 42-54.
- Walker, A.J. (1985). Reconceptualizing family stress. *Journal of Marriage and the Family*, 47, 827-837.
- Walsh, F. (1982). Conceptualizations of normal family functioning. In F. Walsh (Ed.), *Normal Family Processes* (pp. 3-44). NY: Guilford Press.
- Yamamoto, K. & Felsenthal, H.M. (1982). Stressful experiences of children: Professional judgements. *Psychological Reports*, 50, 1087-1093.

Appendix A

Daily Events Scale for Siblings of Children with a Disability or Illness

Instructions: Everyone has problems or hassles that bother them from time to time.

Below are some things that can make you feel upset, bothered or stressed out.

For each problem, we would like to know:

- 1) How often does the problem happen?
- 2) How stressed out does the problem make you feel?

Do you feel bothered about....	How often does the problem happen?					How stressed out does the problem make you feel?				
	Never 0	1	Sometimes 2	3	Always 4	Not at all 0	1	A bit 2	3	Very 4
Getting up in the morning.	0	1	2	3	4	0	1	2	3	4
Being tired, sick or hurt.	0	1	2	3	4	0	1	2	3	4
Cleaning my bedroom.	0	1	2	3	4	0	1	2	3	4
Losing or misplacing things.	0	1	2	3	4	0	1	2	3	4
When my parents ask me to do jobs.	0	1	2	3	4	0	1	2	3	4
Getting into trouble with my parents.	0	1	2	3	4	0	1	2	3	4
When my brothers/sisters (without a disability or illness) do not get into trouble for things they do.	0	1	2	3	4	0	1	2	3	4
Not being allowed to do the things I want to do.	0	1	2	3	4	0	1	2	3	4
Arguing with my parents.	0	1	2	3	4	0	1	2	3	4
Worrying about my parents.	0	1	2	3	4	0	1	2	3	4
When my brothers/sisters (without a disability or illness) tease me.	0	1	2	3	4	0	1	2	3	4
When my brothers/sisters (without a disability or illness) interrupt me when I am trying to do something.	0	1	2	3	4	0	1	2	3	4
Going to school.	0	1	2	3	4	0	1	2	3	4
When other kids tease me at school.	0	1	2	3	4	0	1	2	3	4
Talking to friends about important personal things.	0	1	2	3	4	0	1	2	3	4
Having to do homework.	0	1	2	3	4	0	1	2	3	4
Coming home from school.	0	1	2	3	4	0	1	2	3	4
When my brother/sister (with a disability or illness) cries or gets upset.	0	1	2	3	4	0	1	2	3	4

Do you feel bothered about....	How often does the problem happen?	How stressed out does the problem make you feel?
When my brother/sister (with a disability or illness) is sick or hurt.	0 1 2 3 4	0 1 2 3 4
When my brother/sister (with a disability or illness) hurts, hits, pushes, scratches or kicks me or others.	0 1 2 3 4	0 1 2 3 4
When my brother/sister (with a disability or illness) takes my things without asking.	0 1 2 3 4	0 1 2 3 4
When my brother/sister (with a disability or illness) goes into my room.	0 1 2 3 4	0 1 2 3 4
When my brother/sister (with a disability or illness) messes up my room.	0 1 2 3 4	0 1 2 3 4
When my brother/sister (with a disability or illness) teases me.	0 1 2 3 4	0 1 2 3 4
Arguing with my brother/sister (with a disability or illness).	0 1 2 3 4	0 1 2 3 4
Stopping what I am doing so my brother/sister (with a disability or illness) does not get upset.	0 1 2 3 4	0 1 2 3 4
Having to give in to my brother/sister (with a disability or illness), so he/she does not get upset.	0 1 2 3 4	0 1 2 3 4
When my brother/sister (with a disability or illness) cries, screams or yells when he/she doesn't want to do something.	0 1 2 3 4	0 1 2 3 4
When my brother/sister (with a disability or illness) does not do what he/she is asked to do.	0 1 2 3 4	0 1 2 3 4
When my brother/sister (with a disability or illness) does not do what I ask them to do.	0 1 2 3 4	0 1 2 3 4
When my brother/sister (with a disability or illness) interrupts me when I am trying to do something.	0 1 2 3 4	0 1 2 3 4
Not being able to do what I want because my brother/sister (with a disability or illness) interrupts me.	0 1 2 3 4	0 1 2 3 4
Having to remind my brother/sister (with a disability or illness) to do things.	0 1 2 3 4	0 1 2 3 4
Having to do things for my brother/sister (with a disability or illness).	0 1 2 3 4	0 1 2 3 4

