

SPIRITUALITY & RELIGION AS COPING MECHANISMS:  
FAMILIES RAISING CHILDREN WITH DEVELOPMENTAL DISABILITIES

by

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## TABLE OF CONTENTS

ACKNOWLEDGEMENT .....	2
ABSTRACT .....	7
INTRODUCTION .....	8

### CHAPTER ONE

• REVIEW OF LITERATURE .....	10
• Definition of Developmental Disabilities .....	10
• Alarming Statistics .....	11
• Aspects of Stress & Coping: Applications to Families Raising Children with Developmental Disabilities .....	12
A) The General Impact of Disability on the Family .....	12
B) The Family Response to Initial Diagnosis .....	12
C) The Impact of Disability on Marital Relationships .....	18
D) The Impact of Disability on Typically Developing Siblings .....	19
E) The Financial Burden .....	21
F) The Chronic Burden of Care .....	22
G) The Lack of a Grass Roots System .....	23
H) Social Stigmatization .....	23
I) The Need for Social Support .....	25
J) Internal & External Factors .....	25
K) Additional Factors that Influence Familial Stress & Coping .....	26
L) A Proposed Model of Stress in Families of Children with Developmental Disabilities .....	27
• Defining Religion & Spirituality .....	31
• Religion, Spirituality & Coping with a Developing Disabled Child .....	34
• Research Questions & Hypotheses .....	42

### CHAPTER TWO

• METHOD .....	43
• Participants .....	43
• Measures .....	45
• Design & Procedure .....	47
• Ethics .....	48

### CHAPTER THREE

• RESULTS .....	49
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CHAPTER FOUR

- DISCUSSION..... 57
- Implications for future research..... 62
- Limitations ..... 63
- Conclusion..... 65

REFERENCES ..... 66

APPENDIX A..... 73

APPENDIX B ..... 87

## LIST OF TABLES

Table 1: Participants Characteristics

Table 2: Means and Standard Deviations of the Predictor Variables

Table 3: Means and Deviations of the QRS-SF Subtotals

Table 4: Bivariate Correlation with Predictors of QRS-SF Total

Table 5: Correlation Matrix of all Subscales with QRS Total

Table 6: Correlation Matrix for Demographic Variables

## LIST OF FIGURES

Figure 1: A Model of Stress in Families of Children with Developmental Disabilities

## ABSTRACT

The process of rearing a child with a developmental disability is arguably difficult for many families, yet there appears to be some families and parents who cope more easily with their child's disability. Two additional factors, which have been identified as coping resources and have become rather popular in the realm of resiliency research, are spirituality and religiosity. The study sought to address the hypothesis that aspects of spiritual well-being as measured by the Holistic Spirituality Model (Rovers & Kocum, 2010) would predict better familial coping beyond the contribution of other demographic and psychosocial factors. Additionally this study was addressing the hypothesis that other previously significant psychosocial variables would become less predictive of familial ability to cope with the addition of spirituality and religiosity to the model. Lastly it was predicted that individual subscales of the Holistic Spirituality Model would correlate with better scores on the Questionnaire on Resources and Stress which measured the family's ability to cope with raising a child with a developmental disability. This study is a replication of a previous study conducted by Jones and Passey (2004), with the addition of the Holistic Spirituality Model developed by Rovers and Kocum (2010). A hierarchical regression analysis was conducted, blocking variables by questionnaire while controlling for specific demographic variables. Results suggest no support for the first two hypotheses. A positive correlation was found between the existential well-being subscale of the Holistic Spirituality Model and the Questionnaire on Resources and Stress which measured familial coping while raising a child with a developmental disability.

## **INTRODUCTION**

In the words of Desmond Tutu; “You don’t choose your family. They are God’s gift to you, as you are to them.” When a baby is born, parents are usually overjoyed and have great expectations and hopes of what their child will someday become. However, for those parents who, for whatever reason, give birth to or have a child who develops some kind of debilitating disability, the experience of having and raising a child becomes an entirely different story.

In the past year, two autistic boys have been murdered by their overwrought parents. An outraged society responded; horrified by the apparent heartlessness of parents who could take the lives of their own children. These examples highlight the extreme levels of stress families of children with developmental disabilities experience and the potential negative outcomes for those who struggle to cope with their situations. Raising a child with a disability is an onerous job that carries with it the burden of constant care and supervision, incredible financial strain, pressure on marital and sibling relationships, and often social isolation (CBC News Report, September, 2009).

Though the process of rearing a child with a developmental disability is arguably difficult for many families, there appears to be some families and parents who cope more easily with their child’s disability (Gupta & Singhal, 2004). Over the past years there have been a number of studies conducted with respect to factors that either promote or hinder resiliency in families coping with children who have developmental disabilities (Chan & Sigafos, 2001, Kausar et al., 2003, Margalit & Kleitman, 2006). Some of these factors include social support, financial stability, and accessibility to resources such as respite.

Two additional factors, which have been identified as coping resources and have become rather popular in the realm of resiliency research, are spirituality and religiosity (Gall et al., 2005) While there is considerable evidence suggesting that spirituality and religiosity are useful coping resources in stressful situations, there has been very little investigation done in regards to the relationship between spirituality, religiosity and the ability of families to cope with the rather stressful task of raising a child with a developmental disability.

The following literature review provides definitions for the variables that were examined in this study, as well as a summary of research concerning the issues families encounter in attempting to cope with their child's disability. A number of studies supporting the relationship between religion, spirituality and coping are also highlighted.

## CHAPTER ONE

### REVIEW OF LITERATURE

#### Definition of Developmental Disability

A definition of developmental disabilities is provided in order that the reader may conceptualize the population that is being discussed in this paper. The DSM-IV-TR refers to pervasive developmental disorders which are characterized by severe deficits and pervasive impairments in multiple areas of development (DSM-IV, 4<sup>th</sup> ed., revised, 2000). These areas include impairment in reciprocal social interaction, impairment in communication, and the presence of stereotyped behaviour, interests and activities. The disorders encompassed by these criteria are Autism, Rett's Disorder, Childhood Disintegrative Disorder, and Pervasive Developmental Disorder (DSM-IV, 4<sup>th</sup> ed., revised, 2000). Down syndrome is not included in the current DSM as a pervasive developmental disorder. Unlike Autism and other pervasive developmental disorders, Down syndrome is a result of a common chromosomal disorder. The addition of an extra chromosome, number 21, causes mental retardation, ultimately causing certain intellectual handicaps and developmental delays (Crosta, 2009). Despite that Down syndrome has an identified organic cause, many of the developmental delays commonly seen in DSM disorders are also observed in children diagnosed with Down syndrome (Crosta, 2009). For the purpose of this study, all mentioned disorders and syndromes are referred to as developmental disabilities. For the purpose of brevity the abbreviation DD will be used in the place of developmental disabilities.

## Alarming Statistics

New statistics on the prevalence of Autism in America have just been released. Shockingly; 1 out of 91 children and 1 out of every 58 boys are being diagnosed Autistic (Perrin, 2009). Countless more children receive a diagnosis of Asperger's syndrome or Pervasive Developmental Disorder Not Otherwise Specified; both of which are on the Autism spectrum. Additionally, according to a study carried out by the Canadian Government in 2002, 1 out of every 800 children is born with Down syndrome (Congenital Anomalies, 2002). Results from the 2006 census indicate that 3.7% of Canadian children under the age of 15 have at least one or more diagnosed disability (Participation & Activity, 2006). These statistics are important as they highlight that the diagnosis of various DD are on the rise. If these numbers prove to be accurate, there are definite implications in regards to how accessible various social, financial and community resources are to families coping with raising children with DD. The lack of social and financial support that the Canadian government provides to such families is briefly discussed later in this paper: however such realities cause families to seek resources that are more accessible. In one respect religion and spirituality can be considered more accessible to families who have children with DD because such coping mechanism tend to operate more existentially and tend not to be associated with monetary and political value.

One does not need to go on a 'wait list' to pray to God or to worship with their religious or spiritual community, or to have an existential belief that their predicament holds a greater meaning in the scheme of life.

## Aspects of Stress & Coping – Applications to Families Raising Children with Developmental Disabilities

### A) The General Impact of Disability on the Family

Prior to delving into the various coping mechanisms that families rely on for raising their children with DD, it is useful to first look at the issues these families face, which make it difficult to function as a so-called ‘typical family’ would.

Parents of children with DD have been found to have elevated scores on the Parenting Stress Index, signifying that they perceive far more stress in their role as parents than do parents of children without disabilities (Healy, 1996). Some of the most frequently mentioned stressors by parents and families of children with DD are: parent guilt, worry about the future, parent’s perception that other people think they may be the cause of the problem, difficult behaviour of children with disabilities, feeling a need to protect their child, disagreement between parents about dealing with the child, disagreement between parents about the existence of a problem, increased financial burden, finding competent professional services, and sibling resentment of attention given to the child with DD (Healy, 1996). Further research provides additional stressors such as the disabled child’s lack of responsiveness, temperament, repetitive behaviour patterns and additional or unusual caretaking demands (Byrne & Cunningham, 1984).

### B) The Family Response to Initial Diagnosis

Examining the family’s initial response to their child’s DD diagnosis, as well as the various stages of coping that they go through is important in conceptualizing the difficulties that are encountered as families attempt to come to terms with and manage stress while raising children with DD.

Heiman (2002) examined the responses of parents whose children had been diagnosed with an intellectual, physical, or learning disability, as well as their patterns of adjustment, and their future concerns and expectations, and found that most parents tended to react in an emotionally and physiologically negative way. It also found that the transition in a family with a special-needs child brought about significant changes in that family's social life. Many parents had to make changes in their social life and experienced significant frustration and dissatisfaction. Some experienced considerable stress as well as feelings of depression, anger, shock, denial, self-blame, guilt, or confusion.

For a parent, finding out that a child has a DD, whether at birth or at a later point in life, is a devastating experience. Parents may go through a whole series of losses; the loss of the child they expected to have, the loss of their dreams for their child's future, the loss of their child's quality of life, the loss of their own way of life and the loss of their expectations for their family life (Latson, 1995). When these losses happen unexpectedly, there is the added shock of things going wrong at a time of life when parents expect everything to go well. Research has shown that some parents cannot distinguish between the unconscious wish for an idealized normal child from an unthinkable, sudden reality of one who is not (Dammeyer, 2009). For some parents, just trying to comprehend the disparity between their desires for their child and the disability that exists, compounds their emotional and intellectual efforts to adjust to the situation (Latson, 1995). Parents may also ask the existential question of "why me" and conclude that they are being punished for some reason. Depending on the severity of the disability and the magnitude of the demand for coping, a few parents may even contemplate death for the child or themselves. These thoughts represent an all-encompassing need to achieve inner peace (Latson, 1995).

A number of researchers have suggested that the symptoms or stages that parents go through when learning they have a child with a DD are quite similar to those symptoms or stages that are commonly identified in people dealing with the experience of death or dying (Seligman & Darling, 2007). These can include shock, disbelief, anger, blame, guilt, questioning of why it happened to their child and panic or fear that parents and family members will not be able to cope (Latson, 1995). These feelings can come back at different stages throughout the child's life as new losses happen. For example; the loss of ability to go to school, or to have friends, or to become independent impacts the grieving process. Therefore, there is not just one loss but many losses that happen over the lifespan (Seligman & Darling, 2007).

Until parents, who are having difficulty accepting their child's DD, can cope with their own pain and frustrations, their full energies generally cannot be directed toward understanding the child's disability, level of development, readiness for instruction, or participation in the intervention process (Healy, 1996). It is therefore relevant to identify the stages of adjustment as they apply to parents and family members coping

In the first stage, a parent may be shocked and may cry or become dejected. Sometimes parents may express their feelings through physical outbursts or, occasionally, inappropriate laughter (Healy, 1996). The second stage is an extension of the first. Some parents may deny their child's disability or try to avoid the reality in some other way. Denial is an unconscious coping mechanism which helps to ease anxiety but can also become problematic if persistent. When parents push their children with DD beyond their capabilities, fail to enrol them in early intervention programs or continuously seek out additional professionals in order to receive a different diagnosis, these are clear signs that denial is at work (Batu & Cetin, 2008).

The third stage is the stage of bargaining where many parents will feel that if they work very hard with their child, the disability will improve. Some parents may turn to spirituality and look for a miracle or they will bargain with God (Seligman & Darling, 2007). They may try to propose various actions in an attempt to change the reality. Some may "shop for a cure" or try to bargain for a different reality (Healy, 1996).

When parents come to the realization that their child will likely not lose their disability, anger can present. This presentation of anger signifies the fourth stage. In some cases parents can be angry with God, with their spouse and with the health care and educational professionals who work with their children. It is common for parents to feel guilty or somehow blame themselves for causing their child's disability. When feelings of guilt or self-blame manifest; parents often become angry with themselves (Seligman & Darling, 2007). Parents may demonstrate their anger outwardly, in the form of rage, or become withdrawn and passive from intense feelings of guilt. (Healy, 1996).

In the fifth stage, after anger has been thoroughly expressed, parents may feel a release, but often realize it is counterproductive when they see that it does not change their child's circumstance. At this point parents may begin to feel depressed with the notion that there is nothing they can do to fix their child. Depression unlike some of the other feelings that parents experience will be temporary but also episodic (Batu & Cetin, 2008).

While many parents will eventually accept their child's disability, it is likely that at a later point in time they will once more struggle with it (Seligman & Darling, 2007). At this stage, parents become resigned to the fact that their child has a disability. Feelings of shame, guilt, hopelessness, and anxiety stemming from a new overwhelming burden of responsibility can become intense (Healy, 1996). For a few parents, retreating, accompanied by an attempt to hide

the child, especially from friends and other people during organized or routine social encounters, may be the first sign that they have begun to accept the fact their child has a disability. However, any inclination toward or demonstration of behavior that results in abnormal isolation of one or any family members must be prevented or eliminated (Healy, 1996).

