

**Exploring the relationship of parental stress, child behaviour, and child
adaptive skills to different types of respite**

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By

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ABSTRACT

Parents of children with developmental disabilities have been reported to experience higher levels of stress than parents of typically developing children. This stress has been found to lead to adverse effects for both parents and children. Respite has been found to be a buffer of stress in the short term. The objective of this study was to: determine the types of respite Saskatchewan parents are using; and examine the correlational relationship between formal and informal respite use and child behaviour concerns, child adaptive skills, and parental stress. Open-ended questions related to additional influences on respite use were also analyzed.

The current study examined respite use in 26 parents in Saskatchewan who have children between the ages of 6 and 18 with a diagnosed developmental disability. The Respite Information Questionnaire (adapted from Preece & Jordon, 2007) was used to explore the types and hours of respite use, child behaviour concerns, and child adaptive needs. Parental stress levels were measured with the Parental Stress Scale (Berry & Jones, 1995). Descriptive statistics, correlations and Mann-Whitney U statistical tests were used to analyze data gathered from the questionnaire and Parental Stress Scale. Results from this research showed that Saskatchewan parents used a range of formal (e.g., care homes, trained individual respite providers) and informal respite (e.g., siblings, grandparents) both in type and hours of use. No relationship was found between formal and informal respite use and child adaptive skills or parental stress. A preliminary relationship between child behavioural concerns and stress was found, indicating that as child behavioural concerns increase so does formal respite use. However, a basic thematic analysis of open-ended questions showed that parents felt respite services were limited as a result of their child's behavioral concerns. This suggests child behavioural concerns should be considered in respite policy and program development.

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DEDICATION

*This thesis is dedicated to the memory
of my mother. While she may no longer be physically with me,
the lessons she taught and the love she gave
have been with me every step of the way.*

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CHAPTER 1: INTRODUCTION

Psychological stress occurs when a person appraises a situation between themselves and the environment as surpassing their coping resources and as a result endangers their well-being (Lazarus, 1993). Parenting stress is experienced by a subset of the population and occurs when parents feel distress regarding their thoughts, beliefs, or attributions about themselves, their child or their relationship with their child (Deater-Deckard, 2004). Prolonged levels of stress can lead to less affection, increased hostile discipline practices, (e.g., yelling, spanking), and abuse which in turn can increase child behaviour and emotional problems, such as chronic aggression, noncompliance, and anxiety (Deater-Deckard, 2004).

Stress levels have been found to be further exacerbated in a subset of the parenting population, specifically, parents who have children with disabilities (Brehaut et al., 2004; Britner, Morog, Pianta, & Marvin, 2003; Can Child, 2003; Raina et al., 2004; Wulffaert, Scholte, Dijkxhoorn, Bergman, van Ravenswaaij-Arts, & van Berckelaer-Onnes, 2009). This increase in stress is related to characteristics of parenting a child with a disability, such as increased financial burden and increased levels of care (Brehaut et al., 2004).

It is important to note that while stress levels in parents with children who have disabilities have been found to be higher, not all parents experience negative effects of this stress, as specific child and parent characteristics act to buffer this stress (Brehaut et al., 2004). For example, it has been reported that among other characteristics, child behaviour is related to parental stress levels. Children with more severe behavioural challenges have parents with higher levels of stress (Baker, Blacher, Crnic, & Edelbrock, 2002; Gupta, 2007; Ketelaar, Vortman, Gorter, & Vermeer, 2008; Wulffaert, Scholte, Dijkxhoorn, Bergman, van Ravenswaaij-Arts, & Van Berckelaer-Onnes, 2009). In addition, one study found that children

who place high demands on their parents in terms of their ability to care for themselves also led to higher stress levels (Gupta, 2007). This was not supported in a study by Ketelaar et al. (2008), who found the child's ability to care for themselves had no relationship to increased parental stress levels.

Parent characteristics can also act as a buffer of parental stress. Parents who have higher levels of social support have been found to have lower stress levels, however, the type of social support that is mediating appears to depend on the child's specific disability (Gupta, 2007). Support from professionals (early intervention) has been found to be most helpful in mediating stress when the parents were directly involved in decisions relating to the care of their children (Dempsey, Keen, Pennell, O'Reilly, & Neilands, 2008). Social support (e.g., guidance, positive feedback, behavioural assistance, and positive social interaction) can improve maternal psychological adjustment, specifically when the network is large and includes a high proportion of family members (Bakarat & Linney, 1992). The quality (self-reported amount of agreement/disagreement) of the parents' marriage also may have a buffering effect, as mothers who reported high levels of marital satisfaction reported less parental stress and found their supports more helpful (Britner, et al, 2003).

Child and parent characteristics can also be thought of as resources, as outlined by Conservation of Resources (COR) theory (Hobfoll, 1988, 1998). The main assumption of COR theory is individuals endeavor to retain, protect, and build resources. Stress occurs when these resources are threatened by loss, are actually lost, or when an individual fails to gain resources following significant resource investment (Hobfoll, 2001). Those who have adequate resources are better at meeting challenges and not experiencing negative influences of the stress.

Parenting a child with a developmental disability requires significant resource investment including time, money, and social support.

Therefore, it is important to understand and consider resources that can buffer parental stress, as high levels can lead to negative child and parent outcomes (Brehaut, et al., 2004; Dumas, Wolf, Fisman, & Culligan, 1991; Gallagher, Phillips, & Carroll, 2010; Oelofsen & Richardson, 2006). In the case of parents of children with disabilities, stress or distress has been found to have a relationship with physical and emotional dysfunction, elevated levels of chronic conditions and psychological concerns (Brehaut, et al., 2004; Dumas, Wolf, Fisman, & Culligan, 1991; Gallagher, Phillips & Carroll, 2010; Oelofsen & Richardson, 2006). Negative child outcomes can include increased levels of maltreatment, most often of which is neglect (Schormans, 2002). Despite this not being directly linked to increased parental stress levels, they have been identified as a risk factor (Beckman, 1991; Rodriquez & Murphy, 1997).

It is important for researchers to investigate ways to mitigate stress for parents of children with disabilities, since negative outcomes associated with the increased stress include caregiver burnout, child neglect and parental psychological distress (Brehaut et al., 2004; Dumas, Wolf, Fisman, & Culligan, 1991; Dunbrack, 2003; Gallagher, Phillips, & Carroll, 2010; Oelofsen, & Richardson, 2006). Respite is used throughout the world to mitigate parental stress. Respite is a service that gives the caregiver or family a break from the routine of caregiving (Dunbrack, 2003; Pollock, King, & Rosenbaum, 2001) and can reduce stress in parents in the short term and psychological distress in the long term (Mullins, Anoil, Boyd, Page, & Chaney, 2002; Slavik Cowen & Reed, 2002). No research has supported the benefits of respite in the long term, however if families have regular access to respite care it stands to reason that their stress would continue to be mitigated. One of the biggest challenges for

families is that respite care is not always regularly available, and stringent criteria for certain respite programs can limit families' access to such services (Dunbrack, 2003). More research regarding respite is required in order to ensure families are receiving the most appropriate help possible.

Statement of Purpose

Canada's Participation and Activity Limitation Survey (PALS) reported that 202,350 children under the age of fifteen in Canada have a disability and of those 41.7% are considered to be severe or very severe (Statistics Canada, 2006). Parents of these children have the potential to experience higher levels of stress than those of typically developing children (Brehaut et al., 2004; Britner, Morog, Pianta, & Marvin, 2003; Lopez, Clifford, Mines, & Oulette-Kuntz, 2008; Nachshen & Minnes, 2005), and therefore often require services to help mitigate that stress and its potentially negative impact on both children and parents. One of the services reported to have been effective, at least in the short term, is that of respite (Chan & Sigafos, 2001). However, research has focused on reasons for use and non-use (e.g., Damaini, Rosenbaum, Swinton & Russell, 2004; Neufeld, Query, & Drummond, 2001) and parental perceptions of respite (e.g., Chadwich et al., 2007). Only a handful of studies have examined the actual benefits of respite (e.g., Mullins, Anoil, Boyd, Page & Chaney, 2002; Slavik Cowen & Reed, 2002). Moreover, little attention has been paid to the type of respite being used. After an extensive literature search, only one study was found to have type of respite as a primary focus of their research (Stalker & Robinson, 1994). Stalker and Robinson (1994) compared certain characteristics of families using a variety of services (e.g., family based schemes, local authority residential homes, and health authority provision), but these characteristics did not include parental stress levels or child behavioural characteristics. Parental stress levels and

child characteristics have been demonstrated below as reasons to use respite and they also may be predictors of the types of respite people choose. Therefore, this research study examined child characteristics, behaviour and adaptive behaviour, and the parent characteristic of stress to determine if these factors influence the type of respite families will use. Specifically, this study addressed the following research questions:

1. What respite services are Saskatchewan families with children who have disabilities using?
2. Are parental stress levels, severity of adaptive needs, and severity of behavioural challenge related to the types of respite used by families?

Definitions

Parenting Stress

Parenting stress is considered to be a stress reaction specific to the demands of being a parent. It is a distinct domain of stress and a reaction to the stress of parenting and may or may not be related to the stress created from other aspects of life. In addition, all parents will experience parenting stress to some degree and that experience is individual to the person and family (Deater-Deckard, 1998).

Respite

Respite has been defined in many different ways but the differences often lie in the nuances. At the core, respite is a service that gives the caregiver or family a break from the routine of caregiving (Dunbrack, 2003; Pollock, King, & Rosenbaum, 2001). It can occur either in the home or community. The majority of respite options are found out of the home and include: summer camps, group day care, group respite facilities, community residences, residential treatment facilities, pediatric nursing homes, and hospice sites (Zimmerman &

Chapple, 1996). Respite can also be viewed as a break for the person receiving care (Dunbrack, 2003).

Developmental Disabilities

Developmental disability is a term often used to define an array of disabilities (Government of Alberta, 2010). Statistics Canada defined developmental disabilities as “cognitive limitations due to the presence of a developmental disability or disorder, such as Down syndrome, autism or mental impairment caused by a lack of oxygen at birth” (Statistics Canada, 2006 p. 7). More specifically,

Three criteria are generally used to make the determination of developmental disability:

- Significantly below average intellectual capacity evidenced by a sub-average performance on an individually administered intelligence test
- Onset prior to age 18
- Related limitations in two or more of the following adaptive skills areas: communication, home living, community use, health and leisure, self-care, social skills, self-direction, functional academics, work. (Government of Alberta, 2010, p. 2)

Parent

For the purposes of this research parent is defined as a person who considers themselves a primary caregiver. A parent could include a mother, father, grandparent, older sibling, or any other legal guardian who takes on a parental role (Alberta Alcohol and Drug Abuse Commission & Royal Canadian Mounted Police, 2008).

Significance of Study

Despite an abundance of research on the descriptive aspects of respite (e.g., who uses it, reasons for non use), the majority of research has done little to consider the importance of different respite types beyond the number of families that use a particular type (Neufeld, Query, & Drummond, 2001). Alternatively, studies will focus on one or two types of respite care with little or no comparison between them (Meltzer & Johnson, 2004; Rimmerman, Kramer, Levy, & Levy, 1989). In doing this, researchers have failed to address the importance of the relationship between respite type and child/parent characteristics, and the impact this relationship could have on providing better service. This study investigated how parental stress, child behaviour concerns, and child adaptive skills are related to different types of respite. A better understanding of how child and parent characteristics are related to respite type will provide more information about how services are currently being utilized. This information could lead to more effective respite services that are tailored to child and family needs being developed in the future. If parents are using the service or services that best fit their family's needs, then parental stress may be more effectively mitigated or alternatively managed.

Chapter Organization

A review of the literature with regard to stress, stress in parents, stress in parents of children with disabilities, and respite can be found in Chapter 2. Chapter 3 outlines the methodology and analyses of data for this study. Chapter 4 discusses the study's results. Lastly, Chapter 5 discusses the results and their relationship to other research and future practice.

CHAPTER 2: LITERATURE REVIEW

A review of the literature regarding parenting stress and respite will be discussed within this chapter. Parenting stress exists for all parents, however, research has found parents of children with disabilities experience higher levels of stress which can result in psychological distress, poor physical health, and strained family relationships (Dumas, Wolf, Fisman, & Culligan, 1991; Brehaut, Kohen, Raina, Walter, Russell, Swinton, O'Donnell, & Rosenbaum, 2004; Oelofsen & Richardson, 2006; Gallagher, Phillips, & Carroll, 2010). One of the resources parents can use to mitigate these higher stress levels in the short term is respite (Meltzer & Bennett Johnson, 2004; Mullins, et al. 2002; Slavik Cowen, & Reed, 2002). Therefore, it is important respite is a well understood resource, including predictors and motivations for choosing different types of respite.

If we better understand why parents choose specific types of respite, more effective programming or services can be developed. This is increasingly important given the detrimental effects prolonged parental stress can have on the child and parent (e.g., psychological distress, neglect, and caregiver burnout) (Brehaut et al., 2004; Dumas, Wolf, Fisman, & Culligan, 1991; Dunbrack, 2003; Oelofsen & Richardson, 2006; Gallagher, Phillips, & Carroll, 2010). If effective respite services are put in place that address family's needs or wants, parental stress may be better managed and respite could be a proactive solution rather than an emergency measure. The following topics will be discussed below: concepts and models of stress and coping, general parental stress, parenting stress related to parenting a child with a disability, respite and how respite can mitigate stress.

Stress

The evolution of the term stress is not clearly understood. Robert Hooke first used the term stress with technical importance in the 17th century in the field of engineering (Cooper & Dewe, 2004; Lazarus; 1993). His ideas centered on demands placed on manmade structures (bridges) and how they could withstand such demands without collapsing. Hooke's theory focused on ideas of load; the weight on a structure, stress, the area affected by the load, and strain, the change in the structure as a result of the interaction between load and stress. While these concepts are not directly transferrable across fields, these ideas ultimately influenced 20th century stress models in physiology, sociology and psychology (Lazarus, 1993). The theme remaining from Hooke's work, according to Lazarus, is, "the idea of stress as an external load or demand on a biological, social or psychological system" (1993, p. 2).

Other early influences on the concept of stress include Descartes, Claude Bernard (1974) and Walter Cannon (1935). Descartes contributed with one of the first discussions of the mind and body as connected entities and their influence on one another. While this idea may not have directly shaped the concept of stress, the view of the mind and body changed, and as a result the way we examine stress (Cooper & Dewe, 2004). Another initial influence, French physician Bernard (1974), discussed the milieu interieur; the idea that nothing within the body could be allowed to deviate far from normal because it could result in illness or death. His work on this concept contained three main themes, wear and tear, concept of steady state or homeostasis, and the impact of the pace of life. All three of these themes are still heard today in current discussions of stress (Cooper & Dewe, 2004).

Walter Cannon (1935), whose work spanned three decades in the early 1900's, expanded upon the concept of homeostasis. Cannon (1935) defined homeostasis as the "stable

state of the fluid matrix” (p.2), the fluid matrix being where the organs and tissue are set under the skin. He stated, “as long as this personal individual sack of salty water, in which each one of us lives and moves and has his being, is protected from change, we are freed from serious peril” (Cannon, 1935, p. 2). The described stable state is homeostasis. If homeostasis is upset by the external environment, regulatory mechanisms are used to bring individuals back to homeostasis (Cooper & Dewe, 2004). Cannon (1935) did not often directly refer to *stress* and discusses mostly physiological stress in his work. However, his work was the precursor for understanding stress as a state in which the body’s equilibrium is disturbed by outside sources and requires a compensatory system to return it to a stable state (Cooper & Dewe, 2004). This evolution of the term stress to include human stress led to the development of many theories to address *how* stress is experienced by humans, physiologically and psychologically.

Theories of Stress

Aforementioned scientists influenced the concept of stress but Hans Selye (1955), a Canadian endocrinologist, amalgamated past ideas of stress into what he called General Adaptation Syndrome (GAS) or stress syndrome (Cooper & Dewe, 2004; McGuigan, 1999; Selye, 1955). He proposed stress as a consistent biological bodily reaction, occurring the same way no matter what elicited it (Cooper & Dewe, 2004; McGuigan, 1999). The GAS is a system of protection, including physiological responses to stressors. The GAS occurs following a period of prolonged stress and involves all parts of the body, most prominently the hormonal and nervous systems.