Do you feel bothered about....	How often does the problem happen?					How stressed out does the problem make you feel?				
	Never		Sometimes		Always	Not at all		A bit		Very
When my brother/sister (with a disability or illness) does not share things with me.	0	1	2	3	4	0	1	2	3	4
When people ask questions about my brother/sister's disability or illness.	0	1	2	3	4	0	1	2	3	4
When people don't understand about my brother/sister's disability or illness.	0	1	2	3	4	0	1	2	3	4
When my brother/sister (with a disability or illness) embarrasses me when I have friends over.	0	1	2	3	4	0	1	2	3	4
When my brother/sister (with a disability or illness) bothers me when I have friends over.	0	1	2	3	4	0	1	2	3	4
Going to bed at night.	0	1	2	3	4	0	1	2	3	4

There are also good things that happen in our lives that make us feel happy. Below are some things that can make you feel happy. For each event, we would like to know:

- 1) How often does the good thing happen?
- 2) How happy does the good thing make you feel?

Do you feel happy about....	How often does good thing happen?					How happy does the good thing make you feel?				
	Never		Sometimes		Always	Not at all		A bit		Very
When my parent/s help me with something.	0	1	2	3	4	0	1	2	3	4
Spending time with my parents.	0	1	2	3	4	0	1	2	3	4
Spending time together as a family.	0	1	2	3	4	0	1	2	3	4
Going out somewhere with my parents.	0	1	2	3	4	0	1	2	3	4
Going out somewhere together as a family.	0	1	2	3	4	0	1	2	3	4
Having a talk with mom or dad about things.	0	1	2	3	4	0	1	2	3	4
Getting new things.	0	1	2	3	4	0	1	2	3	4
Getting food treats.	0	1	2	3	4	0	1	2	3	4
When my parents let me do something I want to do.	0	1	2	3	4	0	1	2	3	4
When my parents are in a good mood.	0	1	2	3	4	0	1	2	3	4
Having a friend over at my house.	0	1	2	3	4	0	1	2	3	4
Spending time or playing on my own.	0	1	2	3	4	0	1	2	3	4
Finishing my homework.	0	1	2	3	4	0	1	2	3	4
Having no homework.	0	1	2	3	4	0	1	2	3	4

Do you feel happy about....	How often does good thing happen?					How happy does the good thing make you feel?				
	Never		Sometimes		Always	Not at all		A bit		Very
When my brother/sister (with a disability or illness) learns something new.	0	1	2	3	4	0	1	2	3	4
When my brother/sister (with a disability or illness) tries hard at something.	0	1	2	3	4	0	1	2	3	4
Helping my brother/sister (with a disability or illness) to learn new things.	0	1	2	3	4	0	1	2	3	4
When my brother/sister (with a disability or illness) gives me hugs or kisses.	0	1	2	3	4	0	1	2	3	4
When my brother/sister (with a disability or illness) does funny things.	0	1	2	3	4	0	1	2	3	4
Playing together with my brother/sister (with a disability or illness).	0	1	2	3	4	0	1	2	3	4
Spending time with my brother/sister (with a disability or illness).	0	1	2	3	4	0	1	2	3	4
When my brother/sister (with a disability or illness) shares something with me.	0	1	2	3	4	0	1	2	3	4
Hearing good news about my brother/sister (with a disability or illness).	0	1	2	3	4	0	1	2	3	4
When my day runs smoothly, without interruptions from my brother/sister (with a disability or illness).	0	1	2	3	4	0	1	2	3	4