The final stage is the stage of acceptance, meaning that the parents have achieved an unconditional positive regard for the child (Healy, 1996). Acceptance of a child's disability can be demonstrated by a parent being reasonably comfortable with discussing their child's difficulties. Parents who are able to encourage their children to be independent, while still showing love are exhibiting acceptance (Dammeyer, 2009). Another way parents demonstrate acceptance is by being able to work with professionals on establishing goals for their child. Parents who are able to make time for themselves and their own activities, who are able to discipline without feeling guilty and who are capable of discarding overprotective or rigid parenting techniques are all demonstrating that they have accepted their child's disability (Seligman & Darling, 2007).

It has been debated whether or not this stage of adjustment includes parents who show only acceptance of their child's condition, or whether it is a new stage of cognition when parents not only begin to understand and appreciate their child, but strengthen their skills in coping with life's trials as well as being able to help their child, themselves, and others. Reaching this stage is highly correlated with the school inviting parents to become team members in a program with caring professionals that is designed to meet all of the child's needs (Healy, 1996). In the final stage, parents are able to put their lives back together and enjoy living, imagine a future, and talk of their child free of undue emotion. They can discuss and participate in designing or providing instruction objectively (Healy, 1996).

While there are obvious similarities between the stages of acceptance of a child's disability and the stages of acceptance of a loved one's death, research has also demonstrated that parents who have children with disabilities may not experience these stages in the order that they were described (Batu & Cetin, 2008). Evidence suggests that parental reactions experienced at each prospective stage can occur repeatedly, even after one stage has apparently been passed, as a result of specific life crises or turning point (Seligman & Darling, 2007). As was mentioned previously, parents may become depressed or demonstrate difficulties coping with their child's disability at a particular stage in time (Seligman & Darling, 2007). For example; a parent may have accepted their child's disability a year or so after diagnosis, but when the child becomes school-aged, there are many other stressors to deal with and the reality of the disability is relived by the parent (Seligman & Darling, 2007). Many parents experience so-called "chronic sorrow", where their sorrow due to their child's disability is present long after the initial diagnosis. However, studies suggest that this experience is a completely normal part of acceptance and parental adjustment (Batu & Cetin, 2008). In a study examining stress factors in families with a school-aged child with a DD, children's demandingness and neediness for care was related more to maternal stress and the child's acceptability was related more to paternal stress. (Keller & Honig, 2004).

Further research on the chronic grief experienced by parents of children with chronic illness demonstrated that these parents experience multiple stressors associated with their numerous roles. In this study, parents revealed the chronic grief they experienced in relation to their child's condition often recurred at various stages of the child's illness. The child's initial diagnosis was found to be the most stressful part of the grieving process, with most feeling their voices as parents were not being heard or valued by health professionals at this time. This affected

parents' confidence in the health care system and triggered the re-emergence of grief, aggravating an already stressful situation (George et al., 2006).

Not all research findings on familial coping and response to disability are considered negative. A particular study examined the potential for transformation that could result from having a child with a DD and a number of positive changes were noted. Results indicated that most parents reported many positive changes in their lives as a result of parenting a child with a disability. These included such changes as personal growth, improved relations with others, and changes in philosophical or spiritual values. (Scorgie & Sobsey, 2000).

### C) The Impact of Disability on Marital Relationships

As has been clearly established, having a child with a DD is a stressful process in and of itself. One area that this paper has not yet addressed in relation to the impact of stress is that of the marital relationship. It is important to consider the impact of a child's DD on the marital relationship, as this relationship also impacts the entire family functioning and influences not only the way parents relate to each other, but also to their typically developing children and their child with the DD. A strong marital relationship has a positive influence on the overall family functioning and can serve as a coping mechanism; however a weak marital relationship has the opposite effect. Therefore the following research speaks to the impact of disability on the marital relationship.

Many parents often become so overwhelmed by the challenges of having a child with a DD that they devote all of their time and energy to the child with the disability and neglect other family relationships. Countless parental relationships break down after the birth of a child with a disability, or when a child becomes disabled (Healy, 1996). A survey conducted by Stats Canada, 2002, which considered the impact of the child's disability on the parental relationship, found that in

situations where the child's condition did present some difficulties, stress, depression and arguments accounted for 85% of the relationship problems. Of the parents who responded, 76% said that their child's disability resulted in either separation or divorce (Participation & Activity, 2006).

In a study examining the contribution of marital quality to the well-being of parents of children with DD, greater marital quality predicted lower parenting stress and fewer depressive symptoms above and beyond socio-economic status, child characteristics and social support (Kersh et al., 2006).

Despite a significant amount of research that supports the negative impact of raising a child with a disability on the marital relationship, additional research suggests that having a child with a disability may also distract from more fundamental problems within the marital relationship. These findings suggest that it is important to discriminate family problems that are caused by a child's disability from those that arise under any circumstance (Seligman & Darling, 2007). Another useful finding which is supported by a number of studies is the positive relationship between healthy and lasting marital relationships and religious and spiritual identification. Interestingly, research suggests that those who view their marriage from a sacred, religious or spiritual perspective tend to cope more easily with familial or marital stressors than do people who do not identify with this perspective.

#### D)The Impact of Disability on Typically Developing Siblings

The siblings of children with DD are not immune to the stressors that disability can create for their families. As such, this paper also considers the impact that disability has on the coping ability of typically developing children. Many typically developing children who have siblings with DD experience feelings of anger and guilt, due to the fact that that they feel ignored or

unappreciated by their parents (Mulroy et al., 2007) Typically developing siblings are often aware of the psychological and financial demands placed on the family by their disabled sibling and are also perceptive to reactions from their peers. A number of siblings feel burdened by having to care for their developmentally disabled sibling, especially when their friends do not have these responsibilities (Sanders, 2004). Such responsibilities may lead to resentment, guilt and in extreme cases, psychological disturbances. Factors such as lower economic status, smaller families and female gender all contribute to an increased likelihood of psychological disturbance in children who have a DD sibling (Sanders, 2004). Parental expectations for typically developing siblings have also been shown to impact sibling coping, as often parental expectations will be unrealistically high in order to compensate for the inability of their developmentally disabled sibling to fulfill such expectations (Sanders, 2004).

Additional factors which appear to be strong contributors to maladaptive coping of typically developing children are; anxiety about catching their sibling's disability, lack of communication or education within the family in regards to what the disability means, and negative attitudes or beliefs that the parents convey towards their DD child (Williams and Piamjariyakul, 2010). Sibling rivalry is common and can be exaggerated in families where there is a child with a DD (Williams & Piamjariyakul, 2010). Typically developing children often feel that that they need to compete for their parent's attention and will often act out or begin to over-achieve in an effort to garner attention from their parents.

Very often, typically developing children are also sensitive to different discipline techniques that their parents will use with them versus their sibling with a disability. Some parents tend to over-discipline the so-called normal child and provide less of a consequence to the child

with a disability. Siblings are very conscious of these differences and may become angry over differential treatment (Mulroy et al., 2007).

While so much of a parent's time is spent caring for a child with a disability, the typically developing child often feels neglected or resentful that they do not spend more time with their parents. The child may feel angry or annoyed with their disabled sibling if they are always around when they want to have friends over or do something independently of their sibling. Future care for one's disabled sibling is a source of stress for older siblings who recognize the burden of care that their parents carry (Sanders, 2004).

Further research has also been carried out in regards to the adjustment of siblings of children with DD. While behavioural problems that are linked to the child's DD do result in some sibling anger, siblings have not been found to blame their disabled brother or sister, or themselves. Coping strategies or knowledge of the disability do not appear to affect sibling adjustment (Ross & Cuskelly, 2006). A study which compared siblings of Down syndrome and siblings of non-handicapped children on the basis of behaviour, found a significant increase in anti-social disorder in older sisters of children with Down syndrome (Byrne & Cunningham, 1984). In another study examining the benefits of having a sibling with a developmental disability, 45% of the participants interviewed suggested they had benefited from their experience (Byrne & Cunningham, 1984).

### E) The Financial Burden

As if the initial diagnosis of such disorders is not shocking enough, the cost associated with caring for and raising children with DD through to adulthood is atrocious. The financial burden for many families of children diagnosed with DD is one of the biggest factors contributing to familial stress. The costs for specialized care and education are often so exorbitant that only the very wealthy can escape the impact of this burden. In a study conducted in 2000 on the educational, health and social services related to Autism, the minimum lifetime cost estimated per individual with Autism was two million dollars (Zwack, 2000). While this estimate might appear steep to those unaware of the services required by people who are developmentally challenged, one needs only to consider the yearly costs of respite services, early intervention programs and therapy, specialized medical care and private education. Bearing in mind that the average annual income per person in Canada is 35,498 dollars (Stats Canada, 2006), and that the wait list for many of these funded programs and respite services require an average wait time of about two and half years, the financial pressures of raising a child with a disability appear daunting (Sharp & Baker, 2010). With a financial outlook as bleak as this one and an obvious scarcity in government funded resources, it is not surprising that many families elicit the support of alternative revenues. Many families go into debt re-mortgaging their homes, others seek out the support of family members and some who are religious or spiritual acquire the financial support of their church or faith group communities.

### F) The Chronic Burden of Care

In many cases, families who have a DD child must provide care and supervision 24 hours a day, 7 days a week for the rest of their lives. Due to the fact that constant care is required, these families must adapt in order to successfully function (Seligman & Darling, 1989). This may mean

that family members will have to take on roles that are not typical of so-called regular families. For example, a sibling might need to help with caretaking more than they otherwise would. In addition, families who have children with disabilities are often encouraged to access respite services which will allow them to have a break from providing constant care. And while in theory the concept of respite appears sound, being able to afford expensive respite care and obtain reliable service providers presents as yet another substantial challenge and source of stress for families who already have significant pressures (Seligman & Darling, 1989).

#### G) The Lack of a Grass Roots System

Families meet another road block in dealing with their child's disability when they attempt to locate and access services that are supposedly readily available to them. It is unfortunate that the current system is configured in such a way that there is no central point of access. What it meant by this is that there is no direct source of resources that parents can consult in order to attain these services (Moseley, 2004). Parents spend hours making phone calls, doing internet research and filling out forms, and more often than not, only to be told that their child "does not meet the criteria" or that they have to get in contact with another person, because someone does not have the information or skills required to meet the needs of their child. As a result of the current system configuration, many parents who have children with DD are left feeling overwhelmed and powerless because they have no idea how to get the help they need for their child (Moseley, 2004).

#### H) Social Stigmatization

While we have come leaps and bounds in regards to becoming a more inclusive and accommodating society, the stigmas surrounding DD are still very much present (Seligman & Darling, 1989). The stigmatization of disabilities is viewed on a sort of spectrum in that some disabilities are considered to be "discredited" where others are considered to be "discreditable"

(Seligman & Darling, 1989). The term discreditable in this case referring to those disabilities that are not readily apparent to general society and the term discredited referring to a disability that is immediately obvious to others (Howell et al., 2007).

In an effort to avoid or decrease stigmatization families who have a child with a discreditable disability may engage in what is referred to as “impression management”, which will in essence make their child appear more normal. Even when families use such coping mechanisms, public outings and events are generally still quite stressful as parents must decide whether they should continue to convey the assumption of normality, also keeping in mind that their child may behave in such a way that would expose the truth (Seligman & Darling, 1989).

In the case of families of discredited children, when the general public comes in contact with these children, there is often no acknowledgement that the disability exists which presents as fictional acceptance because the DD child is not truly accepted as an equal (Howell et al., 2007). Often time, people are also hesitant to become close to the families of these children because they in turn might be stigmatized (Seligman & Darling, 1989). Due to this mutual stigmatization, many families who have DD children will create their social networks by incorporating other families who also have children with disabilities and who also experience similar stigmatization (Seligman & Darling, 1989). Stigmatization is not only experienced by the child who has the disability, but also by the family in general. The parents, siblings and grandparents can and often do feel devalued, which can result in a sense of shame and stigma. Research has also demonstrated that families who have a child with a DD are subject to an increase in the number of stressful encounters as the discrepancy between the child’s size and functioning increases (Howell et al., 2007).

### I) The Need for Social Support

Social support has undoubtedly been one of the main factors contributing to resiliency in families coping with raising a child with a DD. Social support resources, including the spousal relationship, have been found to be significant predictors of depression in both mothers and fathers (Trute, 1995). In a study which investigated parental stress of preschool children with and without DD, it was found that parents with DD children reported higher levels of parenting stress, weaker social coherence and less social support than did parents with typically developing children (Oelofsen & Richardson, 2006).

A comparative study, which assessed the need for social support in parents of children with Autism and Down syndrome, found that parents of children with Autism were significantly more dissatisfied with the support services they had received since their child's diagnosis (Siklos & Kerns, 2006). Across most studies, families who have offspring with Down syndrome tend to cope better than do families of children with other DD (Hodapp, 2007). Also related to social support is the concept of respite care. A literature review on the use of respite care as a coping strategy for parents raising children with developmental disabilities has suggested that at least in the short-term, respite care is associated with significant reductions in stress, for a majority of the parents who use it (Chan & Sigafos, 2001).

### J) Internal and External Factors

Research has also been conducted on the differing internal and external stress factors which influence parents. Internal stress factors have been identified as those which come from within the individual; and include attitudes, perceptions, assumptions, and expectations (Latson, 1995).

Expectations of parents about their child lie at the root of burnout.