The four events of the GAS are alarm, resistance, exhaustion, and death (Cooper & Dewe, 2004). The alarm reaction is a call for action by the body’s defense system. The resistance event is entered if the individual is able to return breathing and heart rate back to

levels occurring prior to the stressor. During this stage the body is particularly vulnerable to infections (Selye, 1955). Exhaustion may occur if further stress occurs and the body processes start to break down and the final event of death may occur if this continues (McGuigan, 1999).

In addition to GAS, Selye (1955) discussed four different variations of stress, eustress, distress, hyperstress and hypostress. Eustress is known as good stress, distress is bad stress, hyperstress and hypostress are when an individual experiences overstress and understress, respectively. It is ideal to arrive at a stress balance and produce as much eustress as possible (Cooper & Dewe, 2004). However, in Selye's writings of GAS there is no discussion of psychological appraisal. Lazarus (1993) likens GAS as the physiological parallel to the psychological concept of coping.

Lazarus (1993) was actually one of the first scientists to discuss the concept of psychological stress as opposed to physiological stress. Lazarus and Folkman (1984), defined psychological stress as, "a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being" (p. 19). According to Lazarus (1993), a potentially stressful condition may not impact every person in the same way. Extremely stressful events for one person may be minutely stressful for another, depending upon their personal appraisal. Individual differences in motivation and cognition must be considered as a mediating factor between stress and stress reactions. Lazarus (1993) discussed four components that must always be considered in the stress process, the stressor, an evaluation that distinguishes between what is threatening from what is benign, a coping process that is used by the body or mind to deal with stressful demands and a complex effect on the mind and body (stress reaction).

Lazarus and Folkman (1984) created a theory of stress referred to as the Transactional Model of Stress. It is transactional for three reasons: (1) it holds stress is a relationship between the person and the environment, (2) what is integral to the transaction is the person's appraisal of the potentially stressful situation, and (3) the situation must be seen as threatening, challenging or harmful (Brannon & Feist, 2004). The cognitive processing of stress reactions is appraisal. People use three different kinds of appraisal to assess potentially stressful situations, primary appraisal, secondary appraisal and reappraisal (Brannon & Feist, 2004; Lazarus, 1993). Primary appraisal involves an individual assessment of a situation and how it will affect their well-being. A situation can be appraised as benign, positive or stressful (Brannon & Feist, 2004). Lazarus (1993) defined three types of stressors: harm, threat and challenge. Harm is psychological damage that has already occurred, threat is the anticipation of the damage that is imminent, and challenge results from demands that individuals feel they can overcome using their coping resources. These are brought upon by different antecedent conditions both in the environment and within the person (Lazarus, 1993). After the initial appraisal an individual forms a secondary appraisal to determine their ability to control or cope with the stressful situation they have deemed to be harm, threat or challenge. The final type of appraisal is reappraisal (Lazarus, 1993). Appraisals of situations change whenever new information becomes available (Brannon & Feist, 2004). It is important to understand the stress response, as well as how an individual copes with stress. Both of these concepts will help service providers determine what supports and services will be most useful to a stressed individual (Brannon & Feist, 2004).

Coping with Stress

Psychological stress occurs when there is an unfavorable person-environment relationship (Lazarus, 1993). We have the ability to alter our circumstances or how we interpret them through an action called coping (Lazarus, 1993). Coping appears to be contextual as opposed to an individual trait or style and there are two types (Lazarus, 1993). Problem focused coping involves an individual changing their relationship with the environment through coping actions. As a result psychological stress may be positively changed. Emotion focused coping requires an individual change the way they attend to, or interpret what is happening (Lazarus, 1993). In extensive research of coping, Folkman and Lazarus (1993) discovered the following important replicable findings. First, coping is multifaceted and people use basic strategies of coping in every stressful situation. Second, coping requires the individual appraise the situation to see if something can be done to change the situation. If so, problem-focused coping often occurs. If not emotion-focused coping predominates. Third, when the type of stressful experience is constant women and men show similar coping patterns. Fourth, some coping strategies are stable across a variety of stressful events while others are linked to a specific stressful experience. Fifth, coping strategies may change throughout one stressful experience. Sixth, coping is a buffer for emotional outcomes; positive coping is related to particular outcomes as is negative coping. Lastly, the usefulness of some coping strategies varies with the type of stressful event, what works in one situation may be counterproductive in another (Lazarus, 1993).

Conservation of Resources Theory

Two leading theories of stress in the past 20 years are Lazarus and Folkman's (1984) Transactional Theory of Stress, and Conservation of Resources (COR) theory (Hobfoll, 1988,

1998, 2011). The COR theory departs from the personal appraisal view of stress taken by Lazarus and Folkman (1984). That is, rather than focusing on individual appraisals of a stressful situation the COR theory emphasizes threat and loss, and the common appraisals held by people who share common biology and culture (Hobfoll, 2011). The COR theory is based on a set of tenets, principles, and corollaries. The basic tenet is that individuals will strive to obtain retain, protect, and build resources (Hobfoll, 1988, 1998). Resources fall into four main categories: (1) object resources (e.g., valuable household items); (2) personal resources, including personal skills (e.g., occupational skills, leadership ability) and traits (e.g., self-esteem, self-efficacy); (3) condition resources (e.g., being healthy, employment, marriage); and (4) energy resources (e.g., money, knowledge; Hobfoll, 1998). Stress occurs when these resources are threatened by loss, are actually lost, or when an individual fails to gain resources following significant resource investment (Hobfoll, 2001). Resource loss from one individual would be perceived as a loss by others in a similar circumstance, as resources are objectively determined or observable and not based on personal appraisal (Hobfoll, 2001).

Following from this central tenet are two principles and four corollaries that help to define the theory (Hobfoll, 1988, 1998). The first principle states, given equal amounts of resource loss and gain, loss will have a significantly greater impact (Hobfoll, 1988, 1998). The second principle states, individuals must invest resources in order to protect against resource loss, recover from loss, and gain resources (Hobfoll, 1988, 1998). From this principle follows three corollaries. The first discusses how those with greater resources are less vulnerable to resource loss and more able to facilitate resource gain (Hobfoll, 1998). On the contrary those with fewer resources are more vulnerable and less able to facilitate resource gain. Also, those who lack adequate resources are more likely to experience significant consequences. That is, if

individuals do not have any resource reserves, they are less likely to have resources to invest when there is a loss (Hobfoll, 1998). The second corollary discusses individuals who lack resources are both more vulnerable to resource loss, and that initial loss leads to future loss. This becomes a cycle where by each iteration leads to fewer resources to gather in defense of resource loss or invest in a resource reserve (Hobfoll, 1998). The third corollary is a mirror of corollary two, but relates to resource gains and gain cycles (Hobfoll, 1998). That is, those who have resources are more capable of gain in that, initial resource gain produces further gain. The fourth and final corollary states individuals who lack resources are likely to be defensive in guarding their resources (Hobfoll, 1998). Understanding general stress and coping responses, as outlined by the COR theory (Hobfoll, 1988) and transactional stress theory (Lazarus & Folkman, 1984), leads us to better understand these responses for specific populations. Central to this research study is understanding stress specific to parenting, as respite is seen as a response to this stress (Mullins, et al. 2002; Meltzer & Bennett Johnson, 2004; Slavik Cowen & Reed, 2002).

Parenting Stress

Parenting stress is a type of stress experienced only by a subset of individuals (Deater-Deckard, 2004). It can be caused by experiences of distress, parent's thoughts, beliefs and attributions, such as a belief that they lack control and include roles for both parents and children. There are two primary theories that examine stress of this nature: Parent-Child Relationship Stress (PCR-Stress) and Daily Hassles Theory (Deater-Deckard, 2004).

P-C-R theory was developed by Richard Abidin and involves three different domains, parent, child, and the parent-child relationship (Abidin, 1995). The parent domain is associated with problems in the parent's own functioning such as depression and competence. The child

domain is characterized by problems happening primarily within the child, such as, behavioral problems. The final domain, parent-child relationships, considers the degree of conflict within the relationship. These three domains of stress can cause deterioration in the quality of parenting including less affection, increased hostile discipline practices, less consistent parenting behavior, and abuse which in turn can increase child behaviour and emotion problems, such as chronic aggression, noncompliance, and anxiety (Abidin, 1995; Deater-Deckard, 2004).

This theory puts forward bidirectional stress effects for parents and children (Deater-Deckard, 2004; Abidin, 1995). For example, if a child's behavioral difficulties increase over time, parenting stress likely will increase and may escalate difficulties in the parent child relationship (Deater-Deckard, 2004). Similarly, parental difficulties such as depression can create the same effect. This theory is dependent upon the parental stress reaction; a maladaptive stress reaction can propel the negative process forward (Deater-Deckard, 2004). While this is a well-accepted theory, the research consists of mostly correlational studies and more work needs to be conducted using experimental designs (Deater-Deckard, 2004). Moreover, P-C-R theory involves samples of parents and/or children who have been diagnosed with emotional and/or behavioural disorders. A distinction should be made between parenting stress as normal and parenting stress as dysfunctional (Deater-Deckard, 2004).

Daily Hassles Theory created this distinction and examines how typical parenting stress develops and how it influences parenting and child development (Cnic & Booth, 1991; Cnic & Greenberg, 1990). Adaptation is part of the parenting role and so it is important that parents are able to do this for the *everyday* hassles that occur. Daily Hassles theory does not contradict P-C-R theory but rather complements it by including everyday stressors (Deater-Deckard,

2004). Daily stressors are not major when they occur in isolation. For most parents it is the accumulation of these everyday stressors that matter in the prediction of problems in mental health and well-being (Crnic & Greenburg, 1990; Deater-Deckard, 2004). However, both theories only focus on the parent as an individual instead of as a part of a family and does not consider cognitive appraisal of the situation as much as child and parent characteristics (Deater-Deckard, 2004).

The researcher who developed the Parenting Stress Index (Abidin, 1995) (as based on P-C-R theory), created a more comprehensive model examining the paths of influence that determine parenting behaviour. This model takes into account not only parent/child characteristics but it also includes other important variables on the stress to behaviour continuum (Abidin, 1992). It hypothesizes both parenting behaviour and child adjustment is impacted by a number of variables as seen through the eyes of the parent. Therefore, the parenting role *variable*, symbolizes a set of beliefs and moderators that act as a buffer for peripheral influences. Each parent has a working model of how they fit the parenting role and it is through this they assess both the harm and benefit that comes their way as a parent (Abidin, 1992). Parenting stress is defined as “a series of appraisals made by each parent in the context of his or her level of commitment to the parenting role” (Abidin, 1992, p. 410). Therefore, parenting stress acts as a motivator to encourage parents to use the resources available to them to support them in their parenting role. Abidin (1992) likened the dynamics of this model to those in Lazarus and Folkman’s (1984) transactional model of stress within a specific application.

In addition to the model theorized by Abidin (1992), Deater-Deckard (1998) proposed a theory using Lazarus and Folkman’s (1984) transactional model of stress to provide a

framework to understand the complex processes involved in parenting stress. They used the concepts of a causal event or agent, cognitive appraisal, coping mechanisms and the stress reaction to provide a framework for their theory. Deater-Deckard (1998) discussed the role of the child and parent as the causal agent. The external causal event is *parenthood* or the child is the causal agent as the parent has primary responsibility over them. The dependence of a child is greater as an infant, but all stages of childhood place additional stress on parents that are not experienced by childless individuals (Deater-Deckard, 1998) In addition to meeting their children's needs, parents must meet their own needs which can create increasing levels of stress (Deater-Deckard, 1998).

When the external event or agent is the parenthood role or the child, there are individual differences both in families and in parent's appraisal of stressors (Deater-Deckard, 1998). Even within the same family, two parents can view a stressor in different ways. These individual differences in stress appraisals are important to the understanding of parenting stress and lead to a better understanding of parents' psychosocial adjustment (Deater-Deckard, 1998).

Coping strategies, following an appraisal of a situation as stressful, are a large part of parenting stress in Deater-Deckard's theory (1998). Passive strategies such as denial and rumination are said to be associated with greater parenting stress. Whereas, problem focused coping strategies and positive parental belief systems are associated with lower levels of parenting stress (Deater-Deckard, 1998). In addition to lessening the stress reaction, adaptive coping strategies increase the quality of the child-parent relationship.

The final portion of the theory examines the stress reaction which can be observed in a parent's behaviour and affect (Deater-Deckard, 1998). Most studies have focused on parenting behaviour and feelings toward the child; however, it is more likely that most affected is the

parent's overall well-being which may result in psychopathology (Deater-Deckard, 1998). The availability of social and emotional support is crucial to a positive adaptation to the parenting role and mitigating the effects of related stressors (Deater-Deckard, 1998). This is especially important for parents of children with developmental disabilities, as they have been found to display higher levels of stress than parents of typical children (Brehaut et al., 2004; Britner, Morog, Pianta, & Marvin, 2003; CanChild, 2003; Raina et al., 2004).

Stress in Parents of Children with Developmental Disabilities

Parenting stress is a subset of stress found in the general population (Deater-Deckard, 2004). A subset of parenting stress is stress resulting from parenting children with specific challenges, such as disabilities. Increased financial burden (Brehaut, et al., 2004), greater medical needs, and increased caregiving responsibilities (Neufeld, Query, & Drummond, 2001), are also associated with caring for children with disabilities. However, little research can be found that compares experiences of parents of typical children to those with parents of children with disabilities on the dimension of stress. What research has been undertaken, related to stress level differences, appears to focus specifically on parents of children with cerebral palsy (CP), (Brehaut et al., 2004; Britner, Morog, Pianta, & Marvin, 2003; CanChild, 2003; Raina et al., 2004), although a few studies with other populations such as, general developmental disabilities, have been conducted (Baker, Blacher, Crnic, & Edelbrock, 2002; Nachshen & Minnes, 2005).

Britner et al. (2003) found parenting stress was higher among mothers with children who had CP than controls. Families of children with CP had less family resources and greater contact with professional support services but no difference was found in marital satisfaction. For some families, it was suggested marital quality may have buffered the level of maternal

parenting stress with marital quality being self-reported concordance/discordance over a variety of topics (Britner et al., 2003).

Brehaut et al. (2004) found similar results through questionnaires and in home interviews of 468 primary Canadian caregivers. They concluded caregivers of children with cerebral palsy are more likely to experience mental and physical health differences than do other adult Canadian parents. Moreover, they noted caregivers of children with CP were likely to have lower incomes, even after accounting for lower education differences. Caregivers had less time available to work for pay. Further challenges specific to parents of children with CP were identified by caregivers (34% of the sample of 468) in a research brief a year prior to this publication (CanChild, 2003). Identified challenges included: a need for society to be more educated about CP, constant advocating for their child, a lack of information on resources and services, barriers to accessing and maintaining services, a lack of flexibility and coordination of services, balancing work and caregiving, uncertainty/concern for their child's future, balancing time with other children in the family, personal health, financial issues, preserving self, and lack of support from others for the caregiver role (CanChild, 2003).

In an individual study examining behaviour problems and parenting stress in families of three year old children with and without developmental delays, parenting stress was found to be higher in parents of children with developmental delays (Baker, et al., 2002). Both mothers and fathers of children with developmental delay reported that there was a greater negative impact of the child on the family than mothers and fathers without a child with developmental delay. However, the report of positive impact was the same across both groups (Baker, et al., 2002).

This result was also found in an examination of factors that contribute to empowerment in parents of school-aged children with developmental disabilities (Nachshen & Minnes, 2005). Parents reported significantly higher stress scores than controls. However, despite higher stress levels, parents still felt as empowered as controls further demonstrating that higher stress levels do not negatively impact all areas of a parent's functioning (Nachshen & Minnes, 2005). Regardless, these studies support that the child characteristic of disability increases parental stress levels across types of disability (Baker et al, 2002; Brehaut et al., 2004; Britner, et al., 2003; Canchild, 2003; Raina et al., 2004). Given these parents experience different levels of stress, it stands to reason models of their stress would differ from those of typical parents. Therefore, it is important to consider the models of stress specific to parents of children with disabilities.