Appendix B

KIDCOPE (Younger version)

Coping Strategy	Did You Do This?		How Much Did It Help?		
1. I just tried to forget it.	Yes	No	Not at all	A little	A lot
2. I did something like watch TV or played a game to forget it.	Yes	No	Not at all	A little	A lot
3. I stayed by myself.	Yes	No	Not at all	A little	A lot
4. I kept quiet about the problem.	Yes	No	Not at all	A little	A lot
5. I tried to see the good side of things.	Yes	No	Not at all	A little	A lot
6. I blamed myself for causing the problem.	Yes	No	Not at all	A little	A lot
7. I blamed someone else for causing the problem.	Yes	No	Not at all	A little	A lot
8. I tried to fix the problem by thinking of answers.	Yes	No	Not at all	A little	A lot
9. I tried to fix the problem by doing something or talking to someone.	Yes	No	Not at all lot	A little	A
10. I yelled, screamed, or got mad.	Yes	No	Not at all	A little	A lot
11. I tried to calm myself down.	Yes	No	Not at all	A little	A lot
12. I wished the problem had never happened.	Yes	No	Not at all	A little	A lot
13. I wished I could make things different.	Yes	No	Not at all	A little	A lot
14. I tried to feel better by spending time with others like family, grownups or friends.	Yes	No	Not at all	A little	A lot
15. I didn't do anything because the problem couldn't be fixed.	Yes	No	Not at all	A little	A lot

Appendix C

Family Crisis-Oriented Personal Scales (F-COPES)

Purpose: The Family Crisis-Oriented Personal Evaluation Scale is designed to record problem-solving attitudes and behaviours which families develop to respond to problems or difficulties.

When we face problems or difficulties in our family, we respond by:	Never 0	Sometimes 1	Often 2	Most of the time 3
Sharing our difficulties with relatives.				
Seeking encouragement and support from friends.				
Knowing we have the power to solve major problems.				
Seeking information and advice from persons in other families who have faced the same or similar problems.				
Seeking advice from relatives (grandparents, etc.).				
Seeking assistance from community agencies and programs designed to help families in our situation.				
Knowing that we have the strength within our own family to solve our problems.				
Receiving gifts and favours from neighbours (e.g. food, taking in mail, etc.).				
Seeking information and advice from the family doctor.				
Asking neighbours for favours and assistance.				
Facing the problems "head-on" and trying to get a solution right away.				
Watching television.				
Showing that we are strong.				

When we face problems or difficulties in our family, we respond by:	Never 0	Sometimes 1	Often 2	Most of the time 3
Attending religious services.				
Accepting stressful events as a fact of life.				
Sharing concerns with close friends.				
Knowing luck plays a big part in how well we are able to solve family problems.				
Exercising with friends to stay fit and reduce tension.				
Accepting that difficulties occur unexpectedly.				
Doing things with relatives (get-togethers, dinner, etc.).				
Seeking professional counseling and help for our family difficulties.				
Believing we can handle our own problems.				
Participating in religious activities.				
Defining the family problem in a more positive way so that we don't become too discouraged.				
Asking relatives how they feel about problems we face.				
Feeling that no matter what we do to prepare, we will have difficulty handling problems.				
Seeking advice from a religious leader.				
Believing if we wait long enough, the problem will go away.				
Sharing problems with neighbours.				
Having faith in God.				

Appendix D

Disability Index

Please report on the present level of your child's disability using the following scale.

1 = Low

2 = Low to Medium

3 = Medium

4 = Medium to High

5 = High

1. Intellectual Impairment _____

2. Physical Disabilities _____

3. Need for Ongoing Medical Attention _____

4. Future Need for Physical Assistance in Everyday Functions _____

Appendix E

Demographic Questionnaire for Parents

Please circle or fill in the appropriate answer

1. Marital Status

Single Married Separated/Divorce Other _____

If married, please report the number of years you have been married. _____

2. How many children are there in your family? _____

Please report each child's age and sex, beginning with your child with special needs.