Beliefs that lead to internal stress for parents of children with developmental disabilities are the expectation that they should give one hundred percent everyday, that the success or failure of the child depends entirely on the parents and or family members, that they would be seen by society as a good and honourable person based on their efforts for their child, that they should refuse to let anyone else care for or influence their child, that the needs and recreation of parents and other family members should be denied in order to help the disabled child, that everything should be done for the child with the disability, that every possible moment should be spent with the child with the disability, that the role of caring for the needs of the disabled child can satisfy and support the personal dreams of parents and other family members, that the child with the disability appreciates the things that are done for them and that other people perceive the parent of a child with the disability as a parent who can handle everything (Latson, 1995).

External factors are those which are situational, and often involve relationships with others. External forces also impose upon parents of children with disabilities. Neighbours, friends, and relatives don't understand why the child is having academic problems. Teachers frequently don't fully understand the ramifications of a child's problem (Latson, 1995). Parents are called upon by the school to help make decisions about the child's school program, but often feel helpless as the child's advocate because of their own lack of understanding. Situations which lead to external stress include: dealing with schools or therapy programs concerning the child's curriculum, coping with difficult child behaviours, educating neighbours and relatives about the child's problems, helping siblings understand the problems associated with disabilities, sending the child to an appropriate school, helping child with homework, financial pressures surrounding funding expensive home or centre-based therapy programs and working with one's spouse and other family members on child management (Latson, 1995).

### K) Additional Factors that Influence Familial Stress and Coping

There is also indication that parental personality traits are a predictive factor in determining a parent's ability to cope with raising a child with DD (Glidden, Billings & Jobe, 2006). The research conducted by Glidden, Billings & Jobe (2006) suggests that neuroticism is a trait which is especially predictive of coping strategy use, and that higher levels of positive reappraisal are associated with higher levels of subjective wellbeing, whereas higher levels of escape-avoidance were associated with lower levels of subjective well being, but only for mothers.

In a study examining the positive effects that parent's perception play in the coping process, it was found that positive perceptions do indeed assist in helping to deal with traumatic and stressful events. Not only do they benefit the parents and the siblings in coping with the child, the disability, and the difficulties associated with it; but it also helps the family unit as a whole. The way in which a family functions, is influenced by the parent's perception of their child's difficulties (Gupta & Singhal, 2004).

### L) A Proposed Model of Stress in Families of Children with Developmental Disabilities

In order to better comprehend one of the foremost constructs in the present study, we will draw upon an article put forth by Perry (2004), which presents a theoretical model for understanding stress and related issues in families of children with DD. Permission to use this model was requested and consent was granted for the purpose of this thesis. (see appendix)

Prior to explaining her own model, Perry reflects on some pre-existing models that examine stress and coping. She touches on one of the earlier theories put forth by Selye (1980) where stress is understood as the stages of physiological and psychological reactions that an organism experiences in the face of stress. She also reflects on the paradigm model which suggests that stressful life events have a negative impact on mental and physical health, as well as

the daily hassle paradigm which infers that it is not necessarily a major life event that causes people to experience stress, rather it is an accumulation of many minor situations that is the basis of stress. The last theory she refers to, touches on the notion of a resource imbalance which results from a disparity between demands and available resources. Perry implies that these models are lacking in the sense that they are evaluating stress from an individual perspective rather than from a family systems approach. Therefore her model proposes four major components which include; stressors, resources, supports, and outcomes, each of which she divides into the domain of stressors and resources.

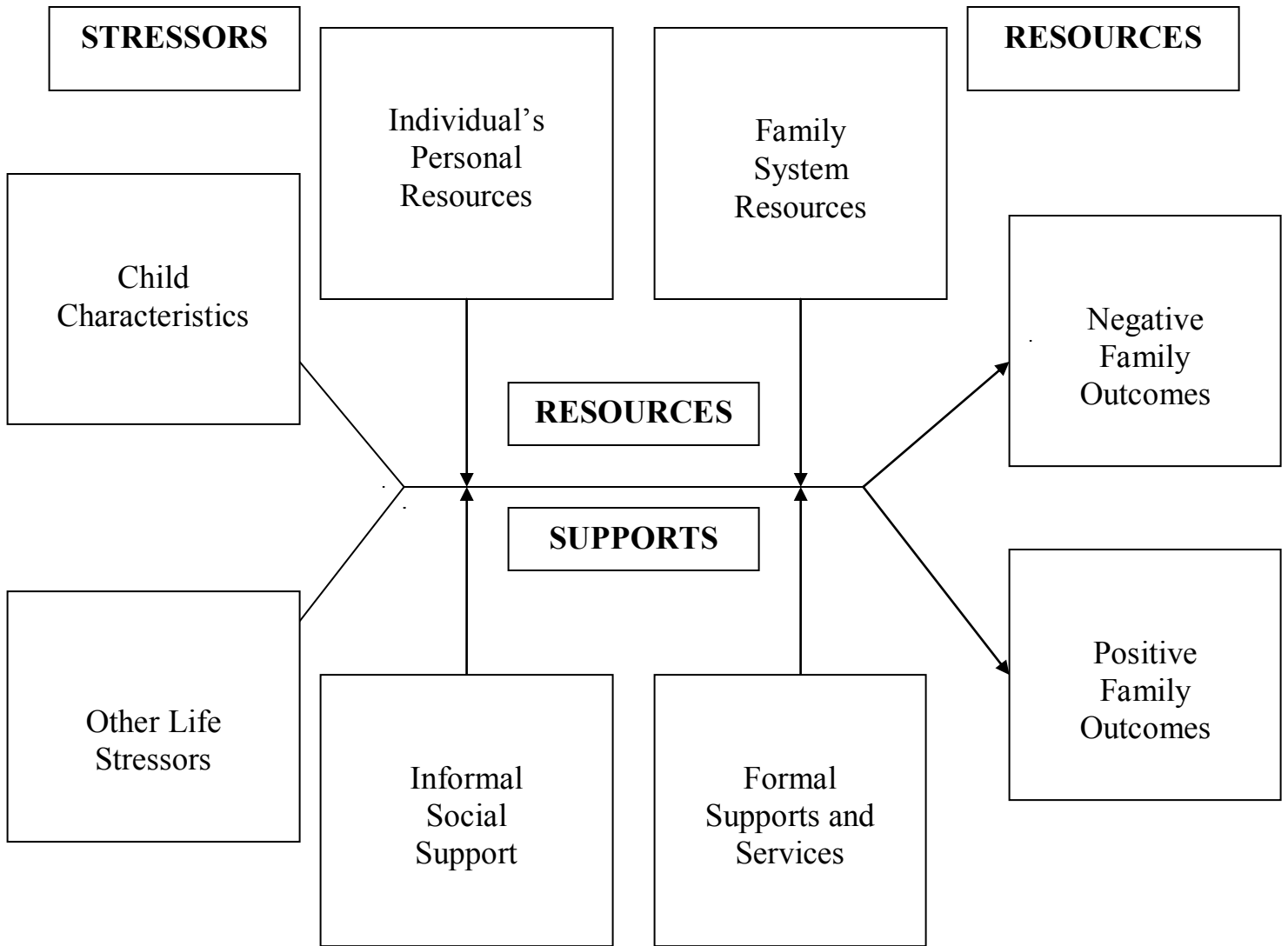
Stressors, according to Perry, are major or minor stressful stimuli in the lives of families of children with DD (Perry, 2004). Resources she suggests refer not only to the personal resources of the family but also to external resources outside the family such as social networks and formal support services. The last aspect of this model is the outcome which it is said will be negative or positive based on the stressors and resources involved and including the emotional state, as well as the cognitive appraisals and attributions a family makes about their emotional state.

Perry (2004) reports that a number of child characteristics that may be perceived as stressors include the level of dependency in self-help tasks, cognitive or developmental level, frequency and severity of maladaptive behaviour, diagnosis or type of DD, age and gender. Other life stressors that Perry includes which also may be experienced as stressful are issues related to employment, illness or financial problems.

Individual personal resources refer to such variables as cognitive coping strategies and beliefs, as well as demographic qualities such as education and employment status. Family system resources include such variables as family functioning, marital satisfaction and marital status. Informal support refers to having emotional needs met, or tangible help that is received and or

perceived to be available from extended family, friends, neighbours, social organizations, and religious communities. Formal supports are professional or paraprofessional services such as education, treatment programs, counselling, respite care, behaviour management training and support groups. Perry concludes that while much of the family stress research has focused on negative outcomes, this particular model measures outcome as two separate variables, in order to consider not only the negative, but also the positive outcomes of raising children with developmental disabilities. Below is a replication of the diagram used to visually conceptualize Perry's model of stress in families of children with DD.

**A Model of Stress in Families of Children with DD  
Proposed by (Perry, 2004)**



Perry's model does an excellent job at highlighting the ways in which families perceive the stress of raising children with DD, as well as the coping resources and possible outcomes based on the use of such resources. However, her model does not address spirituality and religion as coping mechanisms or the way in which such resources would impact the coping process.

### Defining Religion and Spirituality

Religion and Spirituality are terms which come up either independently and or together in many of the studies which are discussed further on in this paper. It is therefore relevant to provide a brief definition as to what these concepts mean as they relate to the topic being discussed. It is also important to understand how both of these concepts will be evaluated in relationship to other variables being examined in this study.

Zinnbauer et al. (1997) conducted a study which examined the relationship between spirituality and religion. In their research they found evidence to support distinct differences between the two. Religion was correlated with authoritarianism, religious orthodoxy, intrinsic religiousness, parental religious attendance, self-righteousness, and church attendance, while spirituality was correlated with mystical experiences and new age beliefs and practices. In addition, a literature review which examined scholarly definitions of both spirituality and religiosity, described spirituality as more experiential and linked it to people's belief in a relationship with God or a higher power (Zinnbauer et al. 1997). While definitions of religion also included belief in a higher power, they spoke to organizational or institutional beliefs and practices such as church membership and attendance and commitment to institutional belief systems. More specifically, institutional beliefs in this case referring to beliefs that are founded within the context of formal and organized religion rather than on personal spiritual beliefs. Zinnbauer et al. (1997) found that despite clear differences between religion and spirituality, the

two concepts are not entirely independent. Self-rated religiousness and spirituality were found to have a modest relationship with each other and both were associated with frequency of prayer, church attendance, intrinsic religiosity, religious orthodoxy and traditional concepts of the sacred.

According to Wulff (1997) scholarly resources have produced three specific roles for religion which include; a supernatural to which individuals are committed; a feeling of being present in the individual who believes in such a power; and ritual acts that are carried out for the purposes of honouring this supernatural power. Contrastingly Wulff (1997) presents three separate approaches for understanding spirituality which include; a God-oriented approach to spirituality, where thought and practice are given ground in theologies; a world-oriented approach to spirituality highlighting a person's relationship to the natural world; and lastly a humanistic approach to spirituality which highlights the human potential. Pargament (1999) suggests that overtime, as religion and spirituality have begun to be viewed more distinctly, spirituality has taken with it some elements of religion and as a result, modern definitions of religion have become associated more with institutional elements. Spirituality, on the other hand, has been linked with individual experiences such as transcendence, supraconscious sensitivity and meaningfulness.

In their aim to conceptualize both religion and spirituality, Hill et al. (2000) developed a criteria to evaluate the differences between the two. The criteria they established for defining both spirituality and religion include; feelings, thoughts, experiences and behaviours that arise from a search for the sacred. In their criteria, both religion and spirituality define the word search as an attempt a person makes to identify, articulate, maintain or transform. The term sacred in both concepts, refers to a divine being, divine object, ultimate reality and or ultimate truth as it is perceived by the person. The way in which these criteria differ is based on additional features that religion carries with it. That is, religion also included the search for non-sacred goals such as

identity, belongingness, meaningfulness and health. Hill et al. (2000) also suggest that religion differs in its methods such as the ritual or prescribed behaviours that people receive validation for or support within the identifiable group of people to whom they belong. However, Hill et al. (2000) point out that it is important to recognize the concept of the sacred as it is central to the experience of both religion and spirituality. Being aware of both the similarities and the differences between religion and spirituality is important for understanding how these constructs will influence the coping process.

As the present study utilizes the Holistic Spirituality Model developed by Rovers and Kocum (2010) to directly measure the construct of spirituality, their definition is particularly important. They refer to spirituality as a “catch-all word that is used for a vast array of experiences that reflects a tension between secular, sacred, and religious views” (Rovers & Kocum, 2010). They suggest that it may be possible for all of these experiences to be encapsulated within the definition of spirituality. The research findings of Rovers and Kocum (2010) infer that it is plausible to have a holistic model of spirituality, whereby the concepts of faith and hope also encompass measures of religiosity, existentialism and spiritual well-being. It is for this reason that the “Holistic Model of Spirituality” was used to directly measure the concept of spirituality and to more broadly measure the concept of religiosity. The Holistic Spirituality Model (HSM) is made up of three specific constructs which include spiritual well-being, communal well-being and existential well-being. Rovers and Kocum (2010) suggest that spiritual well-being is understood as one’s relationship with God, existential well-being concerns one’s sense of purpose and life satisfaction, and communal well-being refers to the importance of one’s participation or involvement in spiritual and or religious communities or faith groups (Rovers & Kocum, 2010) and that all these combined make up a holistic spirituality.

## Religion, Spirituality & Coping with a Developmental Disabled Child

Prior to delving into a discussion on the topic of how religion and spirituality positively influence people's ability to cope, it is pertinent to first identify some of the research findings that have demonstrated ways in which religion and spirituality are useful.