Models of Stress in Parents of Children with Disabilities

A variety of stress models and theories have been developed specifically for caregivers of people with disabilities due to different causal events and agents of stress (Lavee, McCubbin, & Patterson, 1985; Perry, 2004; Saloviita, Italinna, & Leinonen, 2003). Some theories from general stress and coping research have been reapplied to caregivers of people with disabilities, such as Hans Selye's stimulus response type (1955), P-C-R (Abidin, 1995), and Daily Hassles (Crnic & Greenberg, 1990) theories, and Lazarus and Folkman's (1984) transactional model of stress and coping. Some theories have further been varied to apply specifically to families. For example, ideas from Lazarus and Folkman's (1984) transactional model of stress and coping were included in the adaptation of Hill's (1949) ABCX model to the Double ABCX model (Lavee, McCubbin. & Patterson, 1985; McCubbin & Patterson, 1983; Saloviita, Italinna, & Leinonen, 2003).

The Double ABCX model (McCubbin & Patterson, 1983) has been discussed in both sociological and psychological papers, including those concerning families who care for an individual with a disability, in the geriatric and child populations (Lavee, McCubbin, & Patterson, 1985; Nolan, Grant, & Keady, 1996; Perry, 2004; Trute & Hiebert-Murphy, 2002). It contains pre and post crisis variables to describe additional life stressors and strains that occur prior to or following the crisis producing event. The post-crisis stage variables were an addition to Hill's (1949) original model, as was the dimension of time (Lavee, et al., 1985; McCubbin & Patterson, 1983).

In this model within the pre-crisis stage, a is the stressor, b is the existing resources, and c is the perception of 'a'. When the crisis or x occurs, post crisis aA represents the pile up of demands, bB equals adaptive resources and Cc stands for the perception (coherence) (Lavee, et al., 1985; McCubbin & Patterson, 1983). Family adaptation, xX, is the result of the family's ability to cope with demands and outcomes are placed on a continuum from maladaptation (continued discrepancy between demands and capabilities to meet demands) and bonadaptation (little discrepancy between demands and capabilities. The pile-up of demands on a family is a cumulative effect over time of pre and post crisis stressors and strains (Lavee et al., 1985). The family adaptive resource factor is further described as the family's existing resources and those that are expanded in response to the demands posed by the stressor (Lavee et al., 1985). The resources mediate between the pile-up of demands and adaptation. Resources may include personal resources (self-esteem), family system resources (family cohesion), and social support (Lavee et al., 1985). The perception and coherence factor refers to the family's orientation to the stressor. Coherence is the intervening factor between crisis and adaptation and facilitates the family's ability to adapt to the crisis (Lavee et al, 1985).

The Double ABCX model (McCubbin & Patterson, 1983) has been used in a handful of studies of parents of children with disabilities as a conceptual framework (e.g., Brannen, Heflinger, & Foster, 2003; Saloviita, Italinna, & Leinonen, 2003). One study actually examined if the original ABCX model (Hill, 1949) or the Double ABCX model (McCubbin & Patterson, 1983) was a better fit for data gathered about parents of children with and without developmental disabilities. Researchers found that in fact both models could effectively fit the data, although the original ABCX model (Hill, 1949) was found to be more easily interpretable (Nachshen & Minnes, 2005). This framework was also used in a study of caregiver strain and child use of mental health services as it attempts to describe how families respond to life stressors, and recognizes that there are interrelated factors both internal and external to the family (Brannen, Heflinger, & Foster, 2003). In a study explaining parental stress in mothers and fathers of children with intellectual disabilities, the model was also used (Saloviita, Italinna, & Leinonen, 2003). Researchers discussed the use of the model in both predictive and causal modeling studies. However, this study focused on using it to predict for different causes of parental stress. Using the model to frame their study, researchers found the single most important predictor of parental stress was a negative definition of the situation (Saloviita, Italinna, & Leinonen, 2003). The Double ABCX model has also been used to examine the adjustment in mothers of children with Asperger's syndrome and to frame understanding of culturally diverse families of children with disabilities (e.g., Pakenham, Samios, & Sofronoff, 2005; Xu, 2007).

The lack of a framework to guide previous research related to parental stress has been identified by researchers as a limitation (e.g., Raina et al., 2004). However, even with the use of the double ABCX model (McCubbin & Patterson, 1983) as a structure for research of

parental stress and disabilities, there are some criticisms. Perry (2004) found limitations to the model and how it is used to research families of children with developmental disabilities. For example, her first critique is the X and Xx factor which is conceptualized as a crisis (X) or as an adaptation to a crisis or stressful life event (Xx). However, this conceptualization may not be a helpful one to families of children with developmental disabilities as it should not be defined as a crisis as there may not be a crisis or singularly stressful life event. She also stated a level of confusion between the A and C variables (Perry, 2004). She questioned if parent reports of child difficulty are part of the stressor, or a part of the meaning they attribute to the stressor. In addition, she posits that the bB variable, while taking into account both new and old coping mechanisms, does not account for the distinction between individual parent resources and it is excessively broad (Perry, 2004). Finally, while these models are deemed family models they still use individual measures to operationalize each domain. In addition, models of this nature have become so intricate that many of the variables included cannot be easily measured (Perry, 2004).

As an answer to her own criticisms, Perry (2004) created a model she proposed can be used to guide applied research and clinical practice. It contains four major components: stressors, resources, supports and outcomes, of which each has two domains. Stressors were defined as the minor and major stressful stimuli in lives of parents of children with developmental disabilities, including child characteristics and other life stressors, such as financial problems or employment (Perry, 2004). Resources include personal (e.g., hardiness, optimism, task-oriented coping) and family system resources (e.g., family functioning, marital satisfaction). The supports component includes informal social supports (e.g., emotional or tangible help received from family, friends, social organizations etc.) and formal supports and

services (e.g., professional or paraprofessional interventions). Finally, the outcomes component of the models consists of positive parental outcomes or negative parental outcomes (Perry, 2004). Strengths of this model include that it is simple, concise and could be tested using multiple regression or structural equation modeling (Perry, 2004). However, the model is static and does not focus at looking on a person over time (Perry, 2004).

In conclusion, many theories and models exist to identify stress in both broad and specific contexts (e.g., Lazarus & Folkman, 1985; McCubbin & Patterson, 1983; Perry, 2004). However, it appears that research fails to consistently use these models to examine the stress in families of children with disabilities (Perry, 2004). This may be due to the fact models are simply too complicated and aspects of them too difficult to research. Alternatively, it is logistically problematic to research all aspects of the model at one time (Perry, 2004). Therefore, while ideally it would be beneficial to research all parts of the stress models, it is likely more feasible to study individual aspects within the model (Perry, 2004). Considering all the models discussed have some element of resources or supports, this is a valuable area to investigate. Therefore, this research focused on resources or supports received by families through respite, which is considered by families and those who work with them to be a buffer of stress (Chan & Sigafos, 2001). It is important to consider the child and parent characteristics that buffer or exacerbate parental stress prior to discussing respite as a support, as these may impact the effectiveness of resources and supports.

Stress and Parents of Children with Disabilities

Child characteristics. Research models have supported differences in stress levels in parents of typically developing children and those who have children with disabilities (Brehaut et al., 2004). For example, caring for a child with a disability has been found to be associated

with negative effects on the physical and psychological health of the caregiver (Brehaut et al., 2004). However, not all parents of children with disabilities experience these negative outcomes. This may be because specific parent and child characteristics can act to buffer and exacerbate parental stress (Brehaut, et al., 2004).

Research focusing on a variety of childhood disabilities has examined the characteristics these children possess that contribute to the overall stress of their parents (Baker et al., 2002; Gupta, 2007; Ketelaar, Volman, Gorter, & Vermeer, 2008; For example, parental stress levels and contributing child characteristics have been studied in parents of children with Attention Deficit Hyperactivity Disorder (ADHD), Developmental Disabilities (DD), children with Human Immunodeficiency Virus (HIV), children with Asthma, and typically developing children who attended a pediatric clinic in an urban hospital (Gupta, 2007). This study reported parental stress is related to overall type of disability. Child related stress was highest in parents of children with ADHD as these children were distracted, demanding, moody, and less adaptable (Gupta, 2007). Mothers of children with ADHD and DD reported higher stress levels in the demandingness domain, which suggested that children with these disorders place high demands on the parents for behavioral reasons or poor developmental competence (Gupta, 2007). It was concluded that parenting stress in families of children with special needs is largely determined by the nature of the disorders in children; specifically children with behavioral and developmental disorders contribute to higher levels of parenting stress than children with chronic health conditions (Gupta, 2007).

This was further confirmed in a study of children with cerebral palsy (Ketelaar, Volman, Gorter, & Vermeer 2008). Researchers found children with high levels of maladaptive behaviour significantly contributed to stress parents feel in their parenting role. Specifically,

these children's maladaptive behavior explained the variance in parental stress in the areas of relationship with spouse, attachment, depression and sense of competence (Keetelar et al., 2008). However, unlike the Gupta (2007) study, the child's functional skills or developmental competence was not found to be directly related to increases or decreases in parental stress (Keetelar et al., 2008).

Further evidence of child characteristics contributing to the stress of their parents in a study that purported stress appeared to be related to specific behavioral problems in children with CHARGE syndrome (Coloboma of the eyes, Heart defects, Atresia of the choanae, Retardation of growth and/or development and /or central nervous system abnormalities, Genital hypoplasia, Ear anomalies and/or deafness) (Wulffaert, Scholte, Dijkxhoorn, Bergman, van Ravenswaaij Arts, and van Berckelaer Onnes, 2009). Higher levels of parental stress were reported for children who scored high on scales of depression, disruptive/antisocial behaviour, self-absorbed behaviour, and the autism screening algorithm on the Developmental Behaviour Checklist-Primary Carer (DBC-P) (Einfeld & Tonge, 2002). While there was no difference in parenting stress found in children with a variety of levels of adaptive functioning, there was a difference found for communication skills (Wulffaert et al., 2009). Parents of nonspeaking children reported higher levels of stress than those with children who could speak, although the difference was not significant at a .05 level. No evidence was found that the age of the child had an impact upon parental stress levels (Wulffaert, et al, 2009).

In a study investigating parental stress levels and child characteristics in children with autism, it was reported that different aspects of a child's behaviour were predictive for mothers and fathers (Ornstein Davis & Carter, 2008). Related directly to the diagnosis of autism, the child's social skills were a predictor of stress for both parents. Non-autism specific behaviours

that predicted stress in mothers was the child's ability to self-regulate (Ornstein Davis & Carter, 2008). For fathers it was the externalizing behaviour that was a predictor of stress. It was reported that cognitive and verbal functioning were not predictors of stress for mothers or fathers (Ornstein Davis & Carter, 2008).

Baker, Blacher, Crnic, and Edelbrock (2002) also examined the relationship between child behaviour problems and parental stress in three year old children with and without developmental delays. Researchers asked, "Do children with and without delays already show a different extent of problem behaviours by age 3?" (Baker et al., 2002, p. 441). Children were found to be most different from their non-delayed peers on measures of social withdrawal and attention problems. An additional question asked by the researchers considered parental stress levels and the relationship to the child's cognitive delay and behavioural challenges (Baker et al., 2002). Similar to previous research, both mothers and fathers of children with delays reported a greater negative impact of the child on the family. In a regression analysis, it was found that child behaviour problems were a stronger contributor to parenting stress than intellectual capacity (Baker, et al., 2002). This finding demonstrated even at a young age families of children with disabilities, especially those with behavioural challenges, experience more stress than families with typically developing children (Baker, et al., 2002).

In summary, research has found that parents who have children with high behavioural needs report more stress than parents of children without these needs (e.g., Baker et al., 2002; Gupta, 2007; Ketelaar et al., 2008; Ornstein Davis & Carter, 2007; Wulfaert et al., 2009). There was also some evidence for increased parental stress for parents of children who had poor developmental competence (Gupta, 2007) and were non-verbal (Wulfaert et al., 2009). Consequently, child behavioural needs and developmental competence are important

characteristics to consider when developing supports and services for parents of these children including respite as are parental characteristics.

Parent characteristics. In addition to child characteristics, there are parent characteristics that buffer stress levels in parents of children with developmental disabilities (Gupta, 2007). These parent characteristics include quality of marriage, social support, and parenting competence (Britner, Morog, Pianta, & Marvin, 2003; Dempsey, Keen, Pennell, O'Reilly, & Neilands, 2009; Gupta, 2007). An additional parental variable that has been investigated was parent's attachment to their child with a disability (Hoffman, Sweeney, Hodge, Lopez-Wagner, & Looney, 2009). A key mediating variable supported by research is that of social support (Gupta, 2007). This has been reported for parents of children with Attention Deficit Hyperactivity Disorder (ADHD), chronic illness, and developmental disabilities (Gupta, 2007). The type of social support mediating parental stress depends on type of disability. For example, parents of children with ADHD required psychosocial supports such as parent training and educational accommodations for their children (Gupta, 2007). Parents of children with chronic illness required supports such as medical care, money, transportation and additional help when their children are ill. Finally, parents of children with developmental disabilities required the highest level of support requiring all the previously mentioned types in addition to societal understanding of their child's disability (Gupta, 2007).

The importance of social support was further substantiated in a study that examined this concept with parents who had children enrolled in a support service (Dempsey, Keen, Pennell, O'Reilly, & Neilands, 2008). Despite a small sample size, researchers reported for some families of children with disability, family centered support (support from professionals that directly includes the family) did have some effect on parenting stress levels. Further analysis

revealed that lower levels of stress were related to how comfortable parents were in their relationship with program staff. Parents who felt more autonomous in their decisions experienced higher levels of parental stress (Dempsey et al., 2008).

Family support not organizational support was also found to buffer parenting stress (e.g., Barakat & Linney, 1992). Researchers reported the larger the support network the more family members in the support network, and the more satisfied individuals were with the support received, the better the psychological adjustment of mothers of children with Spina Bifida. That is, the more supported the mother felt, the less externalizing behaviour problems were reported for the child (Barakat & Linney, 1992). This is important to note because previous research has indicated that increased externalizing behaviour problems often leads to higher stress levels in mothers (e.g., Baker et al., 2002; Gupta, 2007; Ketelaar et al., 2008; Ornstein Davis & Carter, 2007; Wulfaert et al., 2009).

Britner et al. (2003) looked at parenting stress and coping in parents of children with Cerebral Palsy (CP) and those with no medical diagnosis. Overall, no difference in marital satisfaction was found, despite high levels of parenting stress, less family resources, and more contact with support professionals. However, in parents with and without children with CP marital quality may have buffered parenting stress. That is, mothers who reported high levels of marital satisfaction reported less parental distress, and find their supports more helpful (Britner et al., 2003).

Parents' sense of attachment to their children was surprisingly found to not be an important component in parenting stress (Hoffman et al., 2009). They reported that despite the high levels of child stress reported by mothers of children with autism, the closeness of their relationship to their children was similar to that of typically developing children. This shows

that despite previous ideas that parents of children with autism were cold and *refrigerator mothers*, their attachment to their children is quite strong (Hoffman et al., 2009). Despite this high attachment, parenting stress was still significantly higher in parents of children with autism than of those with typically developing children. However, a significant difference in attachment was not found (Hoffman et al., 2009). It is unknown if parenting stress would have been even higher without this attachment. Regardless, researchers recommended parents need a way to manage their children's behaviour in order to significantly reduce their stress (Hoffman et al., 2009).