3. Mother's age _____

Father's age _____

4. Mom: Do you work outside of your home? YES NO

If so, what do you do? _____

Dad: Do you work outside of your home? YES NO

If so, what do you do? _____

5. Mom: Please list any education or degrees you have obtained, beginning with your high school diploma.

Dad: Please list any education or degrees you have obtained, beginning with your high school diploma.

6. Please circle the combined yearly income level your family falls in.

- a) Under \$20,000 a year
- b) Between \$20,000-\$35,000
- c) Between \$35,000- \$50,000
- d) Between \$50,000-\$75,000
- e) Over \$75,000

7. Please describe your family's cultural and religious affiliation.

8. a) Does your family receive any help caring for your child with special needs within the home? YES NO

If yes, please describe the assistance in terms of:

This individual's general position (i.e. nanny, rehab worker). _____

How many hours a week does this person come? _____

b) Does your family receive any help caring for your child with special needs outside the home (such as community resources)?

YES NO

If yes, please describe the assistance in terms of:

The specific resources _____

How many hours during the week do you use these resources? _____

Do you receive any financial assistance for these resources? YES NO

If yes, do you find the financial assistance to be adequate?

Do you find the support and resources available to you to be adequate?

Do your children *without* special needs participate in any resources for themselves (i.e., support group, therapy)?

9) Aside from the diagnosis of your special needs child, has your family experienced any of the following stressful life events in the past year?

- | | | |
|--|-----|----|
| a) Death of an immediate family member (sibling, mother, father). | YES | NO |
| b) Death of an extended family member (grandparents, cousins etc). | YES | NO |
| c) Divorce/Separation in the immediate family. | YES | NO |
| d) Serious injury or illness in the immediate family. | YES | NO |
| e) Unemployment or serious financial difficulty in the immediate family. | YES | NO |
| f) Moving | YES | NO |
| g) Legal trouble within the immediate family | YES | NO |
| h) Other _____ | | |

Finally, I'm interested in how you as parents have perceived your child's adjustment to having a sibling with special needs. Please explain any thoughts on the subject, as well as provide an overall rating of your child's functioning concerning their sibling.

Please circle the appropriate number corresponding to your overall rating of your child's adjustment to their sibling with special needs.

1 2 3 4 5 6 7 8 9 10

2 = Seems to have trouble adjusting and exhibits several behaviour problems.

4 = Has trouble in some areas, however improvement has been seen.

6 = Has ups and downs, but generally seems to be adjusting well.

8 = Seems to have minimal adjustment problems.

10 = Seems to be unaffected by their sibling with special needs and rather often displays positive effects of their relationship.

Thank you for your time and effort.

Appendix F

How I See My Children's Sibling Relationship

Please circle the number that best fits your feelings about the following aspects of your children's relationship during the past 2 weeks.

How frequently would you say each of the following occurs in your children's relationship?	How much would you say this is a problem?	If this is a problem, how easy would it be for you to improve this if you want to?	How much would you like help with this?
1. Physical aggression (hitting, pushing, etc.) (1) Never (2) Rarely (3) Sometimes (4) Usually (5) Always	(1) It's not a problem (2) It's a small problem (3) It's a big problem (4) It's a very big problem	(1) Very difficult (2) Difficult (3) Neutral (4) Easy (5) Very easy	(1) No help (2) A little help (3) A lot of help
2. Sharing (1) Never (2) Rarely (3) Sometimes (4) Usually (5) Always	(1) It's not a problem (2) It's a small problem (3) It's a big problem (4) It's a very big problem	(1) Very difficult (2) Difficult (3) Neutral (4) Easy (5) Very easy	(1) No help (2) A little help (3) A lot of help
3. Jealousy (1) Never (2) Rarely (3) Sometimes (4) Usually (5) Always	(1) It's not a problem (2) It's a small problem (3) It's a big problem (4) It's a very big problem	(1) Very difficult (2) Difficult (3) Neutral (4) Easy (5) Very easy	(1) No help (2) A little help (3) A lot of help