The following is a summary of a model proposed by Gall et al. (2005) which accounts for the role of spirituality in relation to coping and health. This model is valuable within the context of the present study as it helps readers to understand the spiritual coping process. In this model, it is suggested that the initial step in the coping process is the spiritual appraisal of the stressor. During the process of appraisal, it is said that there is a causal attribution made, followed by a primary and secondary appraisal. When a causal attribution is made, a person is evaluating a stressor and assigns credit to either self, chance, others or God, which also provides as an approach to understanding the meaning or purpose behind a particular stressor. Spiritual causal attributions, as they have been described by Gall et al. (2005), have been linked to religious coping activities such as positive re-framing and adjustment to negative life events. At the level of primary appraisal Gall et al. (2005) assert that events are viewed as being due to God's will, punishment, and anger in general. When the level of secondary appraisal is reached, people begin to evaluate the availability of coping. Person factors are at the core of this model and drive spiritual appraisals, and more specifically coping and selection of resources.

Religion and spirituality have many benefits which aide in the coping process. Countless studies have consistently demonstrated that religious beliefs and practices are related to greater life satisfaction, happiness, positive affect, morale, and other indicators of well being (Koenig et. al., 2001). Strong positive associations have been found between religiousness and greater hope or optimism about the future. It appears that where there is a belief in the miraculous or supernatural,

there is hope. Other findings suggest that having a greater sense of purpose, meaning, and coherence in life provides a powerful boost for hope and optimism. It is for this reason that the religious person lives in a world that has purpose and meaning (Koenig et al., 2001).

Many people believe in a purposeful creator who has a will for humanity. This often includes a belief that each person plays a vital and important part in the divine plan, which further strengthens people's sense of purpose (Koenig et al., 2001). Statistics show a significant association between greater religious involvement and a greater sense of purpose or meaning in life. Studies demonstrate that those who are more religiously involved have greater self-esteem (Koenig et al., 2001). Research also suggests that religious beliefs and teachings, by discouraging both excessive pride and self-condemnation, may foster a healthier view of the self that is more in line with reality (Koenig et al., 2001). The need to help and support others is encouraged by virtually every one of the world's major religions. Religious beliefs and practices, particularly when they include active participation in religious communities, can help relieve loneliness and counteract isolation (Koenig et al., 2001). Rates for depression, anxiety and other psychological symptoms are lower amongst people who identify themselves as religious. Also not surprising is the finding that greater marital stability and happiness has been found to exist among people who identify themselves as religious (Koenig et al., 2001). These findings lend support to the strong role that spirituality plays in the coping process.

Understanding why people may choose to use religion and or spirituality to cope over other resources is important for the purposes of this study. The main reasoning behind why people chose to cope religiously is due to the fact that religion is relatively available and accessible to them (Pargament, 1997). In addition, religion offers a more compelling route to significance than nonreligious alternatives. People typically rely on religious coping in boundary conditions and

when the limits of human resources are apparent. For those who are aware of their own limitations and seek to connect with something beyond themselves, religion and spirituality can offer solace (Pargament, 1997). Religious support or coping mechanisms come from many sources. Some people seek support from the divine directly. The divine refers to instances where people report having experienced a divine visit, or the sense of a spiritual presence (Pargament, 1997). Such an experience is able to offer comfort and reassurance in many difficult and tragic situations. Another example of religious support can be found in the form of religious literature (Pargament, 1997). For many people who are experiencing stress or difficulty with coping, images of a loving, supportive God, hymnals, devotional literature and scripture can be very comforting. Interestingly enough, the bible has even been described as a “Book of Comfort” (Pargament, 1997).

Religious practice has been found to bring meaning, solace, and strength during difficult times and friendship and support through different religious communities and organizations (Poston & Turnbull, 2004). Therefore it is apparent that religious support can also come in the form of interpersonal relationships. With most religious traditions or faiths, followers are asked to express their faith not only in relationship to the divine, but in relationship to others as well. As such, interpersonal support has two distinct functions in that, it is sought and it is offered. What is meant by this is that many people turn to their religious communities for help while experiencing stress, but that there are also those who respond to stress by devoting themselves to others (Pargament, 1997). Religious support is offered both by individuals and groups. When the concept of congregation is considered, the idea of people coming together to minister to the needs of others is an image that presents itself. The idea of ministry is important because it refers to the notion of service from a spiritual perspective, in that providing service is a way of sharing God’s presence with someone in distress (Pargament, 1997). Clergy and congregation members, not

unlike family, play a special role as they offer the possibility of sustained contact throughout the lifespan. As such, congregation members are accompanied by a convoy of friends and acquaintances who share a history of experience and concern for one another and will therefore be there to support one another in times of need (Pargament, 1997).

In regards to the influence of personal religious values on the process of coping with stress, there are two distinct ways in which religious values have been found to help reduce stress. Firstly, religious values give the impression of helping people change their perception of the world. It appears that having a strong, deeply-rooted system of religious beliefs is able to change people's overall sensitivity to a stressful situation or life circumstance. As such, people are more easily able to escape some of the threat and fear that such situations would otherwise evoke, and also find a deeper meaning for their circumstance (Grzymala-Moszczyńska, & Beti-Hallahmi, 1996).

Religion also appears to have superficial influence in regards to helping people cope with stress as it provides behaviours which help people to cope with their negative emotions. Some of these behaviours include prayer, reading the bible and attendance of religious services. It also seems that people who possess internalized religious values appeal more readily to religion as a helpful means of coping with stress and that the more intense these religious values, and the greater the stress experienced, the more they will rely on religion as a resource (Shumaker, 1992).

In an investigation of the relationship between religious rituals and mental health, it has been found that cross-culturally, religious ceremonies play a significant role in reducing anxiety and isolation as emotions are acknowledged, expressed, and resolved within a social milieu of attachment and connection to significant others (Shumaker, 1992). In this process, the relationship between the release of feeling and the interactive social relations is emphasized. This process is

quite apparent in the rituals of mourning, confession and confrontation. It is for this reason that there are obvious psychological benefits to religious ritual (Shumaker, 1992).

There are certain aspects of organized religion that have also been identified as providing hope and strength for parents raising children with disabilities. Prayer, church attendance and specific religious beliefs were all found to be sources of support (Bennett et al., 1995). However, additional research which investigated organized religion and personal beliefs as resources and coping strategies for parents of children with autism, found that parents received significantly less support from their organized religion, than they did from their personal beliefs, particularly through the use of prayer (Coulthard & Fitzgerald, 1999). In addition, the sense of grounding in faith that religious tradition provides is shaken when impacted by the all-encompassing reality of having a child with a disability, especially in church communities that are not accepting, or who preach in judgment (Speraw, 2006). In one study involving the Evangelical Christian church, participants even spoke out, suggesting that increased assistance should be provided by the church in promoting theological understanding of disability and religious support (Treloar, 2002).

Nevertheless, those who regard religion as a positive coping strategy, in general have been found to show greater stress-related growth (Tarakeshwar & Pargament, 2001). Furthermore, emotion-focused coping strategies, such as religion, are some of the more common strategies used by parents coping with having a child with a developmental disability (Gray, 2006).

Individual studies have also been conducted on the coping skills of both mothers and fathers. In a study which examined maternal acceptance of mentally retarded children, it was found that there was a positive relationship between maternal acceptance and religious background, particularly in regards to Catholic mothers, who tended to be more acceptant of their mentally retarded children than non-Catholic mothers (Zuk et al., 1961). Beyond the role that religiosity or

spirituality plays in promoting coping, another factor that has been identified as contributing to maternal stress is having a higher sense of coherence (Oelofsen & Richardson, 2006). A literature review examining the demographics associated with the amount of stress experienced by mothers raising children with disabilities found that the number of parents in the home was the main predictor of mother's stress levels, with single mothers experiencing more stress (Byrne & Cunningham, 1984). In most studies, the severity and nature of a child's intellectual impairments, as opposed to physical impairments or behaviour problems, were found to be unrelated to reported levels of stress. However, research suggests that mothers of children whose developmental IQ is less than 65 and children with Down syndrome have significantly higher levels of stress than mothers of non-handicapped children, whereas mothers of children whose developmental IQ was greater than 65 did not differ from the control group (Byrne & Cunningham, 1984).

Religion has also been found to act as a resource for fathers coping with their special needs children, as a father's experience revolves around his religious beliefs and practices and his relational resources (Olson et al., 2002). In a study which explored predictors of symptoms of depression in parents of children with a disability, mothers with younger children, and fathers with male children seemed to be at a higher risk for depression (Trute, 1995).

Additional research has found that religious parents tend to be somewhat more familistic than do nonreligious parents and that these parents are also more inclined to emphasize parental nurturance and are less likely to view their DD child as a burden (Weisner, Beizer & Stolze, 1991).

Parents who are motivated by intrinsic religious beliefs are more likely to show higher levels of happiness (Biesinger & Arikawa, 2007); and as well, families who have hope, are more easily able to re-frame their lives in view of their experience of having a child with a DD (Kausar, Jevne & Sobesky, 2003). One study which explored the nature of meaning, including benefit

finding and sense making, in parents of children with Asperger's syndrome, found that meaning was positively related to the adaptive coping process of social support, self-efficacy and problem-focused emotional approach coping strategies (Pakenham, Sofronoff & Samios, 2004). There has been a considerable amount of research conducted in regards to the relationship between meaning in life and psychological well-being. Results from these studies demonstrate that there is indeed a clear link between people's search for and attainment of meaning and their emotional health.

In a study examining the religiosity of parents of children with DD, it was found that some parents, who are considerably religious, view their circumstance as a mission from God and an opportunity rather than a burden (Haworth, Hill & Gildden, 1996). When religion is involved in the reconstruction of traumatic events, this process is usually referred to as religious reframing. In this process of reframing, suffering can become something that is explainable, bearable and even valuable. In this way, it is designed to conserve significance, to soften the blows of crisis, to reaffirm that life has meaning in spite of its pain.

When a parent is given news that their child has just been diagnosed with a DD, their entire world is flipped upside down and all their hopes and aspirations for their child and their life with their child are snuffed out in that instant. As such, a way in which some parents and families chose to cope with this devastating news is by finding a new set of priorities or goals to pursue. The search is one for a new sense of purpose and it is in situations like these that some people look to religion for help. Underlying the search for religious purpose is the belief that life has an ultimate goal and what gives the search its religious quality is the belief that purpose is transcendental in nature and that it goes beyond whatever the individual may make of it on his or her own.

According to most religious perspectives, each of us has a reason for being; no matter how terrible our situation may be, every person is said to have a special mission or calling in life. The mission

is not constructed by the person; it is constructed for the individual. When older purposes are no longer viable, the individual does not have to create a new reason for living, rather the work is in finding the meaning in the new opportunity or situation. When successful, the search for a religious purpose places the individual's life into a different context.

Based on the evidence provided, it is clear that religion and or spirituality are incredibly useful coping mechanisms. That being said, there is also evidence to suggest that spirituality and or religiosity are more predictive of effective coping than other psychosocial factors. A particular study which examined religious coping as a predictor of psychological well-being, when controlling for all other psychosocial variables, found that religious coping was significantly predictive of good mental health (Pargament et al., 2004). In a study examining spirituality as a coping mechanism for adult survivors of childhood sexual abuse, results suggest that spiritual coping predicted the current distress of adult sexual abuse survivors beyond the contribution of other variables (Gall, 2006). Additionally, a study investigating the role that spirituality played in sustaining psychological well-being in a group of HIV positive, African American women, found that spirituality accounted for a significant amount of the variance in reducing depressive symptoms in the HIV positive women, above and beyond other theoretically important psychosocial variables.

It is evident that spirituality and religiosity are powerful coping mechanisms for everything from cancer to sexual abuse, to death and bereavement. The little research that exists in regards to linking spiritual and religious coping to families raising children with developmental disabilities, has either examined religion or spirituality independently from other factors, or has left religion and spirituality out of the model all together.

It was therefore the purpose of the present study to investigate the influence that spirituality and religiosity had on the family's ability to cope with raising prepubescent children with developmental disabilities.

### Research Questions

The questions that will be addressed in this paper are as follows:

1. Will spiritual well-being, religious well-being and existential well-being as measured by the Holistic Spirituality Model predict better familial coping beyond the contribution of other demographic and psychosocial factors?
2. Will other previously significant psychosocial variables including professional, social, familial and informal support become less predictive of familial ability to cope with the addition of spirituality and religiosity to the model?
3. Will the existential well-being subscale, spiritual well-being subscale and the religious well-being subscale of the Holistic Spirituality Model individually correlate with better scores on the Questionnaire on Resources and Stress which measures the family's ability to cope with raising a child with a developmental disability.

### Research Hypothesis

To address these questions the following hypotheses were formed.

1. Spiritual well-being, religious well-being and existential well-being as measured by the Holistic Spirituality Model will predict better familial coping beyond the contribution of other demographic and psychosocial factors.
2. With the addition of religiosity and spirituality to the model professional, social, familial and informal support variables will become less predictive of familial ability to cope.

3. The existential well-being, religious well-being and spiritual well-being subscales of the Holistic Spirituality Model will correlate with better scores on the Questionnaire on Resources and Stress which measures the family's ability to cope with raising a child with a developmental disability.

## CHAPTER TWO

### METHOD

#### Participants

Participants consisted of 30 families from the Ottawa area who have one or more children between the ages of 3 and 12 years old, diagnosed with a DD. A sample of convenience was obtained as families volunteered to participate based on the distribution of questionnaires at various locations.

All of the families who participated had one child with a DD, with the exception of one family who had two children with a DD. The mean age of the child with the DD was 7.3 years old ( $SD=3.26$ ). The mean number of children in each family was 2.67 ( $SD=0.83$ ). Most parents classified their children as functioning at a medium developmental level ( $SD=0.75$ ). Participants were also asked if they identified with any particular cultural background, however no statistics are reported for this category as very few participants responded. For further details on participant demographics including; marital and economic status, as well faith group identification and prevalence of specific DD see Table 1 below.