In summary, parent characteristics are important to consider as mediating factors of parental stress (e.g., Britner et al., 2003; Dempsey, et al., 2009; Gupta, 2007). Social support was found to be important, as seen when, social support was reported to depend upon type of child disability (Gupta, 2007). In addition, the more comfortable parents felt with program staff and involved with their children's programming, the lower were their reported stress levels (Dempsey et al., 2008). Organizational support was not the only support identified as a potential buffer. Family support was also found to buffer stress (Bakarat & Linney, 1992). Parents who had a strong and large family support network were less likely to report their child had high levels of behavioural need (Bakarat & Linney, 1992). In addition, parents who reported high levels of marital satisfaction reported less parental distress than those without marital satisfaction (Britner et al., 2003). A parent's sense of attachment to their child was found to be an unimportant factor in mediating parenting stress (Hoffman et al., 2009). When parents' do not have these buffers to decrease their levels of stress, a variety of outcomes may result.

Outcomes of Stress

Parental outcomes. Stress or distress does not necessarily mean dysfunction (Cadman, Rosenbaum, Boyle, and Offered, 1991). However, research suggests that in the case of parents of children with disabilities, stress or distress does seem to have a relationship with physical and emotional dysfunction (Brehaut et al., 2004; Dumas, Wolf, Fisman, & Culligan, 1991; Gallagher, Phillips, & Carroll, 2010; Oelofsen & Richardson, 2006). Specifically, parents seem to show elevated levels of chronic physical conditions such as ulcers and migraines, and some psychological concerns such as dysphoria, when compared to parents of typically developing children (e.g., Brehaut et al., 2001; Dumas et al., 1991).

Mothers of children with autism and those with children who had behavioural disorders have shown increased levels of dysphoria (state of feeling unwell or unhappy) that was directly associated with parenting a difficult child rather than a truly occurring depressive disorder (Dumas, et al., 1991). In addition, parents of children with a variety of disabilities and health concerns such as blindness, heart problems and cerebral palsy, have reported mental health treatment two to three times higher than parents of well children (Cadman et al., 1991). These researchers hypothesized since parents have such close access to this type of service through their children, it may have been higher recognition of mental health needs and treatment in the parents as a result. This reasoning was supported by research looking at parents of children with cerebral palsy (Brehaut et al., 2001). These parents reported more concerns with their own emotional and cognitive psychological well-being. These parents also reported higher levels of emotional problems, such as: unhappiness; a general loss of interest in life, and cognitive problems, such as difficulties with memory and problem solving when compared to parents of typically developing children (Brehaut et al., 2004).

In addition to psychological health, physical health concerns, such as ulcers, have been found to be more numerous in parents of children with disabilities (Brehaut et al., 2004). Parents of children with disabilities have reported a higher level of chronic health conditions associated with stress, such as ulcers and migraines (Brehaut et al., 2004). However, no difference was found for conditions that were not stress related such as food allergies and chronic bronchitis. These results stood when the researchers controlled for socioeconomic status (Brehaut et al., 2004).

Oelofson and Richardson (2006) also reported parents of preschoolers with developmental disabilities disclosed significantly poorer health. Further evidence of poorer health quality among parents of children with disabilities was found when researchers examined sleep quality in parents of children with developmental disabilities (e.g., autism, Down's syndrome) (Gallagher, Phillips, & Carroll, 2010). After controlling for body mass index, it was found that 72% of parents compared to 22% of controls were found to be *poor sleepers*. Stress levels were considered to be a significant predictor of this finding even after adjusting for confounding variables (Gallagher et al., 2010). In addition to the aforementioned parent outcomes, child outcomes from parental stress must also be considered to further explain the full impact of parental stress on a family.

Child outcomes. There are also negative child related outcomes that are a result of increased parental stress (Schormans, 2002). Children with disabilities have been reported to experience higher levels of maltreatment than their peers who do not have a disability (Schormans, 2002). In addition, children are most likely to be abused by their primary caregiver (Schormans, 2002). Across both groups (children with and without disabilities), neglect was the most common form of abuse, and was even more common in children with

disabilities (Schormans, 2002). However, it has also been noted that the level of care which would be considered adequate for typical children may be neglectful for children with physical, cognitive, or behavioural disabilities (Cahill et al., 1999). While not explicitly stated neglect was a result of increased parenting stress, parenting stress has previously been demonstrated as a risk factor for neglect (Beckman, 1991; Rodriquez & Murphy, 1997).

In a review of research on maltreatment (e.g., physical abuse, sexual abuse, emotional abuse, neglect) and disabilities in children, children with more mild impairments may experience more maltreatment (Vig & Kaminer, 2002). This finding is likely due to the fact children with more mild impairments are more frustrating for families because: (1) their outcomes are uncertain (i.e., parents of children with severe impairments may have more realistic outcomes because they have a clearer knowledge of their child's limitations); and (2) they are less likely to receive intensive services and supports (Vig & Kaminer, 2002). The consequences of physical abuse and neglect (most common) for all children are serious. For example, young children who have been subjected to physical abuse have been found to be: more aggressive, respond to peers' distress in an aggressive manner, and demonstrate noncompliance and lack of self-control (Vig & Kaminer, 2002). Older children have been reported to experience more disciplinary referrals, suspensions, higher dropout rates, and poorer school adjustment (i.e., grades, absence, grade repeats) (Wodarski, Kurtz, Gaudin, & Howling, 1990; Vig & Kaminer, 2002). Consequences of neglect may include: developmental delays, language problems, poor academic achievement, distractibility, impulsivity, and poor self-control (Vig & Kaminer, 2002). While these are studies consider typically developing children who were matched with controls, the findings still demonstrate serious effects of

abuse on children's emotional and cognitive development (Schormans, 2002; Vig & Kaminer, 2002).

It is imperative that different support systems are put in place to decrease parental stress levels since: (1) parenting stress has been found to be higher in parents of children with disabilities than typically developing children and, (2) parenting stress is a risk factor for negative child and parent outcomes (Baker et al., 2002; Brehaut et al., 2004; Gupta, 2007; Shormans, 2002). One such support system or resource that is often used to address parental stress is respite (Chan & Sigafos, 2001). Respite can be defined as a break from caregiving and has been reported to decrease parental stress, at least in the short term (Mullins, et al., 2002; Meltzer & Bennett Johnson, 2004; Slavik Cowen & Reed, 2002). Therefore, it is important service providers and policy makers understand what influences parental choice of respite type, including parent and child characteristics, to ensure appropriate services can be offered. One must consider what respite is, how respite affects parental stress levels, existing barriers and reasons for non-use, and how respite can be made more effective for individual families.

Respite Services as External Support to Buffer Parental Stress

There is no universal definition of respite; however, all definitions include the same basic tenants (Damiani, Rosenbaum, Swinton, & Russell, 2003; Neufeld, Query, & Drummond, 2001; Pollock, Law, King, & Rosenbaum, 2001; Slavik Cowen & Reed, 2002). Respite is the care of a person with a disability, which can occur in a variety of settings in order to provide the family with a break from caregiving (Damiani, et al., 2003; Neufeld, et al., 2001; Pollock, et al., 2001; Slavik Cowen & Reed, 2002). A detailed definition of respite specific to children is that, "Respite care is a service whose main function is to relieve the

parent/family /primary caregiver for a specific period of time while facilitating a positive and rewarding experience for the child with a disability or chronic illness” (Zimmerman & Chappel, 1996 p. 5). Consequences for parents and children can include caregiver burnout, crisis, neglect, and abuse if they do not receive proper respite (Dunbrack, 2003).

The cost of respite to the caregiver varies across Canada from province to province (Dunbrack, 2003). Some provinces have no direct cost to the user for in-home respite (e.g., Ontario), whereas others’ income or income plus assets are used to assess family eligibility for services (e.g., Saskatchewan) (Dunbrack, 2003). Saskatchewan families that are eligible for in-home respite are required to pay anywhere from \$61.00 - \$360.00, any amount incurred after will be paid by the public system to a maximum amount (Dunbrack, 2003). Families that have an income above the required amount will pay a portion of their services all the way up to the full amount (Dunbrack, 2003). In most Canadian jurisdictions programs funded publicly are geared towards serving those with low incomes (Dunbrack, 2003). This leaves individuals with a moderate to high income to hire their own services they have found independently or with help from an agency.

Pollock, Law, King, and Rosenbaum (2001) discussed different models of respite that vary on the dimensions of: purpose, duration, location and provider. Purpose can be divided into two different levels primary and secondary. The intent in the primary level is to provide the family with a break from caregiving. The focus in the secondary level secondary is on the child’s needs. However, a family break is a beneficial additional effect. For example, a model with a primary level of service would be a matching and brokerage program (Pollock et al., 2001). In this type of program workers are recruited in the community and matched with families. The aim is the individual will provide respite to the family on a long term basis. An

example of a secondary model is a summer camp where children with disabilities can go to experience social, emotional, and physical growth while providing a break for the other family members (Pollock et al., 2001).

The durational element of respite models is self-explanatory. That is, some respite is short term and provides relief for only a short time (a few hours to a day), while some respite is long term (a week or longer) (Pollock et al., 2001). Respite can be provided in home or out of home. The majority of respite types are found out of the home: summer camps, group day care, group respite facilities, community residences, residential treatment facilities, pediatric nursing homes, and hospice (Zimmerman & Chapple, 1996). Facility-based respite has a high demand in Saskatchewan, with the need being comparable to Montreal, Manitoba, British Columbia, and Nunavut (Dunbrack, 2003). In-home respite programs are available that match respite workers to families, or families can rely on friends and family members to come into their home. During this type of care, the caregiver may remain in the home or tend to things outside of the home (Dunbrack, 2003). Funding for this type of respite in Saskatchewan is based on an income and asset basis. A case manager will determine need based on financial and psychosocial capacity (Dunbrack, 2003).

The final dimension considered in models of respite is the provider. Respite providers can be: (1) paid professional caregivers who have formal training, or (2) can be more informal co-operative models (e.g., friends, relatives, parent-cooperatives and family to family support groups) (Pollock et al, 2001).

There are a variety of options for respite, and families have to determine which respite service type best suits their needs, consider if they are eligible for the service, and figure out how to access it (Zimmerman & Chappel, 1996). *Access* is defined as the process of obtaining

respite services, whereas *eligibility* refers to the child qualifying for entry into a program (Zimmerman & Chappel, 1996). In Saskatchewan, it may be required that a case manager examine the families' psychological and financial needs in addition to the nature of the child's disability prior to making a decision about respite eligibility (Dunbrack, 2003). Therefore, access and eligibility to respite can be more difficult than simply taking your child to a program or hiring a private caregiver if you are looking for government support. These issues, among others, can be the barriers that determine why families choose to use or not use respite.

Ease of Use and Access: Reasons for Use and Non-use of Respite Services

Researchers examining respite services have reported on the ease with which families are able to use and access said services, and their reasons for use and non-use (e.g., Chadwich, Beecham, Piroth, Bernard, & Taylor, 2007; Neufeld, Query, & Drummond, 2001). Reasons expressed within the literature for non-use of formal respite services were: (1) some families who did not use respite services found they did not feel they required them; and (2) some families were not aware the service was available (Chadwich et al., 2007; Damaini et al., 2004; Neufeld, Query, & Drummond, 2001). Chadwich et al. (2007) further reported that families who were unaware of respite services in their study were more likely to not have the support of a social worker, be of African origin, and have children whose level of functioning was reportedly higher.

Some families do not use respite as a result of access rather than perceived need (e.g., Chadwich et al., 2007; Doig, McLennan, & Urichuk, 2009). For example, Chadwich et al. (2007) found 34.4% of families they surveyed reported they did not receive respite but wanted it. In addition, no difference in child functioning and parental distress was found between families who wanted respite care and had not received it, and those who wanted it and had

received it. Doig, McLennan and Urichuk (2009) surveyed Canadian parents and reported there was a problem with waitlists, needs assessments, and home visits that delayed them from getting service. In addition, having a medical diagnosis for their child, their ability to pay for respite care, the child's age (little service access at infancy and for young children), and behavioural requirements were all reported to be limiting factors to access. Damiani et al., (2004) also had parents report on their survey that barriers to use included: respite care was limited, respite care was difficult to arrange, the particular services required were difficult to find, limited information existed about respite services, and there were concerns regarding the quality of care their child would receive.

Barriers have also been reported for more informal sources of respite, such as support from family and friends (e.g., Grant & Whittell, 2000; MacDonald & Callery, 2004). Asking family and friends to provide respite for their child with a disability was reported as being uncomfortable for parents, because parents did not want to burden their family members (Grant & Whittell, 2000; MacDonald & Callery, 2004). Asking family members to provide respite was also reported by parents to be a strong source of stress in couple's relationships. This stress was usually over whether or not they should ask family for help, and parents preferred family members to offer help and save them this discussion (Grant & Whittell, 2000).

Despite all of these barriers for accessing respite, many people still are willing to navigate the system in order to obtain the service (Chadwich et al., 2007). Parents use this service because they recognize it as being of benefit to them and their families. Through the use of surveys, 66.7% of families who used respite services often reported wanting more (Chadwich et al., 2007). Families who want respite care have been found to have higher

parental distress scores on the Parenting Stress Index and the Malaise Inventory, and often had children with more severe challenges and behavioural concerns (Chadwich et al., 2007).

Other parental reasons have been reported for accessing respite services. For example, Damiani et al., (2004) reported reasons parents wanted to access respite included: wanting to take a planned vacation or break, assistance with daily living, providing a socialization opportunity for their child, coping with a crisis, giving siblings a break, or a combination of these reasons. Nearly all parents who received respite services in this study (90%) reported the services as being beneficial for their family and their child. McGill, Papachristoforou, and Cooper (2006) found that 49% of the families who used respite rated it as helpful. This low finding may be due to some families feeling the help was insufficient, the respite workers being perceived as not having knowledge of dealing with challenging behaviour, and/or some families reporting the only useful support came from friends and family members. Neufeld, Query, and Drummond (2001) reported similar results. Many caregivers who actively used respite did not perceive it as a break. Reasons for this included: lack of people or agencies to provide care, concern about the ability of others to care of the child, lack of funding, and the child's behavioural or physical needs were not accommodated. MacDonald and Callery (2003) also discussed reasons for the use of respite, and categorized reasons into three types: short breaks by family and friends (did not like to ask for these), short breaks by an agency, and long breaks. Short breaks by an individual from an agency were reported to provide parents with the opportunity to attend to household chores, shop, and socialize. Longer breaks afforded parents time to sleep (MacDonald & Callery, 2003). It was important to the parents that in these longer breaks the children were safe and cared for, but the purpose was to rest and replenish (MacDonald & Callery, 2003). It is important to understand why parents do or do not use

respite, however it does not provide useful information regarding its effectiveness (Pollock et al., 2001). That is, knowing if respite is an effective means of stress release can help determine how respite should be used by families to help further facilitate their mental health (Mullins, Anoil, Boyd, Page, & Chaney; 2002; Pollock et al., 2001).

Effectiveness of Respite Care

Studies have reported reasons for using respite care and its perceived benefits (e.g., Damiani et al., 2009; Neufeld et al., 2001). However, these studies typically are descriptive and self-report based and have not examined the actual effectiveness of respite care (Pollock, et al., 2001). Mullins, Anoil, Boyd, Page, and Chaney (2002) examined the psychological benefits of respite services on parents of children who were admitted to an inpatient developmental disability center. Children could receive two types of service: (1) respite care (3 to 7 day inpatient admission with 24 hour nursing care and supervision by recreational therapy staff), or (2) short-term inpatient treatment for 30 days during which a comprehensive evaluation and formal therapy services were provided. Using pre and post report measures, researchers found parental psychological distress was significantly lower at time of discharge for the respite care group and was equal to that of the inpatient group (Mullins et al., 2002). In addition these changes were maintained over a six-month time period. Researchers found a decrease in parenting stress levels at discharge, but no long term maintenance was found. It is important to note that this study did not have a control group. Therefore, it is not possible to ascertain that respite care was the sole factor in parents' stress reduction and psychological improvement (Mullins et al., 2002). Further research examining long term effects with consistent access to respite care (i.e., once a month, once every two months) would also provide a more complete picture of the effectiveness of respite care (Mullins et al., 2002).