How frequently would you say each of the following occurs in your children's relationship?	How much would you say this is a problem?	If this is a problem, how easy would it be for you to improve this if you want to?	How much would you like help with this?
4. Playing together in single activity (1) Never (2) Rarely (3) Sometimes (4) Usually (5) Always	(1) It's not a problem (2) It's a small problem (3) It's a big problem (4) It's a very big problem	(1) Very difficult (2) Difficult (3) Neutral (4) Easy (5) Very easy	(1) No help (2) A little help (3) A lot of help
5. Competition (1) Never (2) Rarely (3) Sometimes (4) Usually (5) Always	(1) It's not a problem (2) It's a small problem (3) It's a big problem (4) It's a very big problem	(1) Very difficult (2) Difficult (3) Neutral (4) Easy (5) Very easy	(1) No help (2) A little help (3) A lot of help
6. Respecting each others property (1) Never (2) Rarely (3) Sometimes (4) Usually (5) Always	(1) It's not a problem (2) It's a small problem (3) It's a big problem (4) It's a very big problem	(1) Very difficult (2) Difficult (3) Neutral (4) Easy (5) Very easy	(1) No help (2) A little help (3) A lot of help
7. Rivalry (1) Never (2) Rarely (3) Sometimes (4) Usually (5) Always	(1) It's not a problem (2) It's a small problem (3) It's a big problem (4) It's a very big problem	(1) Very difficult (2) Difficult (3) Neutral (4) Easy (5) Very easy	(1) No help (2) A little help (3) A lot of help

How frequently would you say each of the following occurs in your children's relationship?	How much would you say this is a problem?	If this is a problem, how easy would it be for you to improve this if you want to?	How much would you like help with this?
8. Sharing worries or concerns (1) Never (2) Rarely (3) Sometimes (4) Usually (5) Always	(1) It's not a problem (2) It's a small problem (3) It's a big problem (4) It's a very big problem	(1) Very difficult (2) Difficult (3) Neutral (4) Easy (5) Very easy	(1) No help (2) A little help (3) A lot of help
9. Anger or Hostility (1) Never (2) Rarely (3) Sometimes (4) Usually (5) Always	(1) It's not a problem (2) It's a small problem (3) It's a big problem (4) It's a very big problem	(1) Very difficult (2) Difficult (3) Neutral (4) Easy (5) Very easy	(1) No help (2) A little help (3) A lot of help
10. Loyalty or sticking up for one another (1) Never (2) Rarely (3) Sometimes (4) Usually (5) Always	(1) It's not a problem (2) It's a small problem (3) It's a big problem (4) It's a very big problem	(1) Very difficult (2) Difficult (3) Neutral (4) Easy (5) Very easy	(1) No help (2) A little help (3) A lot of help
11. Arguments (1) Never (2) Rarely (3) Sometimes (4) Usually (5) Always	(1) It's not a problem (2) It's a small problem (3) It's a big problem (4) It's a very big problem	(1) Very difficult (2) Difficult (3) Neutral (4) Easy (5) Very easy	(1) No help (2) A little help (3) A lot of help

How frequently would you say each of the following occurs in your children's relationship?	How much would you say this is a problem?	If this is a problem, how easy would it be for you to improve this if you want to?	How much would you like help with this?
12. Comforting one another (1) Never (2) Rarely (3) Sometimes (4) Usually (5) Always	(1) It's not a problem (2) It's a small problem (3) It's a big problem (4) It's a very big problem	(1) Very difficult (2) Difficult (3) Neutral (4) Easy (5) Very easy	(1) No help (2) A little help (3) A lot of help
13. Fighting over territory or space (1) Never (2) Rarely (3) Sometimes (4) Usually (5) Always	(1) It's not a problem (2) It's a small problem (3) It's a big problem (4) It's a very big problem	(1) Very difficult (2) Difficult (3) Neutral (4) Easy (5) Very easy	(1) No help (2) A little help (3) A lot of help
14. Protectiveness – looking out for the other's welfare (1) Never (2) Rarely (3) Sometimes (4) Usually (5) Always	(1) It's not a problem (2) It's a small problem (3) It's a big problem (4) It's a very big problem	(1) Very difficult (2) Difficult (3) Neutral (4) Easy (5) Very easy	(1) No help (2) A little help (3) A lot of help