*Table 1. Participant Characteristics*

<i>Marital Status</i>	<i>Percentage</i>	
Married	66.7%	
Divorced/Separated	26.7%	
Single	3.3%	
Not Specified	3.3%	

<i>Income Level</i>	<i>Percentage</i>	
0 – 20, 000	0%	
21, 000 – 40, 000	13.3%	
41, 000 – 60, 000	20.0%	
61, 000 – 80,000	13.3%	
80,000+	53.3%	

<i>Membership to Faith Group</i>	<i>Percentage</i>	
Christian (Catholic, Protestant, Evangelical)	46.7%	
Muslim	3.3%	
None	40.0%	
Unspecified	6.7%	

<i>Attendance of Faith Group Services</i>	<i>Percentage</i>	
Regularly	26.7%	
Occasionally	20.0%	
Not at all	53.0%	

<i>Type of Disability</i>	<i>Frequency</i>	<i>Percentage</i>
Learning Disability	1	3.3%
Autism Spectrum Disorder(Asperger’s)	20	66.7%
Attention Deficit Hyperactivity Disorder	3	10.0%
Sensory Processing Disorder	1	3.3%
Down Syndrome	4	13.3%
Genetic Disorder	1	3.3%

## Measures

### *Child and Parent Characteristics Questionnaire*

Information concerning the child's characteristics was requested. These characteristics included the child's gender, age, disability type and level of functioning. Information on parental characteristics such as marital status, gender, number of children economic status, affiliation with a specific faith group and attendance of faith group services and identification with specific cultural background was also requested.

### *The Holistic Spirituality Model (HSM) (Rovers & Kocum, 2010)*

This 27 question questionnaire assessed spirituality in general and has three sub-scales which measured religious well-being, existential well-being and communal well-being. Ratings were made using a five-point Likert-type scale, ranging from 'strongly agree' (SA) to 'strongly disagree' (SD). This model acknowledges the use of the Spiritual Well-Being Scale (Ellison, 1983). This model has been found to have good internal consistency concurrent validity.

### *Questionnaire on Resources and Stress - Short Form (QRS-SF) (Friedrich, Greenberg & Crnic, 1983)*

Familial ability to cope was assessed using the QRS-SF. The QRS-SF is a 52 item self-report questionnaire, specifically designed to measure stress in families of children with disabilities. (Friedrich et al., 1983) report a KR-20 reliability coefficient for the QRS-SF of .95. The items on this short-form version of the questionnaire were selected from the original longer version of the QRS to create an assessment that concentrated on the issues that concern families of children with disabilities (Friedrich et al., 1983). Respondents are asked to judge whether the 52 items are true or false. Blanks in the items are to be filled in with the child's name. The items are divided into

four scales which include the parent and family problem scale, the pessimism scale, the child characteristics scale and the physical incapacitation scale.

*The Family Support Scale (FSS) (Dunst, Jenkins & Trivette, 1984)*

The FSS measures the helpfulness of sources of support to families raising young children. The scale includes 18 items and 2 self-responder-initiated items that are rated on a five-point Likert-type scale, ranging from 'not helpful at all' (1) to 'extremely helpful' (5). The items are divided in five subscales which include kinship, spouse/partner support, social organizations, informal Support and professional services. (Dunst et al., 1984) report a split-half reliability coefficient of .77, using the Spearman-Brown formula. Correlations with the QRS demonstrate the concurrent predictive validity of the FSS.

*The Coping Health Inventory for Parents (CHIP) (McCubbin, McCubbin, Patterson & Cauble, 1983)*

This questionnaire was designed to assess parental coping styles and perceptions of the helpfulness of certain strategies. The scale used a four-point Likert-type scale, ranging from 'not helpful' (0) to 'extremely helpful' (3). Forty-five items are divided into three sub-scales which include; family (maintaining family integration, co-operation and optimistic definition of the situation), social(maintaining social support, self-esteem and psychological stability), and medical (understanding the medical situation through communication with other parents and professionals). The CHIP has been found to have good internal consistency with an alpha of .79 for the first two factors and .71 for the third factor. It also has fair concurrent validity with several correlations with the Family Environment Scales (McCubbin and Thompson, 1991).

*The Parental Locus of Control Scale (PLOC) (Campis, Lyman & Prentice-Dunn, 1986)*

This questionnaire assessed parental perceptions of a stressor, by measuring internal or external locus of control across 47 items (making up five sub-scales; parental efficacy, parental responsibility, child control of parent's life, parental beliefs in fate/chance, and parental control of child's behaviour). Higher scores indicated a greater external locus of control. The PLOC has good to excellent internal consistency, with an alpha for the total scale of .92 and subscale alphas that range from .65 to .77. Construct validity is also strong with a majority of correlations in predicted directions with General Self-Efficacy, PSI Sense of Competence, GPPI Responsibility, MCRE Overindulgence, PSI Child Demandingness, PSI and Restriction of Role.

Design and Procedure

The present study sought to replicate a previous study carried out by Jones and Passey, (2004), whereby family adaptation and coping resources in reference to children with DD were examined. Although the Jones and Passey study was quite thorough in its exploration of contributing factors, including child and parent characteristics, parental stress, family stress and resources, coping strategies and locus of control, it did not take into consideration religion and or spirituality of the family. Therefore even though results suggested that the strongest predictors of parental stress were family coping style and parental locus of control, it is the belief of this researcher that results in the scores on the other measures would differ with the addition of spirituality and religiosity to the model. It was therefore hypothesised that with the addition of the Holistic Spirituality Model developed by Rovers & Kocum (2010), religious, existential and communal well-being would become the strongest predictors of familial ability to cope with raising a child with a developmental DD.

As this study sought to partially replicate the one carried out by Jones and Passey(2004), some of the same measures were used, with the addition of the Holistic Spirituality Model proposed by Rovers and Kocum (2010). The Family Stress and Support Questionnaire (Minnes and Nachshen, 1997) which was administered in interview format in the original study was not used in this study due to time constraints and because it is believed that family support and stress are addressed in the other inventories that were administered.

Questionnaires were distributed to participants both electronically and in paper form, at various conferences, seminars, and community organizations. Due to the nature and complexity of the questionnaire, the parents or primary care-takers of the family were asked to respond on behalf of the family unit. In two-parent households, the questionnaire was completed collaboratively by both parents and in single-parent households, the sole parent responded.

The rationale for having both parents and or care-takers complete the questionnaire together was based on the logic that the participant was the family unit and that those who were responding to the questionnaire were responding as a family unit.

### Ethics

This research study was designed to safeguard the confidentiality and informed consent of its participants. Precautions were taken to ensure that there was no harm done to the participants. Prior to conducting this study, approval was received from the Ethics Committee of Saint Paul University. All participants were informed of the voluntary nature of their involvement and were free to withdraw at any time.

## CHAPTER THREE

### RESULTS

The means and standard deviations for all predictor variables and QRS-SF subscales were calculated. A bivariate correlation was carried out for all 16 predictor variables with the QRS-SF total. Subsequently a correlation matrix including all variables was conducted in order to determine the level of intercorrelations among variables. A hierarchical regression analysis was carried out, as well as an additional bivariate correlation between the QRS total and demographic variables.

*Table 2. Means and standard deviations of the predictor variables*

<i>Predictor</i>	<i>M</i>	<i>SD</i>
PLOC parental efficacy	30.1 (23-38)	4.7
PLOC parental responsibility	30.0 (15-41)	6.6
PLOC child's control of parents life	24.4 (19-28)	2.9
PLOC Parental belief in fate/chance	39.9 (30-60)	6.2
PLOC parental control of child's behaviour	30.8 (23-44)	5.4
FSQ kinship	1.8 (0-2.5)	1.0
FSQ spouse/partner support	2.2 (0-3.7)	0.8
FSQ informal support	1.6 (0.2-2.8)	0.8
FSQ program/organization support	1.7 (0.5-4.8)	0.9
FSQ professional support	2.2 (0-3.67)	1.0
HSM religious well-being	40.6 (19-55)	9.8
HSM existential well-being	42.6 (28-60)	7.5
HSM communal well-being	25.3 (14-37)	5.8
CHIP family coping style	32.9 (21-49)	9.1
CHIP support coping style	29.6 (18-44)	8.9
CHIP medical coping style	12.4 (8-17)	3.5

*\*Note bracketed numbers indicate the range of scores from minimum to maximum for each sub-scale.*

The means and standard deviations for all predictor variables and QRS-SF subscales can be found in Tables 2 and 3 respectively.

*Table 3. Means and standard deviations of the QRS-SF subscales & QRS-SF Total*

<i>Subscale</i>	<i>M</i>	<i>SD</i>
The parent and family problem scale	11.3	1.9
The pessimism scale	7.0	2.8
The child characteristics scale	7.6	1.5
The physical incapacitation scale	5.1	0.8
QRS Total	31.0	4.2
QRS Total (Jones & Passey)	33.1	6.9

*\*Note QRS Total means and standard deviations from the Jones and Passey study were included in this table for comparison purposes. The means and standard deviations from the corresponding QRS subscales could not be compared as the authors who were unavailable for contact had created their own additional subscales that could not be directly compared to the present sub-scales.*

In the initial bivariate correlation there were a total of 11 out of 16 predictor variables found to have a significant relationship to familial stress as measured by the QRS-SF. The Pearson's product moment correlation was used to examine the bivariate relationships. A summary of these correlations can be found in Table 4.

*Table 4. Bivariate correlations of predictors with QRS-SF Total*

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<i>Predictor</i>	<i>r</i>
PLOC parent efficacy	-.077
PLOC parent responsibility	-.061
PLOC child's control of parent's life	-.612***
PLOC parental belief in fate/chance	-.252
PLOC parental control of child's behaviour	-.584***
FSQ kinship	-.505**
FSQ spouse/partner support	-.354
FSQ informal support	-.728***
FSQ program/organization support	-.566**
FSQ professional support	-.565**
HSM religious	-.174
HSM existential well-being	-.536**
HSM communal well-being	-.105
CHIP family coping style	-.485**
CHIP support coping style	-.491**
CHIP medical coping style	-.339

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\*  $p < .05$ , \*\*  $p < .01$ , \*\*\*  $p < .001$

In the correlation matrix (Table 5) there were a number of variables which were significantly correlated with the existential subscale (informal control, pessimism, child control, kinship and perceived helpfulness of support). These correlations will be discussed in greater detail in the discussion section.

Table 5. Correlation Matrix for all Questionnaire Variables

	Paren Effic.	Paren Resp	Child Contr	Fate Belf	Parent Control	Kinsh	Spou. Supp.	Inform Sup.	Progs	Prof. Serv	Relig W.B.	Exis W.B.	Com WB	Fam. Integr.	Soc. Sup.	Med Sit.	PFPS	Pessim.	Child Char.	Incap	QRS Total
Paren Effic.	1.000	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—
Paren Resp	.0715 .937	1.000	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—
Child Contr	.143 .450	-.308 .098	1.000	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—
Fate Belf	-.103 .588	-.045 .813	-.320 .085	1.000	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—
Parent Control	-.135 .475	-.239 .203	.442* .015	.290 .121	1.000	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—
Kinsh	.179 .344	.063 .741	.233 .216	.226 .230	.269 .150	1.000	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—
Spou. Supp.	.411* .024	.127 .502	.117 .536	.312 .093	.118 .535	.186 .326	1.000	—	—	—	—	—	—	—	—	—	—	—	—	—	—
Infor Sup.	.099 .604	.146 .440	.412* .023	.198 .294	.247 .189	.620** .000	.221 .240	1.000	—	—	—	—	—	—	—	—	—	—	—	—	—
Progs.	-.041 .829	-.290 .120	.427* .019	-.031 .871	.271 .148	.534** .002	-.094 .621	.582** .001	1.000	—	—	—	—	—	—	—	—	—	—	—	—
Prof. Service	.231 .259	.001 .995	.382* .037	.055 .774	.337 .068	.586** .001	.369* .045	.304 .103	.415* .023	1.000	—	—	—	—	—	—	—	—	—	—	—
Relig W.B.	.303 .103	-.148 .437	.166 .382	.010 .960	-.147 .438	.130 .493	.298 .110	.275 .141	.187 .323	.214 .257	1.000	—	—	—	—	—	—	—	—	—	—
Exist W.B.	.321 .084	.034 .858	.522** .033	.134 .481	.277 .138	.446** .013	.344 .063	.613** .000	.267 .153	.263 .161	.273 .144	1.000	—	—	—	—	—	—	—	—	—
Comm WB	.035 .855	-.070 .714	.302 .104	-.289 .122	-.249 .185	-.024 .901	.120 .529	.193 .306	.181 .339	.158 .403	.707** .000	.233 .216	1.000	—	—	—	—	—	—	—	—
Fam. Integr.	.334 .071	.126 .508	.047 .805	.202 .285	.109 .566	.677** .000	.416** .022	.502** .005	.430* .018	.433 .017	.042 .827	.256 .172	-.140 .460	1.000	—	—	—	—	—	—	—
Soc. Sup.	.316 .089	.258 .168	.091 .631	.005 .979	-.014 .943	.519** .003	.469** .009	.486 .009	.423 .020	.422 .020	.234 .213	.218 .247	.064 .738	.907** .000	1.000	—	—	—	—	—	—
Med. Sit.	.226 .230	.118 .536	-.038 .840	.064 .737	.054 .775	.602** .000	.357 .053	.243 .195	.349 .059	.413** .023	.132 .486	.101 .594	.010 .959	.884** .000	.873** .000	1.000	—	—	—	—	—
PFPS	-.086 .651	-.234 .213	-.138 .467	-.164 .387	-.369* .030	-.437* .016	-.188 .319	-.591** .001	.463* .010	-.368* .046	.226 .230	-.370* .044	.252 .180	-.600** .000	-.530** .003	-.428* .018	1.000	—	—	—	—
Pessi.	-.176 .353	.069 .717	.608** .000	-.120 .529	.466** .009	-.380 .038	-.418* .021	-.621** .000	-.339 .067	-.508** .004	-.333 .072	-.464** .010	-.307 .098	-.396* .030	-.432* .017	-.313 .092	.416* .022	1.000	—	—	—
Child Char.	.079 .677	.045 .815	-.418 .022	-.148 .434	-.264 .159	-.075 .693	.048 .800	-.230 .221	-.350 .058	-.069 .717	.004 .983	-.250 .182	.094 .620	.001 .997	-.046 .811	.100 .601	-.008 .966	.218 .248	1.000	—	—
Incap.	.234 .214	.358 .052	-.063 .742	-.280 .134	-.115 .546	-.258 .169	-.116 .540	.027 .889	-.137 .472	-.272 .147	-.307 .099	.053 .782	-.254 .76	.134 .479	.150 .428	.045 .812	-.353 .056	-.186 .324	.119 .530	1.000	—
QRS Total	-.077 .685	-.061 .749	-.612** .000	-.252 .178	-.584** .001	-.505** .004	-.354 .055	-.728** .000	-.566** .001	-.559** .001	-.174 .358	.536** .002	-.105 .538	-.485** .007	-.491** .006	-.339 .067	.624** .000	.864** .000	.519** .003	-.040 .834	1.000