Anoil, Mullins, Page, Boyd, and Chaney (2004) also examined the effects respite care had on reducing child abuse potential during the same data collection process as the previous study. Neither the shorter term respite care nor the long term inpatient care was found to be sufficient to reduce child abuse potential or improve family relationships. However, researchers did note a small sample size may account for these results. Respite or inpatient care is not sufficient to reduce child abuse potential, however it can result in significant improvements in parenting stress at least in the short term (Anoil et al., 2004).

Slavik Cowen and Reed (2002) compared scores on the Parenting Stress Index Questionnaire before and after respite services were given. They found significant decreases in Total Stress Scores, Parent Domain Scores and Child Domain Scores following respite care. These results suggested respite care is an effective intervention to reduce stress in the parent-child relationship. However, no long term results were taken to determine how long reductions in stress would last with or without continuation of respite care (Slavik Cowen & Reed, 2002).

Summer camps, as respite, have also been found to be for parents of children with chronic conditions in the short term (e.g., Meltzer & Bennett Johnson, 2004). Summer camps were found to contribute to improved general psychological functioning up to one month after camp had ended (Meltzer & Bennett Johnson, 2004). However, no positive effects were noted in terms of objective stress as once the child returned home the caregiving needs remained the same (Meltzer & Bennett Johnson, 2004). Therefore, respite in a variety of forms has been found to be beneficial for parents at least in the short term (Anoil et al., 2004; Meltzer & Bennet Johnson, 2004).

Summary

Respite appears to be, and is perceived by parents as, an effective means to reducing parental stress and psychological distress at least in the short term (Anoil et al., 2004; Meltzer & Bennett Johnson, 2004; Mullins, et al. 2002; Slavik Cowen & Reed, 2002). Some studies have found that parental perception of respite services is positive (e.g., Damiani et al., 2004; McGill et al., 2006). However, some exceptions include feeling there are not enough services available, and workers may not be trained to deal with all manners of physical care and behavioural challenges (e.g., Neufeld, et al., 2001). One glaring concern noted across studies was that some parents are unable to use respite services due to the challenging behaviours their child exhibited (e.g., Doig, et al., 2009; McGill et al., 2006). It was also reported that these parents are more prone to high stress levels, chronic illness, and psychological distress (e.g., Baker et al., 2002; Gupta, 2007; Ketelaar et al., 2008; Ornstein Davis & Carter, 2007; Wulfaert et al., 2009).

Despite the abundance of descriptive research completed in the area of respite, there has been only one research study examining parents' perception of the kind of respite they are using (Stalker & Robinson, 1994). No studies have tried to examine types of respite used and/or severity of the challenges associated with the child's adaptive and behavioural functioning. The purpose of this study was to: determine the types of respite Saskatchewan parents are using; and examine the relationship between formal and informal respite use and child behaviour concerns, child adaptive skills, and parental stress. A mixed methods design was used to investigate. It is hoped this information will guide future research targeting the effectiveness of respite services and provide information for future respite programming.

CHAPTER 3: METHODOLOGY

Mixed Methods Research

Mixed methods research involves collecting and analyzing qualitative and quantitative data within a single study (Creswell, 2003). This methodology combines the strength of quantitative approaches (i.e., operationalization and measurement of constructs, group comparisons, and strength of association between variables) and the strength of qualitative approaches such as the capacity to generate rich accounts of data (Castro, Kellison, Boyd & Kopak, 2010). However, just as it is important in qualitative and quantitative research to consider the study design this is also the case in mixed methods research. Researchers require a predetermined research design or they can find themselves unable to answer their research question (Giddings & Grant, 2006).

Different researchers from varied disciplines have outlined mixed methods research designs (Cresswell & Plano, 2007). Of the four main types of designs outlined by Creswell and Plano (2007), the Embedded Design was chosen for this study. Embedded design best fits this study since one type of data plays only a supplemental role within the overall research design. Strengths of this design include: (1) it is good to use when researcher timelines and resources are too tight to perform extensive quantitative and qualitative data collection, and (2) it is logistically more manageable for graduate students as one method is emphasized over another. The challenges with this method include that the researcher must specify why additional data is being collected in relation to the overall study, and integrating the results can be difficult when the two methods are used to answer different research questions (Cresswell & Plano, 2007). This study focused primarily on quantitative data, with qualitative data being collected in the form of open-ended questions on a participant survey.

Participant Recruitment and Selection

Recruitment

Participants were recruited with purposeful sampling which allows the researcher to choose participants based on characteristics that are of interest (Richards & Morse, 2007). Community agencies in Saskatchewan (e.g., Autism Services of Saskatoon, Community Living Association Saskatoon Incorporated, Regina and District Association for Community Living, Saskatchewan Association for Community Living Family Network) were initially contacted by the researcher through email. Each email contained a letter of invitation (see Appendix A) and a copy of the certificate of ethics approval from the University of Saskatchewan Behavioural Research Ethics Board. The letter of invitation for community agencies outlined the purpose and intent of the research, and requested they respond to the researcher via email or phone if they would be interested participating. Agency participation involved sending a participant information email (see Appendix B) to their client lists. The information included a study description and a direct link to the online consent form and questionnaire. Of the Saskatchewan agencies contacted, four had phone meetings with the researcher and agreed to participate. These agencies sent out the email to their client list. Two of the four agencies also agreed to send out a follow-up email after the initial email had been sent. This wave of recruitment resulted in a smaller number of participants than anticipated (n=23), so a second wave of email invitations were sent to Saskatchewan agencies. From this wave one additional agency from the Regina Qu'Appelle Health Region agreed to participate. However, they did not have access to client email so they agreed to print copies of the information letter with the questionnaire link and leave them in the reception area for people to take if they were interested in participating. In addition, because it was not originally anticipated that recruitment would

happen through health regions and there was a slight change in methodology, an additional ethics review application was required by the Regina Qu'Appelle Health Region's Behavioural Research Ethics Board.

The number of recruited participants remained small despite additional efforts to recruit participants from Saskatchewan. As a result, it was decided additional recruitment would occur in the provinces of Manitoba and Ontario. This required an amendment to the University of Saskatchewan Research Ethics Board application. Once approval was obtained, an identical process to Saskatchewan recruitment was undertaken. Of the Ontario agencies contacted, three agreed to participate. Two emailed the participant information email to their clients, and one agreed to post a recruitment poster with the questionnaire link on their agency website (see Appendix C). Once this methodological change was given ethical approval, the Ontario agencies went forward with providing the participant information email/poster and survey link to their clients in the agreed upon manner. Of the Manitoba agencies contacted, one responded but upon further investigation decided asking their staff to email clients violated their union contract and therefore they declined to participate.

Selection and Inclusionary Criteria

Potential participants followed the link to the online questionnaire, and read the consent form (see Appendix D). If participants selected the option to move forward to the next screen, then they were able to begin the study. However, if they did not identify that they were from Saskatchewan, Manitoba, or Ontario and had a child with a diagnosed developmental disability between the ages of 6 and 18, they were unable to continue. All other participants could continue and answer the survey questions, whether they had or had not used formal or informal respite.

Process of Gaining Consent

Participants from the agencies that agreed to take part were provided with a study information letter by either: (1) email, (2) paper copy, or (3) website post. Participants could then choose to follow the provided questionnaire link which would take them to the consent form. The consent form outlined that their participation was voluntary, and they could choose to withdraw from the study at any point without consequence.

Confidentiality

All survey data was provided to the researcher by the Social Science Research Laboratory in an anonymous format. This means while participants were able to withdraw from the study at any point, any data already submitted at the point of withdrawal could not be extracted. Participants were made aware of this in both the initial information letter and consent forms. In addition, given the sensitive nature of some of the questions, participants were made aware of their local distress line in the event they experienced a negative emotional reaction while completing the survey.

Participants were provided information in the Participant Information Letter on how to contact the researcher and her supervisor in the event they had any questions or concerns about the study. They were also encouraged to contact the researcher if they were interested in receiving a copy of the research results.

Measures

Two measures were used in this study: (1) the Respite Information Questionnaire (as adapted from Preece & Jordan, 2007) and (2) the Parental Stress Scale (Berry & Jones, 1995). The Social Science Research Laboratory (SSRL) at the University of Saskatchewan adapted these two measures, and programmed them for an online format.

Respite Information Questionnaire

Preece and Jordan (2007) created a survey examining why some families with children who have Autism Spectrum Disorders accessed short breaks (respite) and others did not (see Appendix E). Their survey consisted of 27 questions broken into four sections: (1) Family, (2) Short Break (respite care) Services, (3) Future Needs, and (4) General Attitude to Respite Care. There was no reliability and limited validity evidence reported for this survey. However, the survey was designed with the involvement from a group of parents with children with Autism Spectrum Disorders from a neighboring community to ensure ecological validity (i.e., questions are applicable to the real-life situation under examination). A portion of their survey, addressing children's dependence levels was taken from Robinson and Stalker's Ten Point Dependence Scale (Robinson & Stalker, 1990). This portion of the survey enabled parents to classify their child's level of dependence. No validity and reliability information was available for this section of the scale, but it was supported by the parent group as being ecologically valid (Preece & Jordon, 2007).

The adapted version of the scale (see Appendix H) has eliminated questions not central to this research study (e.g., ethnicity, school attended, family characteristics, social worker involvement and the future needs section). In addition, terminology was changed to reflect terminology used in American and Canadian research as opposed to research from the United Kingdom. Specifically, the term *short break* was changed to *respite* and the respite types were changed to reflect those used in Canada, such as residential respite services, trained worker in home, untrained worker in home, etc. (Dunbrack, 2003). Directions for each section were modified to increase clarity and to make them more suitable for an online format. For example, the original survey said "Please can you say" the adapted version says, "Please indicate if."

In addition, there were changes made to the actual questions in the survey. Questions about use of respite types were changed to also ask how often services were used in hours per month since the previous survey was not interested in how often types of respite were used. This information is important in this study as we want to distinguish what type of respite families primarily use. Question 8 was changed from the open ended question, “What is your child’s behaviour like most of the time?” to eight questions on a 4-point Likert scale addressing the child’s distractibility, externalizing behaviours, adaptability and engagement. For example, one question asked participants to “Please indicate how often your child exhibits the behaviour listed below: easily distracted.” The question about behaviour was expanded in order to obtain more specific information regarding the child’s behaviour, specifically those related to increased parental stress levels (e.g., externalizing behaviours, adaptability). The question asks parents to rate the behaviours as occurring *often*, *sometimes*, *seldom*, or *never* by placing a checkmark under the appropriate descriptor. These specific behaviours were chosen as other studies have identified them as contributing to increased parental stress levels (Gupta, 2007; Wulffaert, Scholte, Dijkxhoorn, Bergman, van Ravenswaaij-Arts, & van Berckalaer-Onnes, 2009). Three open ended questions were added to address factors influencing parents’ choice of respite, and if they felt their options were limited by their child’s behaviour or cognitive/self-care abilities. The estimated time to complete this questionnaire was 15 minutes.

Parental Stress Scale (Berry & Jones, 1995)

The Parental Stress Scale (PSS; Berry & Jones, 1995) was developed to provide a widely available and easily administered measure of stress associated with being a parent (see Appendix H). The scale is based on the Conservation of Resources (COR) theory whose central tenet is “people strive to obtain, retain, and protect that which they value” (Hobfoll,

1998 p.55). From the model, Hobfoll (1988) defined stress as a reaction to the environment where there is: (1) a threat of resource loss, (2) a loss of resources, or (3) the lack of resources gain following investment or loss of other resources. In early psychometric testing, it was found that the scale was appropriate for both mothers and fathers of children with and without disabilities and was easy to administer and score (Berry & Jones, 1995). These were advantages found over the Parenting Stress Index (Abidin, 1986), which is often used in this type of research. The Parental Stress scale consists of 18 questions representing the positive and negative aspects of parenthood. For example, a positive item would read, "I enjoy spending time with my child," and a negative item would read, "Having children has been a financial burden." Parents were asked to agree or disagree with items pertaining to their relationship with their child on a 5 point scale: (1) *strongly disagree*, (2) *disagree*, (3) *undecided*, (4) *agree*, and (5) *disagree*. This scale was found to have adequate internal reliability ($\alpha = .83$) and test-retest reliability (.81; Berry & Jones, 1995). Convergent validity was also found to be satisfactory when compared with the Total Parenting Stress Score of the Parenting Stress Index (.75, $p < .01$; Berry & Jones, 1995). The estimated time to complete this survey was five to ten minutes.

Data Collection

Following participant agreement with the information provided on an online consent form, data collection occurred through participant completion of an online survey. Participants were provided contact information for the researcher should they have any questions or concerns. The Social Science Research Laboratory (SSRL) at the University of Saskatchewan was responsible for gathering the data from the online survey and providing it to the researcher.

Data Analysis

Data from participant responses to the survey items was provided to the researcher by the Social Science Research Laboratory in a Statistical Package for the Social Sciences (SPSS) Version 21.0 (IBM, 2012) data file. The researcher did a check to determine the accuracy of entered data by looking for data inconsistencies in variables and labels. For example, the total scores for participants on the Parental Stress Scale were checked for accuracy. All non-statistical data (open-ended text questions) were entered into a word document by question in order to allow for thematic analysis.

Independent variables collected included: parental stress level as measured by the total score on the Parental Stress Scale (PSS; Berry & Jones, 1995), and child behaviour and ability as measured by the Respite Information Questionnaire (adapted from Preece & Jordon, 2007). Specifically, child behaviour was measured by the total score from the eight Likert scale behaviour questions. Child ability was measured by the total number of adaptive areas with which parents identified their child needed help. The dependent variable was the total number of formal and informal hours of respite used, both currently and in the past, as dictated by parents' answers on the Respite Information Questionnaire.

Research Question 1

The first research question asked: What respite services are families with children who have disabilities using? This question was answered through descriptive statistics including measures of central tendency, based on the quantitative survey questions.

Research Question 2

The second research question asked: Are parental stress levels, level of help required by child, and severity of behavioural challenge related to the types of respite used by families?

This question was answered using Mann Whitney *U* tests and correlations. Mann Whitney *U* is a non-parametric test that allows the researcher to assess the relationship between the medians of two groups of independent variables that are not normally distributed (Bluman, 2004). Pearson product moment correlations were also used to determine the strength of the linear relationship between two continuous variables (Bluman, 2004). Data was examined as both categorical and continuous to ensure no potential relationship between the variables was missed, as categorizing continuous data can lead to a loss of information. Also, variability that does exist may be subsumed by each of the groups (Royston, Altman, & Sauerbrei, 2006). However, chances were increased that if a relationship existed it would be found by using both types of variables.

Further analyses were conducted to verify relationships found statistically through thematic analysis of the respite survey's open ended questions. Six open ended questions were posed to participants, including: (1) Why are you currently not using any respite services? (2) Why are you no longer using respite services you have used in the past? (3) What factors have influenced the types of respite you choose? (4) Please explain why you feel that respite options for your child are limited as a result of behavioural challenges. (5) Please explain why you feel that respite options for your child are limited as a result of their cognitive and self-care abilities, and (6) If there is anything else you wish to add please do so below. Participants' responses to these questions were qualitatively analyzed together using basic qualitative design (Merriam, 2009). The purpose of basic qualitative design is to understand how people make meaning of their lives and experiences, with the overall goal of uncovering and interpreting these meanings (Merriam, 2009). Merriam (2009) asserts researchers conducting a basic qualitative study are primarily interested in: "(1) how people interpret their experiences, (2)

how they construct their worlds, and (3) what meaning they attribute to their experiences” (p. 23). Data are collected through interviews, observations or document analysis and analyzed by identifying recurring patterns within the data (Merriam, 2009). The findings become the themes and patterns the researcher identified and the findings are supported by the data they were derived from (Merriam, 2009).