How frequently would you say each of the following occurs in your children's relationship?	How much would you say this is a problem?	If this is a problem, how easy would it be for you to improve this if you want to?	How much would you like help with this?
15. Feeling proud of one another (1) Never (2) Rarely (3) Sometimes (4) Usually (5) Always	(1) It's not a problem (2) It's a small problem (3) It's a big problem (4) It's a very big problem	(1) Very difficult (2) Difficult (3) Neutral (4) Easy (5) Very easy	(1) No help (2) A little help (3) A lot of help
16. Conflicts where the problem never gets worked out (1) Never (2) Rarely (3) Sometimes (4) Usually (5) Always	(1) It's not a problem (2) It's a small problem (3) It's a big problem (4) It's a very big problem	(1) Very difficult (2) Difficult (3) Neutral (4) Easy (5) Very easy	(1) No help (2) A little help (3) A lot of help
17. Talking to each other, conversations (1) Never (2) Rarely (3) Sometimes (4) Usually (5) Always	(1) It's not a problem (2) It's a small problem (3) It's a big problem (4) It's a very big problem	(1) Very difficult (2) Difficult (3) Neutral (4) Easy (5) Very easy	(1) No help (2) A little help (3) A lot of help

How frequently would you say each of the following occurs in your children's relationship?	How much would you say this is a problem?	If this is a problem, how easy would it be for you to improve this if you want to?	How much would you like help with this?
18. Fighting over objects (1) Never (2) Rarely (3) Sometimes (4) Usually (5) Always	(1) It's not a problem (2) It's a small problem (3) It's a big problem (4) It's a very big problem	(1) Very difficult (2) Difficult (3) Neutral (4) Easy (5) Very easy	(1) No help (2) A little help (3) A lot of help
19. Helping one another (1) Never (2) Rarely (3) Sometimes (4) Usually (5) Always	(1) It's not a problem (2) It's a small problem (3) It's a big problem (4) It's a very big problem	(1) Very difficult (2) Difficult (3) Neutral (4) Easy (5) Very easy	(1) No help (2) A little help (3) A lot of help
20. Threats (1) Never (2) Rarely (3) Sometimes (4) Usually (5) Always	(1) It's not a problem (2) It's a small problem (3) It's a big problem (4) It's a very big problem	(1) Very difficult (2) Difficult (3) Neutral (4) Easy (5) Very easy	(1) No help (2) A little help (3) A lot of help
21. Teaching (how to play a game, how to read, etc.) (1) Never (2) Rarely (3) Sometimes (4) Usually (5) Always	(1) It's not a problem (2) It's a small problem (3) It's a big problem (4) It's a very big problem	(1) Very difficult (2) Difficult (3) Neutral (4) Easy (5) Very easy	(1) No help (2) A little help (3) A lot of help

How frequently would you say each of the following occurs in your children's relationship?	How much would you say this is a problem?	If this is a problem, how easy would it be for you to improve this if you want to?	How much would you like help with this?
<p>22. Affection (hug, kiss, saying "I love you" etc.)</p> <p>(1) Never (2) Rarely (3) Sometimes (4) Usually (5) Always</p>	<p>(1) It's not a problem (2) It's a small problem (3) It's a big problem (4) It's a very big problem</p>	<p>(1) Very difficult (2) Difficult (3) Neutral (4) Easy (5) Very easy</p>	<p>(1) No help (2) A little help (3) A lot of help</p>
<p>23. Trying to control each others behaviour using phrases like, "don't do that," "stop it," or "leave me alone."</p> <p>(1) Never (2) Rarely (3) Sometimes (4) Usually (5) Always</p>	<p>(1) It's not a problem (2) It's a small problem (3) It's a big problem (4) It's a very big problem</p>	<p>(1) Very difficult (2) Difficult (3) Neutral (4) Easy (5) Very easy</p>	<p>(1) No help (2) A little help (3) A lot of help</p>
<p>24. Kindness</p> <p>(1) Never (2) Rarely (3) Sometimes (4) Usually (5) Always</p>	<p>(1) It's not a problem (2) It's a small problem (3) It's a big problem (4) It's a very big problem</p>	<p>(1) Very difficult (2) Difficult (3) Neutral (4) Easy (5) Very easy</p>	<p>(1) No help (2) A little help (3) A lot of help</p>

In general, how well would you say your children get along with one another?