\*  $p < .05$ , \*\*  $p < .01$ , \*\*\*  $p < .001$

As the primary purpose of the current study was to investigate whether or not spirituality and religion as measured by the HSM were stronger predictors beyond the contribution of other relevant demographic and psychosocial factors, a hierarchical regression analysis was performed. Variables were blocked by questionnaire, meaning that each questionnaire was entered into the model one at a time. The rationale behind the selection of this model was that each of the questionnaires were theoretically measuring different constructs (spirituality, social, professional & familial support, coping styles, perception and locus of control). Two of the demographic variables from the Child and Parent Characteristics Questionnaire (child age and developmental disability level) were entered as controls as these variables were most consistently responded to by participants. Subsequently one questionnaire at a time was entered (PLOC, CHIP, FSS, & HSM) in that order. A summary of this regression can be found in Table 6. From this analysis it is evident that the HSM did not add anything on top of the other measures,  $R^2 = .688$ ,  $F(1,23) = 0.125$ ,  $p = .726$ .

Table 6. Hierarchical Regression blocking variables by questionnaire (controlling for child age and developmental disability)

<i>Variables Entered</i>	<i>R</i>	<i>R2</i>	<i>Adjusted R2</i>	<i>R2 Change</i>	<i>Sig. F Change</i>
<i>First set of variables entered</i> (Constant) Child Age and Developmental Disability	.26	.07	.001	.07	.378
<i>Second set of variables entered</i> (Constant) Child Age and Developmental Disability PLOC	.68	.46	.402	.40	.000
<i>Third set of variables entered</i> (Constant) Child Age and Developmental Disability PLOC CHIP	.75	.56	.492	.10	.026
<i>Fourth set of variables entered</i> (Constant) Child Age and Developmental Disability PLOC CHIP FSS	.83	.69	.621	.12	.005
<i>FIFTH set of variables entered</i> (Constant) Child Age and Developmental Disability PLOC CHIP FSS HSM	.83	.69	.607	.00	.726

A further bivariate correlation was run between the QRS total and demographic variables to insure that these variables would not alter any statistical tests that had been done. There were no significant correlations found, suggesting that these variables did not significantly alter any of the other statistical tests that were conducted (See Table 7).

Table 7. Correlation Matrix for Demographic Variables

	QRSTotal	Income	FaithGroup	ChildAge	DDLevel
QRSTotal	1				
Income	-.202 .283	1			
FaithGroup	.237 .207	-.202 .284	1		
ChildAge	.263 .160	-.069 .719	-.129 .496	1	
DDLevel	.032 .866	.162 .393	-.121 .523	.064 .783	1

\*  $p < .05$ , \*\*  $p < .01$ , \*\*\*  $p < .001$

## CHAPTER FOUR

## DISCUSSION

It was the purpose of this study to investigate the influence that spirituality and religiosity, as measured by the HSM had on the family's ability to cope with raising prepubescent children with developmental disabilities. As such, it was hypothesized that the existential well-being, spiritual well-being and religious well-being subscales of the HSM would predict better familial coping beyond the contribution of other demographic and psychosocial factors. It was also hypothesized that with the addition of religiosity and spirituality to the model, other previously significant psychosocial variables would become less predictive of familial ability to cope. Furthermore, it was predicted that all individual subscales of the Holistic Spirituality Model would correlate with better scores on the Questionnaire on Resources and Stress which measured the family's ability to cope with raising a child with a developmental disability.

Despite the relevant literature in support of this topic and the participant response of 57% indicating identification with some kind of faith group, results from this study do not support the stated hypotheses. More specifically, results indicate that spiritual well-being does not predict better familial coping beyond the contribution of all other variables. Results also suggest that adding religion and spirituality to the model does not alter the significance of professional, social, familial and informal support. These findings are congruent with those found in a study on family caregivers coping with the stress of caring for persons with traumatic brain injuries, where spiritual well-being was secondary to such coping mechanisms as positive reframing and mobilizing and passive appraisal (Minnes et. al, 2000). Despite the lack of support for the first two hypotheses, the third hypothesis was partially correct in that while the spiritual and religious well-

being subscales showed no correlation with the Questionnaire on Resources and Stress, the existential well-being subscale did produce as positive correlation. These findings will be discussed in greater detail following a comparison of the Jones and Passey (2004) paper.

In their research Jones and Passey (2004) found coping styles and locus of control to be the two strongest predictors, accounting for multiple areas of stress in the lives of families raising children with DD. They also found that coping strategies involving family integration, cooperation and optimism, were strongly related to a reduction in stress. They reported that parents who felt they were able to maintain control over their DD child tended to have lower levels of stress. Social support was not surprisingly also highly correlated with a reduced level of stress. Jones and Passey (2004) did not address any aspect of spirituality and religion in their study.

The preliminary bivariate correlations of the subscales of each questionnaire with the QRS total in the present study were quite similar to those found in the study by Jones and Passey (2004). Child control of parent's life and parent control of child's behaviour (both subscales of the PLOC) were similarly correlated to the QRS total for both studies, with the only difference being a negative correlation in the present study for child control of parent's life and a positive correlation in the latter study. As well, family coping style and support coping style (both subscales of the CHIP) were similarly negatively correlated with the QRS total.

Despite the similarities between the two studies some differences were found. Where the latter study found parental efficacy to be significant, the present study did not. Despite using the same inventory as the original paper, the correlations for the FSQ

subscales can not be directly compared as Jones and Passey (2004) represented their subscales differently than the professional scoring instructions directed. The authors of the study were not available for contact. Nevertheless the present study did find kinship, partner/spouse support, informal support, program support (all subscales of the FSQ) to be correlated to the QRS total.

While the previous study did not utilize the HSM inventory, the present study found the existential well-being subscale of the HSM to be positively correlated with the QRS total. This correlation may suggest that the existential well-being subscale contributes towards reducing stress in families of children with DD. As existential well-being is founded on the basis of hope and meaning (Rovers and Kocum , 2010), perhaps these findings suggest that existential well-being could be viewed as a resiliency factor which helps families to make meaning of their predicament and perhaps find some glimmer of hope for their child's betterment

In order to address the first two hypotheses, a hierarchical regression was conducted. While results from this analysis produced no support for either hypothesis, the researcher referred to the correlation matrix to consider if issues of multicollinearity could be responsible for masking or altering the effects of the HSM subscales.

There are some interesting observations that can be made from examining the correlation matrix (Table 5). From this matrix we see that two of the subscales of the HSM (communal and religious well-being) are not significantly correlated to any of the other subscales being measured. However, of particular interest is the significant correlation between the existential well-being subscale of the HSM and the informal support subscale of the FSS. In interpreting these findings, it appears probable that this

relationship is reflective of two variables that are measuring the same thing. This is not to say that both variables are measuring identical things, but that perhaps aspects of existential well-being may be measured within the context of the informal support subscale. This brings into question the issue of multicollinearity, suggesting that perhaps informal support has in some way masked the effect of the existential well-being subscale. If this was indeed the case, it is plausible that the regression analysis may have kept existential well-being in the model, had there been no influence from informal support. In fact, in another study which made use of the HSM, the existential well-being subscale was found to be the only significant subscale for front line shelter workers dealing with stressful situations (McDonald, 2005).

In theorizing how or why two different subscales from two distinct questionnaires could potentially be measuring the same thing, it is useful to have a definitional understanding of both measures. Existential spirituality as described by Rovers and Kocum (2010) is related to the meaning people find in life and their ability to make meaning, or rather, to have hope. Highfield & Cason (1983) suggest that meaning is made in the connections that people make with the transcendent or in the relationships that are had with others. McCurdy (1998) supports this finding, defining spirituality as people's need or ability to engage in relationship to whomever or whatever provides meaning, purpose and direction. In this study, participants found existential spirituality, associated with meaning and hope to be a significant contributor to their ability to cope with the stress of having a child with a DD. Having a sense of hope or finding meaning in the reality of their lives supported and enhanced parent's ability to cope.

At a previous point in this paper, a model of stress for families of children with DD (Perry, 2004) was put forth in order to better conceptualize the variables involved in the coping process. Perry identified a number of resources and supports that ultimately influence the outcome of the family. One such resource as described in her model is informal social support, which is actually directly measured in the current study. Informal support, according to Perry, concerns people's ability to connect emotionally and to receive support from various sources such as extended family, neighbours, friends, social communities and religious organizations. Of significance however, are the comparable themes which are evident in both the definition of existential well-being and informal support; themes of connectedness, meaning and hope. If aspects of existential well-being can be found in informal support and vice versa than this would certainly have implications in regards to the future need for producing a validated instrument that would sufficiently measure both constructs.

In response to the suggestion of creating a coping model that would be inclusive to spiritual and religious components, a melding of both Gall's and Perry's model is proposed, as was suggested earlier in this paper. This combining of models is purely hypothetical in order to create a framework that would reflect the functional aspects of both models. It is suggested that the supports and resources outlined in Perry's model, could include features of Gall's spiritual and religious coping model. Furthermore, it is thought that if 'person factors' are responsible for the resources that people select as asserted by Gall et al. (2005), then perhaps these person factors are at work within the resources named in Perry's model. For example, Perry mentions beliefs under individual personal resources and these beliefs could include religious and or spiritual beliefs. In

regards to the family system, the family could be viewed as religiously or spiritually supportive, informal support could include spiritually or religiously significant relationships, as well as the support of a religious or spiritual community. Finally, professional support could also include such services as religious or spiritual counselling and support from some type of religious or spiritual leader. Therefore it is possible to see the usefulness and purpose of melding these two models together in order to have a better overall picture of the coping process that families of children with DD must engage in.

In further examining the correlation matrix another interesting finding is the negative correlation between the existential well-being subscale from the HSM and the pessimism subscale from the QRS. Paradoxically the definition that Rovers and Kocum (2010) put forth in reference to an existential spirituality, is one in which a person constructs meaning, purpose and ultimately “hope”.

This relationship is supported by another study which examined spirituality as a component of culturally competent therapeutic intervention for African American women. In this study hopelessness, existential well-being, religious well-being and positive religious coping were all correlated with one another. Additionally, lower levels of hopelessness predicted an increase in existential well-being over time. (Arnette et. al, 2007).

Other variables found to be correlated with the existential well-being subscale include child control, kinship and perceived helpfulness of support. Issues of multiculturalism may come into play with all of these variables in relationship to the existential wellbeing subscale.

#### Implications for Future Research

The results from the present study point to a need for further exploration around all constructs correlated with existential well-being. While our society has become less comfortable identifying or relating to experiences that have traditionally been associated with more rigid definitions of religion, they have certainly turned more to libertarian forms of spirituality. Spirituality in a broad sense may be more easily accessible or measured through other previously existing constructs. It is in fact conceivable that a number of other constructs other than informal support could have been evaluating any or all subscales of the HSM. Further research should explore the relationships between such pre-existing predictor variables and all constructs of the HSM model. While this study relied on the conceptual model of stress for families of children with DD, developed by Perry (2004), it is felt that a more compressive model which directly speaks to the spiritual coping of families of children with DD could be developed. Construction of such an instrument could include aspects of Gall's spiritual coping model as discussed earlier in this paper. The present study did not examine gender differences expected with spirituality or differences in parental perception in terms of family coping due to the nature of the collective response required on behalf of the family unit. That being said, these are thought to be relevant and useful research questions for further investigation.

### Limitations

There were a number of limitations to the present study. First, the low sample size and large number of analyses conducted poses the risk of a potential type 1 error. Despite significant effort on the part of the primary researcher to garner participation from families of the local DD community, only 30 families ultimately agreed to participate. A number of reasons for this small sample size are hypothesized.

The particular developmental range of 3 to 12 years old was chosen based on a cohort of children who would be less susceptible to major physical and emotional changes that might occur at the onset of puberty, and ultimately bias family perceptions of the child with the DD. While this particular age range was indeed a safeguard against further variance due to child age, it was also quite restrictive. There were many families who had children that fell outside the specified age range that were interested in participating that could not participate due to this particular constraint.

In attempting to gather participants for this study another road block that was encountered was a requirement by many school boards, community organizations and hospitals to go through additional ethics reviews. Some of these reviews required a time-frame of several months, for which this study did not allow. It is thought that if there was a longer time-frame allowed for data to be collected, that there would be a greater number of participants acquired.