Analyses followed Braun and Clarke’s (2006) six phase model of thematic analysis. “Thematic analysis is a method for identifying, analyzing, and reporting patterns (themes) within the data (Braun & Clarke, 2006 p.70). The first phase of thematic analysis is to familiarize one’s self with the data. All qualitative data was read through by the researcher three times. Initial thoughts and coding ideas were documented in a journal with each read. The second phase involves generating initial codes. Codes identify a feature of the data that is interesting to the researcher and may be the basis of repeated patterns (Braun & Clarke, 2006). The researcher coded the data manually by using highlighters to indicate potential patterns. Following this data was collated by code into a word document. The third phase is searching for themes. Once all data was coded and collated the researcher began searching for broader themes amongst the codes. This was done by cutting out all collated codes and arranging them into a visual representation of potential themes. The fourth phase involves a review of all the themes. This phase involves two parts. First, the researcher reviewed themes at the level of the coded data extracts, to look for thematic consistency. Secondly, the researcher reviewed themes against the whole data set. Any data that was coded incorrectly or not coded initially was re-coded. The fifth phase is defining and naming themes. A narrative is created here that identifies what is interesting about the data extracts and why. This is also the phase where sub-themes were identified. Finally, during the sixth phase, the researcher produced the report

ensuring that the story of the data was told. This analysis was then compared to the statistical relationship found between variables.

CHAPTER 4: RESULTS

Overview

The purpose of this study was to investigate the potential relationships between parent and child characteristics and use of different kinds of respite. Participants were initially recruited from five Saskatchewan community agencies and three Ontario community agencies. However, the recruitment in Ontario yielded no participants so all participants were from Saskatchewan.

Child behavioural and adaptive characteristics, along with the types and use in hours of respite types, were measured with questions on the Respite Information Questionnaire (adapted from Preece and Jordan, 2007). Parental stress levels were measured with the Parental Stress Scale (PSS; Berry & Jones, 1995).

Participants

Fifty-four participants accessed the survey link and of those fifty participants consented to partake in the study. Of the 50 that consented, 27 participants met the inclusionary criterion (i.e., had to be from Manitoba, Saskatchewan, or Ontario, and to have a child with a diagnosed developmental disability between the ages of 6 and 18). An additional two participants were removed from the study as they did not answer any of the core study questions. Parents who identified themselves as having more than one child who had a developmental disability were asked to complete separate Respite Information Questionnaires for each child. However, only one parent was identified as having more than one child with a developmental disability. Therefore, the data from the second child was added to data for the first children. This resulted in a total of 26 participants in this study. Despite recruitment efforts in other provinces, all participants were residents of Saskatchewan.

It is important to note that not all participants answered all questions or were included in the analysis of all questions. The number of participants that completed the entire Respite Information Questionnaire and Parent Stress Scale was 23. Therefore, the participant number ranges from 23 to 26 dependent upon the question. The exact number of participants was made explicit for each analysis.

Of the 26 participants, 23 identified themselves as the child's mother and 3 identified as the child's father. The number of adults living in the child's home ranged from 1 to 3. Five children were from a home with one adult, 15 children were from a home with two adults, and four children were from a home with three adults. The number of children under the age of 18 living in the home also ranged from one to three. Seven of the children were only children, 12 lived with one other child, and five lived with two other children. Two participants did not report the number of children or adults in the household.

The children ranged in age from 6 to 15 years ($M = 11.38$, $SD = 2.68$). Twenty-two of the children were male and four were female. Parents reported a variety of primary diagnoses for their children (see Table 1). Additionally, 45% of parents disclosed at least one additional diagnosis for their child (e.g., autism spectrum disorder and anxiety, cerebral palsy and global developmental disability).

Research Question Results

Research Question 1

The first research question posed was: What kinds of respite services are Saskatchewan families with children who have disabilities using? The percentage of families who use each type of respite and the range, mean and standard deviation of the hours of respite used in an average month were examined.

Table 1

Child's Primary Diagnosis.

	n	%
Diagnosis		
Autism spectrum disorder	14	53.8
Asperger's syndrome	3	11.5
PDD-NOS	3	11.5
Cerebral palsy	3	11.5
Down syndrome	1	3.8
CHARGE syndrome	1	3.8
11:22 unbalanced translocation with partial trisomy	1	3.8

Note. PDD-NOS is Pervasive Developmental Disorder-Not Otherwise Specified, and CHARGE syndrome is Coloboma of the eyes, Heart defects, Atresia of the choanae, Retardation of growth and/or development and/or central nervous system abnormalities, Genital hypoplasia, Ear anomalies and/or deafness.

Informal respite use. Parents were asked to choose from a list of six options all the types of informal respite they were currently using in an average month. The options provided included: the child's siblings, grandparents, other relatives, neighbours, family friends and other. Of the 26, 35% reported using the child's grandparents, 27% used their other children, 27% reported using family friends, 19% used other relatives, 4 % used their neighbours, and 12% identified as using other informal respite types (e.g., significant other). Thirty-five percent of participants reported not currently using any form of informal respite (see Figure 1).

The number of hours parents reported currently using in an average month for each respite type varied. Not all parents who reported using the respite type completed the questions about the number of hours used in an average month. Six parents disclosed that in an average month they used their other children to provide respite between 1 and 8 hours ($M = 4.3$, $SD = 2.33$). Nine parents reported using their child's grandparents between 2 and 48 hours ($M = 12.44$, $SD = 15.19$). Other relatives were used as a source of informal respite by three parents

with the amount of hours used in an average month ranging between 2 and 10 hours ($M = 5.33$, $SD = 4.16$). Only one parent reported currently using neighbors for informal respite for 2 hours in an average month. Friends were used by five parents with a range of 2 to 8 hours in an average month ($M = 4.00$, $SD = 2.45$). Finally, two parents reported using other sources of informal respite (e.g., significant other) between 2 and 3 hours in an average month ($M = 2.5$, $SD = .71$).

Participants were also asked to select which informal respite types they had used in the past from the same list: the child's siblings, grandparents, other relatives, neighbours, family friends and other. Out of 25 participants, 68% had used the child's grandparents for respite in the past, 52% had used their friends, 36% had used the child's siblings, 32% had used other relatives, 12% had used neighbours, and no participants reported using any other types of informal respite. Only 12% of the surveyed parents reported not using any informal respite services in the past.

In an average month the number of hours parents used informal respite in the past varied. Not all parents who reported using the respite type in the past completed the questions about the number of hours used. Thirteen parents reported using their child's grandparents to provide respite in an average month between 2 and 144 hours ($M = 17.92$, $SD = 38.43$). Ten parents provided reported using their friends to provide respite in the past between 1 and 32 hours ($M = 10.10$, $SD = 11.72$). Nine parents reported using their other children to provide respite, in an average month between .5 and 8 hours ($M = 3.83$, $SD = 2.73$). Six parents reported using other relatives in an average month between .5 and 8 hours ($M = 3.58$, $SD = 2.69$). Two parents used their neighbours for informal respite 8 hours in an average month ($M = 8.00$, $SD = 0.00$). No other respite types were reported.

Formal respite use. Parents were asked to choose from a list of eight options all the types of formal respite they were currently using in an average month. The options provided were a residential treatment facility, group day care, group respite facility,

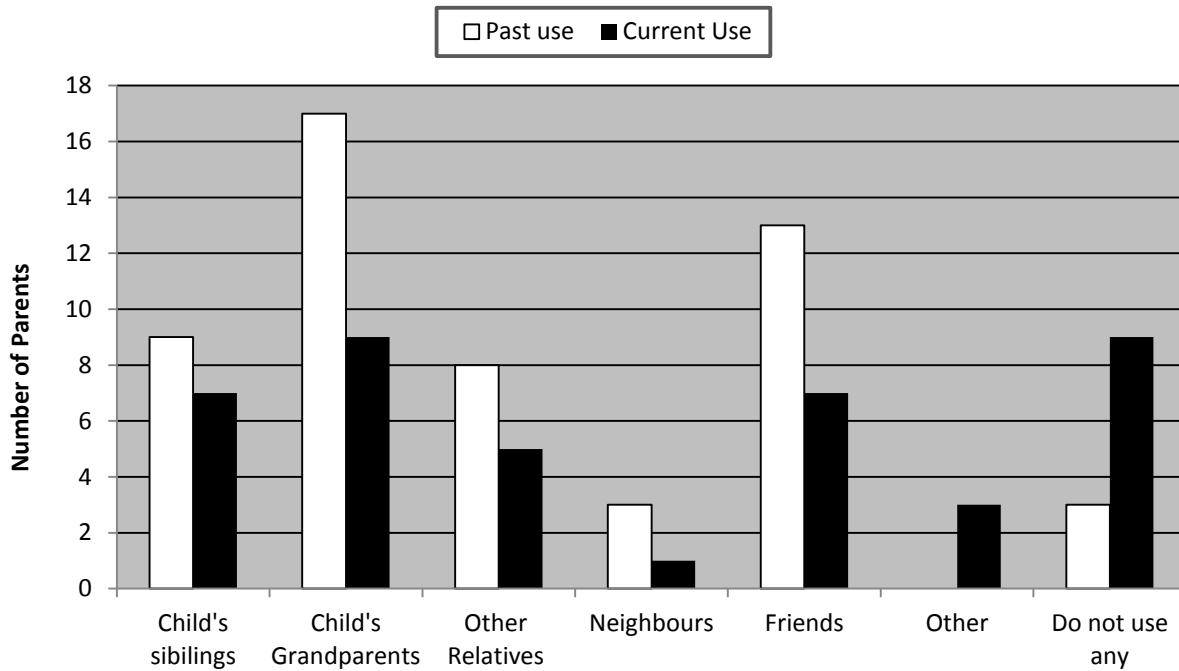


Figure 1. Number of parents using informal respite by type.

day summer camp, overnight summer camp, trained individual respite worker in the home, untrained individual respite worker in the home (babysitter), and other. Of the twenty-six participants, 27% reported using a trained individual respite worker, 19% used a group respite facility, 15% reported using a day summer camp, 12% used an overnight summer camp, 12% used an untrained respite worker (babysitter), 8% used a group day care, 0% of parents reported using residential treatment facilities and, 12% identified as using other informal respite types (e.g., cognitive disability worker out in community). Forty-two percent of participants reported not currently using any form of formal respite (see Figure 2).

In an average month, the number of hours parents used formal respite types varied. Not all parents who stated they used formal types of respite completed the question asking for how many hours formal respite had been used. Further, due to inconsistencies in reporting the number of hours both overnight and day summer camps were used, the hours for these two types of formal respite will not be reported here. Of the seven parents who reported using a trained respite worker, the number of hours ranged between 2 and 60 hours in an average month ($M = 18.57$, $SD = 22.38$). Group respite facilities were used by four parents between 24 and 72 hours ($M = 54$, $SD = 22.98$) in an average month. Three parents reported using an untrained respite worker between 6 and 20 hours in an average month ($M = 11.33$, $SD = 7.57$). Two parents reported using a group day care in an average month from 21 and 30 hours ($M = 25.50$, $SD = 6.36$). One parent reported using another source of formal respite for 16 hours in an average month, but did not specify what the other source was.

Participants were also asked to select which formal respite types they had used in the past from the same list: residential treatment facility, group day care, group respite facility, day summer camp, overnight summer camp, trained individual respite worker in the home, untrained individual respite worker in the home (babysitter), and other. Out of 26 participants, in the past 31% had used a trained individual respite worker in their home for respite, 31% a day summer camp, 23% had used a group respite facility, 15.4% had used an untrained worker in their home, 12% had used an overnight summer camp, 8% had used a group day care, and 4% of participants reported using other types of formal respite (e.g., live-in caregiver). Thirty-one percent of the surveyed parents reported not using any formal respite services in the past.

In an average month, the number of hours parents used formal respite types varied. Not all parents who stated they used formal types of respite stated how many hours a month they

used them. The inconsistencies in reporting the number of hours for both overnight and day summer camps also occurred for questions about past use. As a result, the hours for these two types of formal respite will not be reported. Eight parents reported using a trained respite

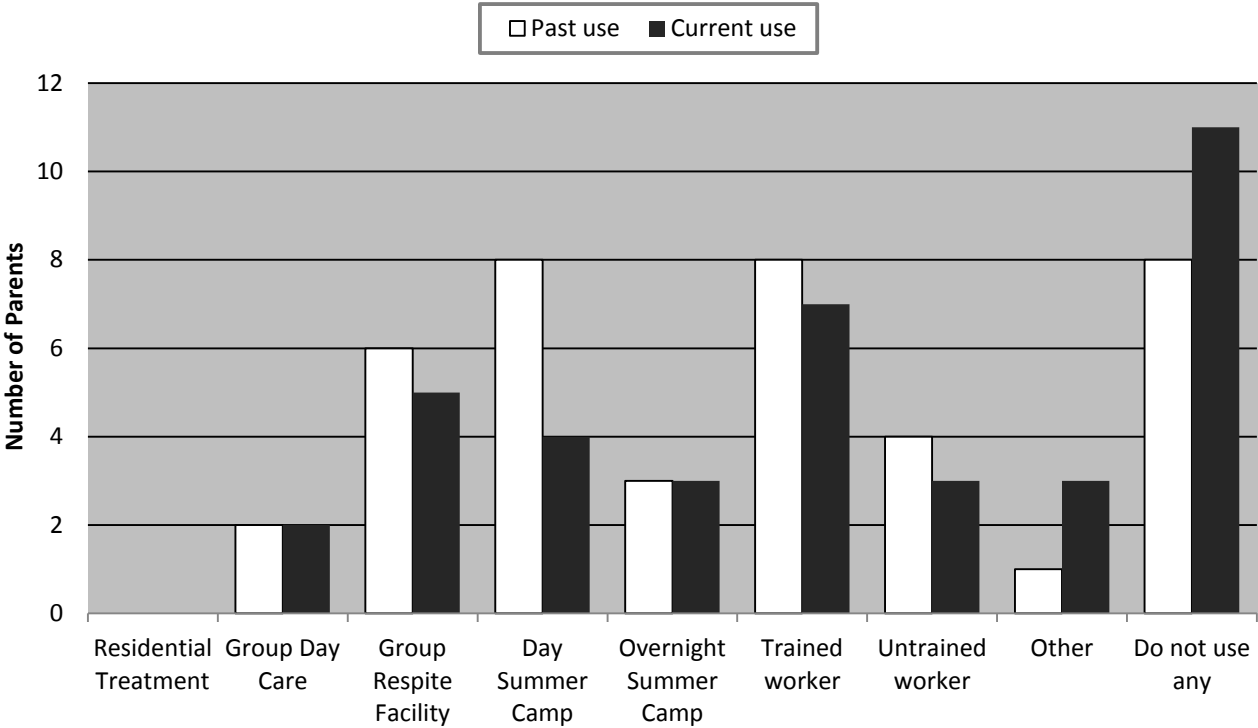


Figure 2. Number of parents using formal respite by type.

worker in the home from 4 hours to 60 hours a month (M = 18.25, SD = 20.98). Six parents reported using a group respite facility in an average month from 12 to 72 hours (M = 37.33, SD = 22.58). Three parents reported using an untrained respite worker in their home from .5 hours to 20 hours in an average month (M = 8.17, SD = 10.40). Two parents reported using group day care for 30 hours in an average month (M = 30.00, SD = 0.00). One parent reported using other forms of formal respite 20 hours in an average month but did not specify what the other type of respite was.

Total respite use. Respite use totals demonstrate that parents currently used anywhere between 0 to 4 types of formal respite ($M = 1.23$, $SD = 1.14$), and between 0 to 4 types of informal respite ($M = 1.04$, $SD = 1.13$). In total, parents currently used anywhere between 0 to 7 types of formal and informal respite ($M = 2.27$, $SD = 1.8$).

Past respite use totals show parents have used between 0 to 5 types of informal respite ($M = 2.00$, $SD = 1.19$) and between 0 to 4 types of formal respite ($M = 1.23$, $SD = 1.11$). In total, in the past parents have used between 0 to 7 types of formal and informal respite ($M = 3.24$, $SD = 1.67$).

In terms of the total number of respite hours parents used, it was reported parents currently used 0 to 103 hours of formal respite in an average month (including all types except for day or overnight summer camps) ($M = 17.3$, $SD = 26.75$). In the past, parents reported using 0 to 76 hours of formal respite in an average month ($M = 18.25$, $SD = 21.67$). As for informal respite, parents reported currently using 0 to 53 hours in an average month ($M = 7.35$, $SD = 12.59$), but in the past used 0 to 176 hours ($M = 16.24$, $SD = 34.90$).