1	2	3	4	5	6	7
Very poorly			Neutral			Extremely Well

Appendix G

Follow-up Survey

Dear Parents,

Thank you so much for participating in my study on siblings of children with special needs. Your family's help is much appreciated. You will be receiving some information on the study's results in the upcoming months.

I'm currently seeking some follow-up information from all parents to help support my results. It would be much appreciated if could answer a few final questions (4 in total).

As with the previous information collected, please be assured that all participants can choose to withdraw from participation at any point during the study. You may also choose not to answer certain questions. Results will be kept confidential, with identities only known the researcher.

Included is the following: one question page (you may attach another sheet if desired), and a stamped return envelope where your answers can be mailed. Should you prefer to answer these questions by email or telephone, this can be arranged. I can be reached through messages left at 848-2424 ext. 2008 and through email at: mt_orfus@education.concordia.ca.

Thank you again for your continued help.

Please accept my best to you and your family.

Melanie Orfus

Please answer the following follow-up questions.
You may write on the back or attach another page if needed.

1) The following are a list of 4 coping mechanisms identified by families.

1. Accepting stressful events as a fact of life.
2. Showing that we are strong.
3. Knowing we have the power to solve major problems.
4. Accepting that difficulties occur unexpectedly.

Please choose any of the above coping strategies and briefly describe a family example of when you used this strategy.

Please elaborate on how the strategy helps or doesn't help your family.

2) Please consider your various support systems (friends, relatives, community, and professional services). Can you briefly provide an example of a family problem and explain where you turned for support?

Why did you turn to this system in this case and not another part of the system?

3) Please describe an occasion (if any) where your son/daughter (who participated in the study) displayed anger or hostility towards their sibling with special needs. Please describe how they coped with this feeling.

4) Please describe an occasion (if any) where your son/daughter (who participated in the study) displayed loyalty or protectiveness towards their sibling with special needs.

Appendix H

Dear Participant,

My name is Melanie Orfus and I'm a Masters student in Child Study in the Education Department of Concordia University studying with Dr. Nina Howe. I'm conducting research for my thesis on the siblings of children with special needs and disabilities. I'd like to tell you a bit about my research and ask your family to consider participating in my study.

I will be researching the experiences of nondisabled siblings and investigating how they cope with having a brother or sister with special needs. I'm also interested in the family's coping style and how it affects the way children cope with a sibling with special needs. Throughout my research on these families and my recent volunteering with a support group for siblings of children with special needs, I have been enlightened to the uniqueness of your family. I hope my research will give siblings an opportunity to share their feelings and that my results might contribute to the research that is helping design resources for these families.

Each family will be asked to participate in a session at home that will take about a half-hour. To participate in the study, the participant sibling (required to be between the ages of 8-12) is asked to do the following:

- ◆ Participate in a sibling interview* with the researcher that is estimated to take approximately a half-hour. This will include:

- a) A questionnaire on daily events involving their sibling with special needs.
- b) A questionnaire on how the child coped with these events.

*The interview will be adapted to an appropriate level for the child by the researcher to ensure their understanding.

In addition, the parent/guardian of the sibling is asked to do the following:

- ◆ Fill out 4 items*:

- a) A demographic questionnaire on your family;
- b) A 4-item form on your child's disability;
- c) A scale on your family's problem solving attitudes and behaviours;
- d) A questionnaire on your perception of the relationship between your child with special needs and their sibling.

* These are estimated to take a total of 30-45 minutes.