When asked to participate in the present study, many of those families who chose not to participate reported that they were already bombarded with a significant amount of paper work and that they constantly are asked to participate in studies surrounding their child's disability.

It is speculated that if potential participants had been offered more of an incentive for participation, there would have been greater success in acquiring participants. This study had no financial resources to provide any type of monetary or material compensation for participation, therefore the only incentive for participation was the potential for useful information to be learned from the study that might be applicable to policy makers and service providers alike.

The researcher felt it necessary to have two-parent or caregiver households fill-out the questionnaires collaboratively in order to represent the family unit rather than the perspective of just one person in the family, however in retrospect this may have caused a limitation to the study in regards to it not being a true assessment of internal control. It is possible that if mothers and fathers filled out the questionnaires independently that their responses may have been quite different. As well there may have been differences between responses coming from two parents or caregivers versus responses coming from one parent or caregiver. In the study conducted by Jones & Passey (2004), they simply say that they obtained a sample of 48 primary caregivers and that the families were a combination of 16 one parent households and 32 two parent households. However Jones and Passey do not specify whether they had caregivers fill-out the questionnaire collaborative or individually. Despite that in the present study, the researcher did ask two parent households to fill-out the questionnaire collaboratively, it is thought that participants, as they were not supervised may have filled-out the questionnaire individually.

A concern that surfaced following the distribution of the questionnaires is that the researcher identified herself as being a student of Saint Paul University. It is thought that, for those participants who were aware of Saint Paul University's strong spiritual and theological foundation, there might have been some responder biases around the religious and spiritual aspects of the study. That is to say that if the participants wanted to please the researcher they may have skewed their responses in favour of pro spiritual or religious responses.

### Conclusion

In conclusion, while the results of this study did not confirm the hypothesis that aspects of spiritual-wellbeing would predict better familial coping beyond the contribution of other demographic and psychosocial factors, nor that with the addition of religiosity and spirituality to the model, other previously significant psychosocial variables would become less predictive of familial ability to cope, there is still support for the usefulness of spirituality in the coping model. It is for this reason that policy makers, educators, service providers and families alike should tap into this resource that is often left untapped. Coping with raising a child with a DD is evidently a very stressful process and being aware of all the resources which exist certainly will help families to succeed in the challenges they are faced with.

In future, it is suggested that further research be conducted with respect to how existential coping resources can be used to help families struggling to raise children with developmental disabilities. If families are able to take some component of hope or meaning out of their struggles then perhaps it would make the difference needed to help them cope.

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## **Questionnaire on Coping of Families of Children with Developmental Disabilities**

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This research is being conducted to evaluate the coping mechanisms of families of children with developmental disabilities. Specifically, we are interested in identifying the coping mechanisms which are most effective in managing and alleviating some of the stressors associated with having a child with a developmental disability. This research has been approved by the Ethics Committee of Saint Paul University.

**YOUR ANSWERS ARE STRICTLY CONFIDENTIAL.** Only our research team, consisting of 2 graduate students from Saint Paul University and Carleton University and the research advisor will have access to this questionnaire. We therefore encourage you to be completely honest as this will give the most accurate results.

You are not obligated to complete this questionnaire. Please be advised that filling out this questionnaire implies consent to having your responses used anonymously in our research project. In the final report, no identifying information will be used.

We suggest that you set aside 40 minutes to complete this questionnaire in the next week. As the questionnaire requires you to express your personal and honest experience, we would request that you answer the questions as

accurately as possible and refrain from discussing the questionnaire with others until completed.

Sincerely,

**Martin Rovers Ph.D, Professor & Supervisor, Saint Paul University**

**Erin M. Shackell, Masters student, Saint Paul University**

**Michael Vandenberg, Masters student, Carleton University**

### **Participant Characteristics**

**What is your marital status? Please identify \_\_\_\_\_**

**What is your total household income in dollars?**

0 – 20,000     21,000 – \$40,000     41,000 – 60,000     61,000-80,000     80,000 +

**Do you have a particular cultural or ethnic background of which you identify with?**

Yes     No    **If yes, please identify \_\_\_\_\_**

**Do you have a particular faith group that you identify with?**

Yes     No    **If yes, please identify \_\_\_\_\_**

**Do you attend faith group services?**

Yes     No    **If yes, how regularly? \_\_\_\_\_**

**How many children do you have? \_\_\_\_\_**

**How many children in your home have some kind of developmental disability?**

\_\_\_\_\_

**What kind of developmental disability does your child/children have?**

\_\_\_\_\_

**How old is/are your child/children who has/have a developmental disability?**

\_\_\_\_\_

**At which developmental level does your child function?**    **Low**    **Medium**    **High**

*This section of the questionnaire deals with your feelings about your child who has a disability. For each blank you see in the questions below imagine your child's name filled in. Give your honest feelings and opinions. Please answer all of the questions, even if they do not seem to apply. If it is difficult to decide, True (T) or False (F), answer in terms of what you or your family feel or do most of the time. Sometimes the questions refer to problems your family does not have. Nevertheless, they can be answered True or False.*

1. \_\_\_\_\_ doesn't communicate with others of his/her age group. T  
F
2. Other members of the family have to do without things because of \_\_\_\_\_. T  
F
3. Our family agrees on important matters. T  
F
4. I worry about what will happen to \_\_\_\_\_ when I can no longer take care of him/her. T  
F
5. The constant demands for care for \_\_\_\_\_ limit growth and development of someone T  
F  
else in our family.
6. \_\_\_\_\_ is limited in the kind of work he/she can do to make a living. T  
F
7. I have accepted the fact that \_\_\_\_\_ might have to live out his/her life in some special T  
F  
setting (e.g., institution or group home).
8. \_\_\_\_\_ can feed him/herself. T  
F
9. I have given up things that I have really wanted to do in order to care for \_\_\_\_\_. T  
F
10. \_\_\_\_\_ is able to fit into the family social group. T  
F

11. Sometimes I avoid taking \_\_\_\_\_ out in public. T  
F
12. In the future, our family's social life will suffer because of increased responsibilities and T  
F financial stress.
13. It bothers me that \_\_\_\_\_ will always be this way. T  
F
14. I feel tense whenever I take \_\_\_\_\_ out in public. T  
F
15. I can go visit with friends whenever I want. T  
F
16. Taking \_\_\_\_\_ on a vacation spoils pleasure for the whole family. T  
F
17. \_\_\_\_\_ knows his/her own address. T  
F
18. The family does as many things together now as we ever did. T  
F
19. \_\_\_\_\_ is aware who he/she is. T  
F
20. I get upset with the way my life is going. T  
F
21. Sometimes I feel very embarrassed because of \_\_\_\_\_. T  
F
22. \_\_\_\_\_ doesn't do as much as he/she should be able to do. T  
F
23. It is difficult to communicate with \_\_\_\_\_ because he/she has difficulty T  
F understanding what is being said to him/her.
24. There are many places where we can enjoy ourselves as a family when \_\_\_\_\_ comes along. T F
25. \_\_\_\_\_ is over-protected. T F
26. \_\_\_\_\_ is able to take part in games or sports. T F
27. \_\_\_\_\_ has too much time on his/her hands. T F
28. I am disappointed that \_\_\_\_\_ does not lead a normal life. T F
29. Time drags for \_\_\_\_\_, especially free time. T F

30. \_\_\_\_\_ can't pay attention very long.  
T      F
31. It is easy for me to relax.  
T      F
32. I worry about what will be done with \_\_\_\_\_ when he/she gets older.  
T      F
33. I get almost too tired to enjoy myself.  
T      F
34. One of the things I appreciate about \_\_\_\_\_ is his/her confidence.  
T      F
35. There is a lot of anger and resentment in our family.  
T      F
36. \_\_\_\_\_ is able to go to the bathroom alone.  
T      F
37. \_\_\_\_\_ cannot remember what he/she says from one moment to the next.  
T      F
38. \_\_\_\_\_ can ride a bus.  
T      F
39. It is easy to communicate with \_\_\_\_\_.  
T      F
40. The constant demand to care for \_\_\_\_\_ limits my growth and development.  
T      F
41. \_\_\_\_\_ accepts himself/herself as a person.  
T      F
42. I feel sad when I think of \_\_\_\_\_.  
T      F
43. I often worry about what will happen to \_\_\_\_\_ when I no longer can take care  
T      F  
of him/her.
44. People can't understand what \_\_\_\_\_ tries to say.  
T      F
45. Caring for \_\_\_\_\_ puts a strain on me.  
T      F
46. Members of our family get to do the same kinds of things other families do.  
T      F
47. \_\_\_\_\_ will always be a problem to us.  
T      F
48. \_\_\_\_\_ is able to express his/her feelings to others.  
T      F

49. \_\_\_\_\_ has to use a bedpan or a diaper.  
T F

50. I rarely feel blue.  
T F

51. I am worried much of the time.  
T F

52. \_\_\_\_\_ can walk without help.  
T F

**Please circle the choice that best indicates how helpful/supportive these people and or groups are to you in terms of raising your child(ren)?**

Person or Group	1 Not Applicable	2 Not at All Helpful	3 Sometime Helpful	4 Generally Helpful	5 Very Helpful	6 Extremely Helpful
V105. <b>Your parents</b>	1	2	3	4	5	6
V106. <b>Your spouse or partner's parents</b>	1	2	3	4	5	6
V107. <b>Your relatives/kin</b>	1	2	3	4	5	6
V108. <b>Your spouse or partner's relatives/kin</b>	1	2	3	4		6
V109. <b>Spouse or partner</b>	1	2	3	4	5	6
V110. <b>Your friends</b>	1	2	3	4	5	6
V111. <b>Your spouse or partner's friends</b>	1	2	3	4	5	6
V112. <b>Your own children</b>	1	2	3	4	5	6
V113. <b>Other parents</b>	1	2	3	4	5	6
V114. <b>Co-workers</b>	1	2	3	4	5	6
V115. <b>Parent groups</b>	1	2	3	4	5	6
V116. <b>Social groups/clubs</b>	1	2	3	4	5	6
V117. <b>Church Members/minister</b>	1	2	3	4	5	6
V118. <b>Your family's or child's physician</b>	1	2	3	4	5	6
V119. <b>Early childhood intervention program</b>	1	2	3	4	5	6
V120. <b>School/day-care center</b>	1	2	3	4	5	6
V121. <b>Professional helpers (social workers, therapists, teachers, etc.)</b>	1	2	3	4	5	6
V122. <b>Professional agencies (public health, social services, mental health, etc.)</b>	1	2	3	4	5	6

**If there are any other people or groups which you identify as supportive or helpful, which were not already mentioned, please rate them below.**

V123. <i>Write in Other Person or Group #1:</i>						
V124. Rating for Other Person or Group (#1):	1	2	3	4	5	6
V125. <i>Write in Other Person or Group #2:</i>						
V126. Rating for Other	1	2	3	4	5	6

Person or Group (#2):						
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**For each coping behaviour you use, please record how helpful it is. Circle ONE number:**  
**3 Extremely helpful 2 Moderately helpful 1 Minimally helpful 0 Not helpful**  
**For each coping behaviour you did not use please record your reason by checking one of the boxes:**  
**“Chose not to use it” or “Not possible.”**

1. Believing that my child(ren) will get better.  
**3 2 1 0     Chose not to use it     Not possible**
2. Investing myself in my children.  
**3 2 1 0     Chose not to use it     Not possible**
3. Doing things with my children.  
**3 2 1 0     Chose not to use it     Not possible**
4. Believing that things will always work out.  
**3 2 1 0     Chose not to use it     Not possible**
5. Telling myself that I have many things I should be thankful for.  
**3 2 1 0     Chose not to use it     Not possible**
6. Building a closer relationship with my spouse.  
**3 2 1 0     Chose not to use it     Not possible**
7. Talking over personal feelings and concerns with spouse.  
**3 2 1 0     Chose not to use it     Not possible**
8. Doing things with family relatives.  
**3 2 1 0     Chose not to use it     Not possible**
9. Believing in God.  
**3 2 1 0     Chose not to use it     Not possible**
10. Taking good care of all the medical equipment at home.  
**3 2 1 0     Chose not to use it     Not possible**
11. Believing that my child is getting the best medical care possible.  
**3 2 1 0     Chose not to use it     Not possible**
12. Trying to maintain family stability.  
**3 2 1 0     Chose not to use it     Not possible**
13. Doing things together as a family (involving all members of the family).

- 3 2 1 0     Chose not to use it     Not possible
14. Trusting my spouse (or former spouse) to help support me and my child(ren).
- 3 2 1 0     Chose not to use it     Not possible
15. Showing that I am strong.
- 3 2 1 0     Chose not to use it     Not possible
16. Getting other members of the family to help with chores and tasks at home.
- 3 2 1 0     Chose not to use it     Not possible
17. Having my child with the medical condition seen at the clinic/hospital on a regular basis.
- 3 2 1 0     Chose not to use it     Not possible
18. Believing that the medical center/hospital has my family's best interest in mind.
- 3 2 1 0     Chose not to use it     Not possible
19. Encouraging child(ren) with medical condition to be more independent.
- 3 2 1 0     Chose not to use it     Not possible
20. Involvement in social activities (parties, etc.) with friends.
- 3 2 1 0     Chose not to use it     Not possible
21. Being able to get away from the home care tasks and responsibilities for some relief.
- 3 2 1 0     Chose not to use it     Not possible
22. Getting away by myself.
- 3 2 1 0     Chose not to use it     Not possible
23. Eating.
- 3 2 1 0     Chose not to use it     Not possible
24. Sleeping.
- 3 2 1 0     Chose not to use it     Not possible
25. Allowing myself to get angry.
- 3 2 1 0     Chose not to use it     Not possible
26. Purchasing gifts for myself and/or other family members.
- 3 2 1 0     Chose not to use it     Not possible
27. Concentrating on hobbies (art, music, jogging, etc.).
- 3 2 1 0     Chose not to use it     Not possible
28. Working, outside employment.
- 3 2 1 0     Chose not to use it     Not possible
29. Becoming more self-reliant and independent.