Research Question 2

The second research question posed was: Are parental stress levels, child adaptive needs, and severity of behavioural challenge related to the types of respite used by families?

Parental Stress Scale results. The parental stress scale (PSS) examines the positive and negative themes of parenthood to assess levels of stress related to parenting (Berry & Jones, 1995). A higher score on the scale indicates a higher level of stress. Participants were divided into two groups based on the midpoint of possible scale scores (higher stress $n = 8$ and lower stress $n = 16$). The midpoint of possible scale scores was used as it was thought having two groups (high, low) would lead to easier interpretation and presentation of results. The

Mann-Whitney U test was then used to determine if there were differences in the hours of current formal, current informal, past formal, and past informal respite used between parents reporting higher or lower levels of stress. Results of the analyses indicated that there was not a significant difference between the higher and lower stress groups in the hours of current formal respite used ($U = 55.00, p = 0.576$), current informal respite used ($U = 75.70, p = .465$), past formal respite used ($U = 46.50, p = .277$) or past informal respite used ($U = 69.50, p = .365$).

Pearson’s product-moment correlations were conducted to further investigate if there was a relationship between PSS scores and current formal, current informal, past formal, and past informal hours of respite use. The continuous total score on the PSS was used for this analysis. Twenty-four participants were included for all but the comparison between PSS and past informal respite hours where 23 participants were included due to missing data. Results of this analysis indicated there were no significant correlations between level of parental stress

Table 2

Correlation between Type of Respite and Parental Stress Scale, Child Adaptive Needs, and Behavioural Concerns.

Type of Respite	PSS Total		Areas of Help Total		Behavioural Concerns Total	
	<i>r</i>	<i>p</i>	<i>r</i>	<i>p</i>	<i>r</i>	<i>p</i>
Current Formal	.013	.953	-.002	.993	.316	.124
Current Informal	.178	.405	-.123	.548	.166	.427
Past Formal	-.109	.611	.113	.583	.351	.086
Past Informal	.147	.503	-.191	.360	.081	.707

Note: No significant correlations at the 0.05 level (2-tailed)

and the hours of current formal respite used, current informal respite used, past formal respite used, and past informal respite used (see Table 2).

Child adaptive needs results. Parents were asked to identify whether or not their child needed assistance in ten key areas: washing, dressing, toileting, eating and drinking, managing behaviour, occupying self, getting around/out and about, communication, sleeping, and supervision. Participants were divided into two groups, children who needed help in five or less areas ($n = 6$) and children who needed help in six or more areas ($n = 20$). This grouping was used as it was thought having two groups would lead to easier interpretation and presentation of results. In addition, given the skewed distribution this was deemed to be the most appropriate way to split the data. The Mann-Whitney U test was used to determine if there were differences in the hours of current formal, current informal, past formal and past informal respite used between these two groups of children. Results of the analyses indicated there were no significant differences between these groups in the hours of current formal respite used ($U = 74.00, p = 0.376$), current informal respite used ($U = 57.00, p = .849$), past formal respite used ($U = 78.50, p = .249$), or past informal respite used ($U = 35.50, p = 0.170$).

Pearson's product-moment correlations were also conducted to further investigate if there was a relationship between the number of areas of child help needed and current formal, current informal, past formal, and past informal hours of respite use. For this analysis the continuous variable of number of areas of help needed was used. Twenty-six participants were included with the exception of the comparison between help needed and past informal respite for which there was 25 participants due to missing data. Results of this analysis indicated there were no significant correlations between the number of areas the child required help in and the

hours of current formal respite used, current informal respite used, past formal respite used and past informal respite used (see Table 2).

Child behavioral needs. Parents were asked to identify, using a 4 point Likert scale, their child's behavior on eight questions addressing the child's distractibility, externalizing behaviors, adaptability, and engagement. Scores on the eight questions were totaled and an overall child behaviour score was generated for each participant. Scores could range from 8 to 32. Therefore, participants were split into three groups to best represent the skewed distribution of this variable: (1) low behavioural needs ($n = 0$), (2) medium behavioural needs ($n = 14$), and (3) high behavioural needs ($n = 11$). No participants were in the low behavioural needs group. A Mann-Whitney U test was used to determine if there were differences in the hours of current formal, current informal, past formal, and past informal respite used between parents reporting their child as having medium behavioral needs or high behavioural needs. No significant differences were found between these two groups on the number of current informal ($U = 65.50, p = .510$), and past informal respite hours used ($U = 71.00, p = .953$). However, hours used of current ($U = 40.50; p = .037$) and past ($U = 38.00, p = .028$) formal respite differ statistically according to whether the child had medium or high behavioural needs. Parents of children with more behavioural needs used more hours of formal respite care in the past and were using more hours of formal respite presently than parents of children with less behavioural concerns.

Pearson's product-moment correlations were conducted to further investigate if there was a relationship between level of behavioural concern and current formal, current informal, past formal, and past informal hours of respite use. For this analysis, the continuous variable used was participants' score on behavioural questions. Twenty-six participants were included

in these analyses. Results of this analysis indicated there were no significant correlations between level of child behavioural needs and current and past informal respite (see Table 2). Current ($r = .316, p = .124$) and past ($r = .351, p = .085$) formal respite hours were also not found to be significant, but did approach significance. This suggests there may be a moderate relationship between child behavioural need and formal respite use. However, given the small sample size and resultant low power, this potential relationship is to be considered with caution.

Qualitative analysis findings. A number of questions on the Respite Information Survey examined parents' use of respite and what influenced their choices. These questions included: (1) Why are you currently not using any respite services? (2) Why are you no longer using respite services you have used in the past? (3) What factors have influenced the types of respite you choose? (4) Please explain why you feel that respite options for your child are limited as a result of behavioural challenges; (5) Please explain why you feel that respite options for your child are limited as a result of their cognitive and self-care abilities (6) If there is anything else you wish to add please do so below. Participants' responses to these questions were qualitatively analyzed together using Basic Interpretive Design (Merriam, 2009) following the step-by step basic thematic analysis approach developed by Braun and Clarke (2006). From this analysis there were six main themes that emerged related to influences on parental use of respite: (1) lack of qualified and credible providers who parents can trust, (2) child's comfort level, (3) available respite options become limited as a child grows, (4) restricted respite options and knowledge of availability, (5) financial restrictions and requirements for respite funding, and (6) respite as more stressful than stress relieving. These themes are now considered in detail.

Theme 1: Lack of qualified, credible, trusted providers. A number of parents expressed they do not or cannot use respite because they are unable to find respite providers that are qualified to care for their children. This finding seemed to apply mostly to formal types of respite. In terms of qualified, parents specifically referred to knowledge about, and experience with autism, as well as being able to deal with child behavioural needs. For example in reference to experience with autism one parent shared, “We need to use people who are trained and have experience working with kids with ASD. That hasn’t always been easy.” Another parent discussing behavioural needs stated:

I feel people aren’t educated enough on the behavioural side of things. They don’t understand that behaviour is a form of communication, and opt for the assumption that the child is acting out because they can. Which is really frustrating.

In addition to training and experience, there were a number of parents reporting caregivers needed to be understanding and accepting of disabilities. For example one parent shared:

If people were more understanding and accepting of disabilities it would not be so hard to find care. For those that are familiar with disabilities know how to handle situation[s] and if other[s] around are accepting of the differences it’s really not that hard.

Related to the idea of understanding and acceptance was the notion of trust and credibility.

Parents expressed that both themselves and the child need to be able to trust the provider. For example one parent shared, “I must trust them completely as my son is highly vulnerable.”

While another parent noted, “A nonverbal child who bites, hits, screams, needs a very special kind of person to stay with him.” A few participants also expressed it is hard for providers to know their children like they or other family members do. Put simply one parent said, “...they do not know how to help my son like I do.” Further, when parents were able to find a qualified

provider they trusted their availability was limited or they were a student who eventually moved on and no longer provided respite. For example one parent noted using family to provide respite because both they and the child trust them the most. “He loves and trusts my mom and sisters. So do I. They can calm him.” As one parent shared “Until we have enough qualified people to care for our children parents will choose not to use respite. Parents want to know their child is safe and cared for when they leave them. The idea is to go and be free of worry.” Parents want to be sure their child is being cared for by a qualified, trustworthy, and credible provider. This is related to the next theme which examines parents need for the child to be comfortable with the respite provider.

Theme 2: Child’s comfort level. Many parents reported wanting to make sure the type of respite used was a comfortable environment that would provide a quality experience for their child. For example, parents shared their choice of respite was influenced by, “how happy and comfortable our son is with them [respite providers]” and “[the] quality of experience for my child, ability of the program to enhance the specific needs of my child.” Some parents mentioned specific aspects that resulted in them not using a certain kind of respite, or any respite at all, related to their child’s comfort level. For example, one parent expressed being unable to use overnight respite because it caused a lot of stress for their child. They stated, “There are very few people who he’s felt comfortable with. We haven’t been able to use overnight respite as he would be so stressed that he cannot calm down...” Another parent noted their child was uncomfortable being anywhere but at home. They shared their respite choice was influenced by “his inability to be left at a place other than his home.” In essence, parents want their children to be comfortable both with the setting in which respite is provided and the provider. Another parent mentioned respite in a social environment was beneficial for her

child. She shared, "...she is becoming more social towards others in the group resource home and looks forward to seeing her friends at times of respite at the home. She enjoys the friendships/special outings/attention from other people outside her family members."

Comments in this theme mostly appeared to refer to formal respite types. One exception to this was a parent who shared their child was comfortable with family members. This parent stated, "He loves and trusts my mom and sisters. So do I. They can calm him."

Theme 3: Available respite options become limited as a child grows. A number of parents reported finding formal and informal respite becoming even more challenging as the child changes and grows. For example one parent shared, "We still require respite but the child feels he is too old for the services and strongly opposes going where the children are much younger." Another parent stated:

In one more year I would not even really need care if it was a typical child. The older they become the more awkward it will be to find care and the more expensive since it requires someone who has an understanding and acceptance.

In terms of formal types of respite, parents reported as children age there is not a lot of respite choices available, especially for those with behavioural concerns. For example one parent expressed:

The older the child the more behavioural issues you have but in a bigger body. As the child gets older, you cannot pick them up and put them in a safe place when they have a tantrum. It is a physically demanding job and there are a limited number of people who can work with older children.

In addition, their children age out or outgrow formal services used in the past. For example one parent shared, “Some of the respite services are no longer available to us as you only get them for a certain time and not based on need...child outgrew service.”

In terms of informal respite supports, both behaviour and adaptive skills such as *personal care* seemed to impact their ability to utilize friends and family. For example one parent expressed:

Family are uncertain what to do with her when she requires bathing assistance, they are embarrassed to help a young woman bathe. They don't know what her needs are because of lack of language. When she was young, this was like taking care of any other young child with needs such as my families own children. But with my daughter aging, it is unnatural to family and friends to meet the physical needs of a tween.

Parents also reported as their children aged and grew physically, it was more difficult to find family and friends who were willing and able to care for their children. This was particularly seen with children requiring a high level of behavioural support. For example one parent shared, “My parents (his grandparents) are no longer able to watch him. My son is getting older, stronger and more aggressive while as my parents have aged, they are unable to manage his behaviours.” Formal and informal respite options available to parents are limited as a child grows. However, often children may also be restricted from accessing respite when they do not meet entrance criteria or parents do not know the service is available.

Theme 4: Restricted respite options and knowledge of availability. This theme encompasses a number of different aspects. First, there were parents who reported they did not feel they had options regarding respite care, in terms of outside influences dictating what types were available and would be used. One parent shared, “I don't get a choice. My...worker signs

her up for what they have available.” It was further expressed respite is not always offered when it is best for families. Summer and holidays seemed to be a challenging time for parents to find respite. For example one parent stated:

We are ... limited in the days we can access, particularly during the summer. It gets even more difficult then to get respite during summer, and during Christmas break and this is when we actually need it more since school is out during this time.

Another parent shared in reference to summer camps, “The respite provided is very little. ... It is only offered a few times a year and it’s only if you get picked. The camp is only 5 days once a year.” In addition, parents reported each formal respite agency had different criteria for accepting a child. For example, one parent shared:

Different agencies have different criteria for respite qualifications/funding. Which is good, but also a negative as well. A lot of our children don’t qualify for respite from one agency because they have a higher IQ. Other agencies will take them on different criteria. This criteria also changes like socks, which is incredibly frustrating for parents trying to get the help they need.

Finally, there were parents who reported that they just did not know what was available to them or even if they qualified for respite support. Parents’ statements about this included the following, “I didn’t know my son could qualify for respite,” and “I don’t really know of any respite providers.” Ideas from this theme were often discussed along with the financial difficulties related to obtaining respite.

Theme 5: Financial restrictions and requirements for respite funding. One of the most commonly reported challenges for parents that influenced their use and choice of respite was related to financial restrictions and qualifications. Parents reported they could not access

respite services because they could not afford the services and there was a lack of funding available. For example parents reported “the largest factor is the cost,” “it is very expensive and we cannot get money for respite services,” and “Respite is expensive. Right now, we pay \$16.00/hour for an unqualified person to come in to our home and help us out.” One parent reported competing financial demands for their child. The decision to not access respite often came down to a choice between respite and another much needed service. “We are not receiving any money any more to pay for such services. We are paying out of our pocket for services for him such as occupational therapy and there is only so much money.” Parents also reported that accessing funding was difficult and required the disclosure of personal information. For example one parent shared:

Saskatchewan respite services are linked to the parent’s income. The time and stress for me to go through all the hoops is not worth the return. It asks for a lot of disclosure about my income, I have to find/hire/train/pay the person. In the end the money that would be granted is insufficient for the amount of work it would take me.

These feelings relate to the idea of respite as more stressful than it is stress relieving.

Theme 6: Respite as more stressful than stress relieving. This was a multifaceted theme, with three main subthemes: (1) accessing respite was too much of a hassle, (2) parents did not want to be a bother to anyone, and (3) there was too much guilt associated with respite. In terms of accessing respite being too much of a hassle, parents reported a few concerns. The first concern expressed was that some respite options provided little relief. That is, more time was spent planning for respite and physically getting them to the service than was worth the few hours of respite it provided. Parents shared sentiments such as, “... the three hour twice a week day camp was not worth my time as it provided little respite relief and caused more

planning/hassle for me,” and “People move (often students) or they have too many other clients so are not often available. It becomes more work to arrange respite than it is worth.”

Additionally, child’s behavioural challenges often result in parents being asked to pick their child up from the respite care facility early. For example one parent shared,

With his behavior changes, the last six or seven times, we have been called [by the respite provider] and had to pick him up because he’s having a meltdown they didn’t feel they could handle. Basically, we don’t have respite right now because we don’t relax and enjoy, we just sit and wait for the phone to ring.

The second concern expressed was parents were worried about being bother, a couple of parents reported they did not like to ask their families or friends to provide respite because they had their own things going on. Parents did not want to bother their relatives and friends with children that may be hard to handle. For example one of these parents shared, “...for my family I don’t like to bother them often, she is very hard to handle.” The final concern expressed was guilt associated with respite. This guilt worked in two ways: (1) guilt for leaving the child in a setting he strongly opposes because they need the break, and (2) guilt of overburdening or adding stress to those they are asking to care for their children. For example, one parent shared, “[My] child has gotten older and the guilt associated with respite has become too great. We still require respite but [my] child feels he is too old for the services and strongly opposes going where the children are much younger.” Whereas another parent shared, “I feel guilty burdening others with additional stress. I live the stress first hand, but I feel bad to put this pressure on someone else.” Guilt, feeling like a burden, and respite being a hassle were all reasons parents reported respite was more stressful than stress relieving.