The study is not anticipated to have any associated risks or to cause any discomfort in the participants. However because children are involved and the subject may be a sensitive one, every precaution is taken to protect the well being of the participant. Interviews will be conducted at the family's convenience and the researcher will travel to the participant's desired location (home or elsewhere). Interviews with siblings will be age appropriate and breaks may be taken at any time throughout. Parents are asked to complete their forms at their leisure and return them as soon as possible either in person or mail. A stamp and addressed envelope will be provided if needed.

Please be assured that participants (parents and siblings) can choose to withdraw their participation at any point during the study. They may also choose not to answer certain questions. Results will be kept confidential, with identities only known to the researcher. A number will be assigned to your family to enhance confidentiality. True names will never be revealed. While the research may one day be published, families will never be identified and only group findings would be reported. In addition, this research project has received ethical approval from a committee within the university.

What follows are two consent forms. The first is for the parent/guardian to sign. It explains the purpose and conditions of the research. The second form is for your child. I will read them this form at the beginning of the interview and if they agree to participate, I will ask them to print their name on the space provided.

I thank you for taking the time to consider participating in my study. Should you choose to participate, you may contact me in any of the following ways:

- 1) Email: mt_orfus@education.concordia.ca
- 2) School Telephone: 848-2424 ext. 2008

You may also contact Dr. Nina Howe, who is supervising my work, with any questions or concerns. She may be reached at 848-2424 ext. 3829.

I'd appreciate your participation as soon as is convenient for you, however an answer is preferred by the end of March, 2005. Please accept my best to you and your family.

Melanie Orfus

Consent Form to Participate in Research

This is to state that I agree to participate in a program of research being conducted by Melanie Orfus of the Department of Education of Concordia University under the supervision of Dr. Nina Howe. I have been informed that the purpose of the research is to ascertain the sibling's experiences in families with a child with special needs. The study will also focus on the sibling and family's coping styles.

Please review the following conditions and discuss it with your family. A parent's signature in the space provided below indicates their family's consent (including the sibling's) to participate in this research study. Thank you very much for your consideration. My best wishes to your family's health and happiness.

- I understand that I am free to withdraw my consent and discontinue my participation at any time without negative consequences.
- I understand that my participation in this study is confidential (i.e., the researcher may know, but will not disclose my identity).
- I understand that the data from this study may be published but only in group form.
- I HAVE CAREFULLY STUDIED THE ABOVE INFORMATION AND UNDERSTAND THIS AGREEMENT.

MY FAMILY FREELY CONSENTS AND VOLUNTARILY AGREES TO PARTICIPATE IN THIS STUDY.

Name (please print) _____

Signature _____

Witness Signature _____

Date _____

Please feel free to email or call me with any questions or comments.

Thank you again for your time.

Melanie Orfus
mt_orfus@education.concordia.ca
848-2424 ext. 2008

If at any time you have questions about your rights as a research participant, please contact Adela Reid, Research Ethics and Compliance Officer, Concordia University, at (514) 848-2424 ext. 7481 or by email at Adela.Reid@concordia.ca

Sibling Consent Form

Dear _____

My name is Melanie Orfus. I am doing a project for school on special sibling relationships. I'd like to ask you to think about helping me.

If you agree to help, you and I would spend some time talking together at your home, just the two of us. I will be asking you some questions about your feelings and about your brother or sister with special needs.

It is important to remember that...

- ◆ There are no right or wrong answers. Anything you answer is okay.
- ◆ Everything you tell me is private and only between you and me. I won't tell your parents or anyone else. My project will not use your name at all.
- ◆ If you don't want to answer some questions, that is okay. You can just tell me that you don't want to answer.
- ◆ If you would like to stop at any time during the interview, that is fine. You can just tell me that you want to stop and we will stop.
- ◆ You can also take breaks at any time during the interview. Your parents can be close by if you want to see them at any time.

Talk to your parents about this if you like. I have also given them some information on my project.

If you decide to help, you can print your name on the line below.

Thank you very much!

Melanie Orfus

- ◆ I would like to help with this project.
- ◆ I understand that I can stop helping at any time.
- ◆ I understand that what I say is private.

Name _____

Date _____