- 3 2 1 0     Chose not to use it     Not possible
30. Keeping myself in shape and well-groomed.
- 3 2 1 0     Chose not to use it     Not possible
31. Talking to someone (not professional counsellor/doctor) about how I feel.
- 3 2 1 0     Chose not to use it     Not possible
32. Engaging in relationships and friendships which help me to feel important and appreciated.
- 3 2 1 0     Chose not to use it     Not possible
33. Entertaining friends in our home.
- 3 2 1 0     Chose not to use it     Not possible
34. Investing time and energy in my job.
- 3 2 1 0     Chose not to use it     Not possible
35. Going out with my spouse on a regular basis.
- 3 2 1 0     Chose not to use it     Not possible
36. Building close relationships with people.
- 3 2 1 0     Chose not to use it     Not possible
37. Developing myself as a person.
- 3 2 1 0     Chose not to use it     Not possible
38. Talking with other parents in the same type of situation and learning about their experiences.
- 3 2 1 0     Chose not to use it     Not possible
39. Talking with the medical staff (nurses, social worker, etc.) when we visit the medical center.
- 3 2 1 0     Chose not to use it     Not possible
40. Reading about how other persons in my situation handle things.
- 3 2 1 0     Chose not to use it     Not possible
41. Reading more about the medical problem which concerns me.
- 3 2 1 0     Chose not to use it     Not possible
42. Explaining our family situation to friends and neighbours so they will understand.
- 3 2 1 0     Chose not to use it     Not possible
43. Being sure prescribed medical treatments for child(ren) are carried out at home on a daily basis.
- 3 2 1 0     Chose not to use it     Not possible
44. Talking with other individuals/parents in my same situation.
- 3 2 1 0     Chose not to use it     Not possible

45. Talking with the doctor about my concerns about my child(ren) with the medical condition.

3 2 1 0     Chose not to use it     Not possible

Please circle the choice that best indicates the extent of your agreement or disagreement with each statement written below.

	SA Strongly	MA Moderately	A Agree	D Disagree	MD Moderately	SD Strongly
1.						
2.						
3.						
4.						
5.						
6.						
7.						
8.						
9.						
10.						
11.						
12.						
13.						
14.						
15.						
16.						
17.						

- |     |   |                 |
|-----|---|-----------------|
| 18. | Most childrens' behaviour problems would not have developed if their parents had better parenting skills.                               | SA MA A D MD SD |
| 19. | I am responsible for my child's behaviour.  | SA MA A D MD SD |
| 20. | The misfortunes and successes I have had as a parent are the direct result of my own behaviour.   | SA MA A D MD SD |
| 21. | My life is chiefly controlled by my child.  | SA MA A D MD SD |
| 22. | My child does not control my life.  | SA MA A D MD SD |
| 23. | My child influences the number of friends I have.   | SA MA A D MD SD |
| 24. | I feel like what happens in my life is mostly determined by my child.   | SA MA A D MD SD |
| 25. | It is easy for me to avoid and function independently of my child's attempts to have control over me.                                   | SA MA A D MD SD |
| 26. | When I make a mistake with my child I am usually able to correct it.  | SA MA A D MD SD |
| 27. | Even if your child frequently tantrums, a parent should not give up.  | SA MA A D MD SD |
| 28. | Being a good parent often depends on being lucky enough to have a good child.   | SA MA A D MD SD |
| 29. | I'm just one of those lucky parents who happened to have a good child.  | SA MA A D MD SD |
| 30. | I have often found that when it comes to my children, what is going to happen will happen.  | SA MA A D MD SD |
| 31. | Fate was kind to me – if I had had a bad child I don't know what I would have done.   | SA MA A D MD SD |
| 32. | Success in dealing with children seems to be more a matter of the child's moods and feelings at the time rather than one's own actions. | SA MA A D MD SD |
| 33. | Neither my child nor myself is responsible for his/her behaviour.   | SA MA A D MD SD |
| 34. | In order to have my plans work, I make sure they fit in with the desires of my child.   | SA MA A D MD SD |
| 35. | Most parents don't realize the extent to which how their children turn out is influenced by accidental happenings.                      | SA MA A D MD SD |
| 36. | Heredity plays the major role in determining the child's personality.   | SA MA A D MD SD |
| 37. | Without the right breaks, one can not be an effective parent.   | SA MA A D MD SD |
| 38. | I always feel in control when it comes to my child.   | SA MA A D MD SD |
| 39. | My child's behaviour is sometimes more than I can handle.   | SA MA A D MD SD |

- |     |  |                 |
|-----|--|-----------------|
| 40. | Sometimes I can feel that my child's behaviour is helpless.                                    | SA MA A D MD SD |
| 41. | It is often easier to let my child have his/her way than to put up with a tantrum.             | SA MA A D MD SD |
| 42. | I find that sometimes my child can get me to do things I really did not want to do.            | SA MA A D MD SD |
| 43. | My child often behaves in a very different manner from the way I would want him/her to behave. | SA MA A D MD SD |
| 44. | Sometimes when I am tired I would let my children do things I normally wouldn't.               | SA MA A D MD SD |
| 45. | Sometimes I feel I do not have enough control over the direction my child's life is taking.    | SA MA A D MD SD |
| 46. | I allow my child to get away with things.  | SA MA A D MD SD |
| 47. | It is not too difficult to change my child's mind about something.                             | SA MA A D MD SD |

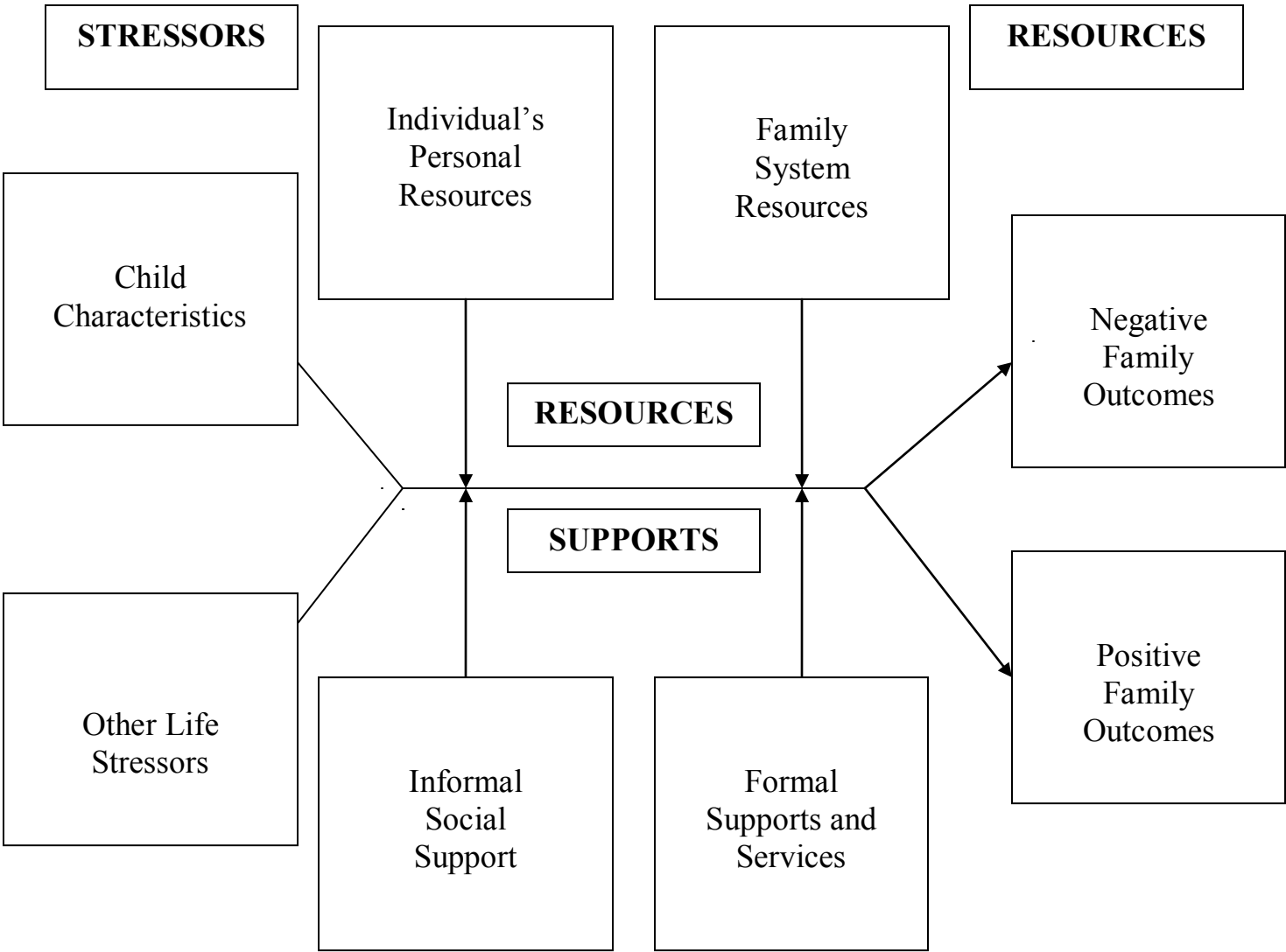
**Think about your spirituality and circle the choice that best indicates the extent of your agreement or disagreement as it describes your spirituality.**

	SA Strongly Agree	MA Moderately Agree	A Agree	D Disagree	MD Moderately Disagree	SD Strongly Disagree	
1) I don't find much satisfaction in private prayer with God. SD					SA	MA	A D MD
2) I don't know who I am, where I came from, SD or where I am going.					SA	MA	A D MD
3) I believe that God loves me and cares about me. SD					SA	MA	A D MD
4) I feel that life is a positive experience SD					SA	MA	A D MD
5) My community of worship is important for my spirituality. SD					SA	MA	A D MD
6) The support of my family brings me closer to God. SD					SA	MA	A D MD
7) I believe that God is impersonal and not interested SD in my daily situation.					SA	MA	A D MD
8) I feel unsettled about my future. SD					SA	MA	A D MD
9) I have a personally meaningful relationship with God. SD					SA	MA	A D MD
10) I feel very fulfilled and satisfied with life. SD					SA	MA	A D MD
11) The family that prays together, stays together. SD					SA	MA	A D MD
12). Helping the poor is central to my spirituality. SD					SA	MA	A D MD
13) I don't get much personal strength and support from SD my God.					SA	MA	A D MD
14) I feel a sense of well-being about the direction my life is headed in.					SA	MA	A D MD SD
15) I believe that God is concerned about my problems. SD					SA	MA	A D MD
16) I don't enjoy much about life.					SA	MA	A D MD SD

- |  |    |    |   |   |    |    |
|--|----|----|---|---|----|----|
| 17) "Where two or more gather" is an important part of my spirituality.                | SA | MA | A | D | MD | SD |
| 18) I don't have a personally satisfying relationship with God.                        | SA | MA | A | D | MD | SD |
| 19) I feel good about my future.   | SA | MA | A | D | MD | SD |
| 20) My relationship with God helps me not to feel lonely.                              | SA | MA | A | D | MD | SD |
| 21). I feel that life is full of conflict and unhappiness.                             | SA | MA | A | D | MD | SD |
| 22) It is important that my partner / significant other support me in my spirituality. | SA | MA | A | D | MD | SD |
| 23) I feel most fulfilled when I am in close communion with God.                       | SA | MA | A | D | MD | SD |
| 24) Life doesn't have much meaning.  | SA | MA | A | D | MD | SD |
| 25) My relation with God contributes to my sense of well-being.                        | SA | MA | A | D | MD | SD |
| 26) I believe there is some real purpose for my life.                                  | SA | MA | A | D | MD | SD |
| 27) Praying with another person can bring God closer to me.                            | SA | MA | A | D | MD | SD |

Thank you for taking the time to fill out this questionnaire

**A Model of Stress in Families of Children with DD  
Proposed by (Perry, 2004)**



**Re: Use of your "Stress Model" in my M.A. Thesis**

Wednesday, April 21, 2010 6:46 PM

"Erin Shackell" <erinshackell@rogers.com>  
[Add sender to Contacts](#)

**From:**

"Dr. Adrienne Perry" <perry@yorku.ca>

**To:**

From: Dr. Adrienne Perry <perry@yorku.ca>  
Subject: Re: Use of your "Stress Model" in my M.A. Thesis  
To: "Erin Shackell" <erinshackell@rogers.com>  
Date: Wednesday, April 21, 2010, 4:07 PM

Hello Erin,

I'm glad you find the model useful. I would be honoured to have you use it (with appropriate credit of course). Spirituality is very interesting. I can't quite make up my mind if it's just a nother coping process or something different. What do you think? I'd love to hear more about your study.

Good luck!

Adrienne Perry

Erin Shackell wrote:

- > Dr. Perry,
- > I am an M.A. in Counselling and Spirituality Student at Saint Paul University in Ottawa. I write to you to request your permission to use your model in my thesis research on spirituality as a coping mechanism for families raising children with developmental disabilities.
- > I am referring specifically to your paper: A Model of Stress in Families of Children with Developmental Disabilities: Clinical and Research Applications, published in the Journal on Developmental Disabilities.
- > I have found this model to be very useful in conceptualizing the coping process of families who have children with developmental disabilities and it is a perfect compliment to another model on spiritual coping which one of my professors developed.
- > I thank you for your time and look forward to hearing from you.
- > Sincerely,
- > Erin Shackell
- >