Summary of Results

This study's first research question asked what kinds of respite services Saskatchewan families with children who have disabilities were using. Results showed parents used a variety of both formal and informal respite supports and often used multiple types to fulfill their respite needs. The second question examined the potential relationship between the use of formal and informal respite supports and parental stress, child behavioural needs, and child adaptive behaviours. Quantitative analyses showed that there was no relationship between type of respite use and parental stress levels or child adaptive needs. However, quantitative analyses showed a potential relationship between child behavioral needs and respite use. Qualitative findings outlining parents' reasons for respite use centred around six main themes: (1) lack of qualified, credible, trusted providers, (2) child comfort level (3) available respite options become limited as a child grows, (4) restricted respite options and limited knowledge of availability, (5) financial restrictions and requirements, and (6) respite as more stressful than stress relieving. These results will now be considered in conjunction with other existing research evidence.

CHAPTER 5: DISCUSSION

Summary

Parents of children with disabilities have been found to have a greater potential to experience higher levels of stress than those of typically developing children (Brehaut et al., 2004; Britner, Morog, Pianta, & Marvin, 2003; Lopez, Clifford, Mines, Oulette-Kuntz, 2008; Nachshen & Minnes, 2005). Therefore, parents may require resources to help mitigate that stress and its potentially negative impact. One of the supports reported to be effective, at least in the short term, is that of respite (Chan & Sigafos, 2001). However, research related to respite has tended to focus on the characteristics of users and non-users and parental perceptions of respite (Chadwich, et al., 2007; Damaini, et al., 2004; Neufeld, Query, & Drummond, 2001). Only a handful of studies have examined the actual benefits of respite (e.g., Anoil, et al., 2004; Metzler & Bennett Johnson, 2004; Mullins et al., 2002). Moreover, less attention has been paid to type of respite being used (Stalker & Robinson, 1995). Therefore, the purpose of this study was to examine the relationship between types of respite used and parental stress levels, child adaptive skills, and child behavioural concerns. Specifically, two questions were investigated: (1) What respite services are Saskatchewan families with children who have disabilities using? and (2) Are parental stress levels, severity of adaptive needs, and severity of behavioural challenge related to the types of respite being used by families?

The current study examined 26 parents in Saskatchewan who had children between the ages of 6 and 18 with a diagnosed developmental disability. They were not required to have used formal and/or informal respite services currently or in the past. Types of respite use were measured using questions from the Respite Information Questionnaire (adapted from Preece & Jordan, 2007). Parents were asked to both identify which types they had used, and how many

hours they used respite in an average month. Child behaviour concerns and child adaptive needs were also assessed using questions from the Respite Information Questionnaire (Preece & Jordan, 2007). Parental stress levels were measured with the Parental Stress Scale (Berry & Jones, 1995). Descriptive statistics were used to examine parental use of respite types and hours used. Correlations and Mann-Whitney U statistical tests were used to examine the relationship between hours of formal and informal respite use and parental stress, child behavioural concerns, and child adaptive needs. Participants responses to six open-ended questions were qualitatively analyzed together using Basic Interpretive Design (Merriam, 2009) following the step-by step basic thematic analysis approach developed by Braun and Clarke (2006).

Research Findings Summary

1. Saskatchewan parents use a variety of both formal and informal supports and often use multiple types to fulfill their respite needs.
2. There appears to be a potential relationship between child behavioural needs and respite use. Parents of children with more behavioural needs used more hours of formal respite care than parents of children with less behavioural needs.
3. No relationship was found quantitatively between parental stress levels and respite choice. However, qualitative findings suggested the additional stress of finding and choosing respite may impact some parents' decisions. Stress is a complex variable, as demonstrated by the aforementioned stress models, and as such there may be a multitude of variables influencing this relationship not represented in these models.

4. No quantitative relationship was found between child adaptive needs and respite choice. However, some qualitative findings based on parent report suggested child adaptive needs and respite choice may impact some parents' decisions.
5. Parents identified the following qualitative themes as reasons influencing respite use: (1) a lack of qualified, credible, trusted providers, (2) child's comfort level, (3) available respite options become limited as a child grows, (4) restricted respite options and knowledge of availability, (5) financial restrictions and requirements, (6) respite as more stressful than stress relieving.

Research Question 1

Formal Respite Use by Saskatchewan Parents

The first research question focused on the types of respite parents in Saskatchewan used and how often they used them. Forty percent of Saskatchewan parents reported not currently using any forms of formal respite. However, of those parents who did report using formal respite most used a trained worker in their home (27%) or a group respite facility (19%). Using a trained worker in the home or a group respite facility were also the types of respite that were used, on average, the most hours in a month by parents ranging between 2 to 60 hours a month, and 24 to 72 hours a month, respectively. In the past, 31% of parents reported not using formal respite. However, of those who did use formal respite services, more parents reported using a trained worker in the home (31%) and day summer camp (31%), with a group respite facility being the third most often used (23%).

This difference between current and past choices of formal respite services may have to do with the nature of summer day camps. That is, children are not always accepted into summer day camps, and may not always meet the programs requirements (e.g., age).

Therefore, parents who used them in the past may still use them currently if they were able. This idea was confirmed in the qualitative findings in reference to summer camps in general, not specific to day or overnight camps. That said, one parent expressed the availability of summer camps are limited for children with disabilities and access is dependent on acceptance. Specifically this parent stated, “The respite provided is very little. ... It is only offered a few times a year and it’s only if you get picked. The camp is only 5 days once a year.” This statement suggests more parents may use summer day camps if the service was more easily and consistently accessible. That said, this may explain why this was not found as one of the respite services a majority of parents were currently using but was found to be used in the past. The number of hours summer day camps were used was reported inconsistently. Therefore, it was not possible to compare the hours of summer day camp usage to the number of hours trained workers and group respite facilities were used. However, it is unlikely summer day camps for respite would have been used more hours in an average month than trained workers and group respite facilities, given summer day camps are often structured programs with set hours lasting a limited amount of time. Instead one can surmise similar to current use, parents used a trained worker in the home or a group respite facility for the most hours in the past, even if a higher percentage of parents used summer day camps.

Given the information on summer day camp usage was limited, it is assumed both currently and in the past a trained worker in the home was used by the greatest percentage of parents for the most number of hours. The popularity of this option may be due to a number of reasons. First, qualitative findings suggest parents may appreciate the control using a qualified person in the home provides. Parents reported it was important to them respite care providers were qualified, credible and trustworthy. For example one parent shared, “Parents want to

know their child is safe and cared for when they leave them. The idea is to go and be free of worry.” Using a qualified person in their home provides them with the ability to choose someone that they feel is qualified, credible and trustworthy. Second, parents discussed respite options becoming limited as their child grows, and services having restrictive requirements. By using a trained worker within the home parents may mitigate some of the limitations placed on them by services provided out of the home. For example, one parent shared, “Different agencies have different criteria for respite qualifications/funding....A lot of our children don’t qualify for respite from one agency because they have a higher IQ. Other agencies will take them on different criteria.” This difficulty in requirements may be less prominent with respite providers who come into the home than in agencies that provide respite out of the home. Services provided in a child’s home can be more suited to the child rather than the child being suited to the services.

Previous research has found parents are concerned with the quality of respite care their child may receive and how well respite staff is trained (Damaini, et al., 2004). This along with restrictive requirements have been shown to be barriers for respite use (Doig, et al., 2009; Damaini, et al., 2004; Resch et al., 2010). These research findings further substantiate the idea that the highest percentage of parents may use a trained worker in their home because it provides more flexibility and control. In addition, previous research reported having a trained worker come into the home provides parents with short term relief, which can allow them to attend to their own needs, their other children, and other responsibilities (e.g., grocery shopping) (MacDonald & Callery, 2004; Merriman & Canavan, 2007). This may be an additional reason why in home care by a trained provider was a popular option.

Group respite facilities were reported as the second most utilized respite option currently, and the third most utilized in the past. Qualitative findings showed parents preferred respite that provided a setting their child was comfortable in. While for some parents this meant in home respite was the only option, for some out of home respite was preferred. One parent shared her child enjoyed the group respite setting because it provided her with an opportunity to be social with people outside of her family members. Therefore, group respite facilities may be used to provide a social experience for the child. Previous research has also found socialization opportunities to be a reason for group respite use (Damaini, et al., 2004; Stalker & Robinson, 1994). An additional reason not reported by parents is the value in longer-term overnight respite. This was found by previous research and while not explicitly reported here may still be a reason group respite was a popular option (MacDonald & Callery, 2004).

Informal Respite Use by Saskatchewan Parents

In terms of informal respite used both in the past and currently, the highest percentage of parents reported using the child's grandparents (68% in the past, 35% currently), followed by family friends (52% in the past, 36% currently) and child's siblings (27% in the past and currently). Moreover, while the highest number of parents reported using grandparents for informal respite, they also were used for the most number of hours currently (between 2 to 48) and in the past (between 2 to 144). These reported findings may be because grandparents are logical caregivers for their grandchildren. Qualitative themes showed parents wanted to be sure their child was comfortable and cared for by someone they trusted. Grandparents are likely to provide the kind of environment parents are comfortable with and children are more likely to be comfortable in this environment. For example one parent shared, "He loves and trusts my mom and sisters. So do I. They can calm him." Similar rationale also applies to family friends

and the child's siblings providing care. All are people that parents trust which makes it more likely they would leave their children with them for respite care.

Total Respite Use by Saskatchewan Parents

A number of parents reported not using respite. Specifically, 42% of parents did not currently use formal respite and 31% did not use formal respite in the past. As for informal respite, 35% of parents did not currently use it and 12% of parents did not use informal respite in the past. There are a number of reasons why parents may not have used respite in any of those cases. Parents' discussed the lack of qualified, credible, trustworthy providers, their child's comfort, respite options becoming limited as a child grows, restricted respite options and limited knowledge of availability, financial restrictions, parental guilt, and the hassle of respite as influencing their choice to use or not use formal respite. There were fewer reasons parents shared as influencing their use of informal respite. Parents reported not wanting to be a bother for family and friends, and that as their child grew informal respite sources (e.g., grandparents, family friends) were less equipped or able to take care of their child. Parents not using respite and the reasons why they do not are important because it provides impetus to change or not change the way respite programs are run. If a majority of parents report not using formal respite because they feel they do not need it, then programs may not have to change. Alternatively, if most parents report they do not use respite because it is a hassle, then that provides important information to funders and service providers that the system does need to change. Parents did not report not using respite because they had no need for it, although previous research has found this (Chadwich, et al., 2007; Damaini et al., 2004). Regardless, there are enough parents who are not using respite because there is something wrong with the system as was found here and in previous research (Chadwich, et al., 2007; Damaini, et al.,

2004; Doig, et al., 2004; Resch et al., 2010). This needs to be addressed because parents who need the service but cannot access it are losing out on potentially important short term stress relief. This stress relief is needed because research has found parents who have children with developmental disabilities experience higher levels of stress than parents of typically developing children (Brehaut, et al., 2004; Britner et al., 2003; Wulffaert et al., 2009) which can lead to negative child and parent consequences (Dumas, et al., 1991; Gallagher, et al., 2010; Oelofsen & Richardson, 2006).

Parents that used respite ranged in the number of types they used and the hours they used in an average month. Specifically, parents used anywhere between zero to seven types of respite currently or in the past, with an average of two types currently or three types in the past. This shows parents are using a range of respite types and on average parents need to use or are using more than one type of respite fulfill their needs. Some parents are using as many as seven types of respite to get the break from caregiving they need while others require or use none. This shows that respite use and need is individual to the family. In terms of hours of use in an average month, current use of formal respite ranged from 0 to 103 hours, and between 0 to 53 hours for informal respite. Past hours of use in an average month for formal respite ranged from 0 to 76 hours and between 0 to 176 hours for informal respite. This pattern of variation further demonstrates families have individual needs both in respite types and amount used which has also been reported by previous research (Damiani et al., 2004; Neufeld, et al., 2001; Stalker & Robinson, 1994).

Considering these results through the lens of Conservation of Resources (COR) theory an explanation for the variety in respite use can be ascertained. The second principle of COR theory states individuals must invest resources in order to protect against resource loss

(Hobfoll, 1988, 1998). Parenting a child with a disability requires a parent to commit many resources. However, each family will need to invest different resources, some more, some less. Some parents may use respite as a social support resource to help with the loss of other resources, while other parents may use different resources which may account for the differences in respite use among parents (Hobfoll, 1988, 1998).

These findings demonstrate not one type or configuration of respite will work for all families. This information should be considered in funding and the development of respite programming to ensure high quality and useful programs are created. This differs from the current model that tries to fit families to services rather than fit services to families. The respite field is beginning to discuss the need for family-centred care as it recognizes each family is unique, and the family is the expert on what their child needs (Chan, Merriman, Parmenter, & Stancliffe, 2012; Merriman & Canavan, 2007). In a family centred model, the family works with the service providers to make decisions about the services and supports the family receives (Law, et al., 2003). Changing respite services to fit this model, may allow families to get what they need more easily. The range of numbers reported by this study for both respite types and hours used demonstrates families may already find services that fit their unique needs meaning families may already function in a family centred way but it is the services that do not. Therefore, services and policies becoming more family centred may be the best way to support families who require respite services.

Another reason for the variation in types and hours used may be because the right service or amount of service for each family is not available. Families may use a variety of respite types because they have to cobble services together to meet their respite needs and help them feel adequately supported. This is important because families may not be using services

that are best suited to them. Also, if you have to use seven services to meet your respite needs this may require a lot of planning and time. Finding adequate respite can involve jumping through *hoops* and can become a source of stress in itself. Parents suggested this leads to respite being more stressful than stress relieving. For example, parents expressed more time was spent planning and physically getting their child to respite than the few hours of a break it provided. Therefore, if you are needed to plan and organize as many as seven types of respite this could ultimately contribute to a parents stress.

Previous research has supported the idea that families do not feel adequately supported by the amount of respite services available to them (McGill, 1996; McGill, et al., 2006) and that sometimes respite is more stressful than stress relieving (Damiani et al.,2004; Neufeld, et al., 2001). The stress was related to the barriers they experienced in trying to access services. Specifically, respite resources were limited, often difficult to arrange, parents' had concerns about the quality of care, and information regarding services was difficult to obtain (Damiani, et al., 2004). Available respite is inadequate for families and there are multiple barriers to access that can lead to respite as stressful rather than stress relieving.

Research Question #2

Child Behavioural Needs and Respite Use

One of the characteristics this study considered as a potential influence on respite use as a resource was child behavioural concerns. These concerns were analyzed with hours of formal and informal respite in two ways: (1) examining behavioural needs as a continuous variable (correlation), and (2) examining behavioural needs as a categorical variable (Mann Whitney U). The Mann Whitney U found parents of children with more behavioural concerns use more hours of formal respite care in the past, and are using more hours of formal respite care

presently, than parents of children with less behavioural concerns. The correlation between child behaviour and hours of formal respite used, indicated child behaviour may be related in some way to the need for formal supports, although these results were only found to be approaching significance. Therefore, this result does not conclusively say there is a relationship between child behaviour and hours of formal respite used but there is a suggested relationship. This relationship may have been more clearly defined through the use of a standardized measure (e.g., Behaviour Assessment Scale for Children 2nd edition) which would be more adept picking up variations in child behaviour. The results of the Mann Whitney U and correlational analyses suggested a relationship between formal respite use and child behavioural needs. These findings provide impetus for future research to further examine child behaviour and respite use but with a larger sample size and a standardized measure of behaviour. Understanding how child behaviour affects parents' choice of respite types allows for more appropriate services and policies related to respite for this population. For example, if parents with children who have challenging behaviours are more likely to use formal respite, it provides further evidence that these services should be developed and provided with this population in mind.

The qualitative findings from the thematic analyses supported statistical findings that child behaviour was an influence to parents' respite use. While the quantitative analyses suggested parents used more formal respite if their child had high behavioural needs the qualitative analyses found the child having high behavioural needs was also a barrier to respite use. This was seen within three themes: (1) a lack of qualified, credible, trustworthy providers, (2) limited respite availability as the child's develops, and (3) respite as more stressful than stress relieving. Within the first theme parents reported respite providers were often not

adequately trained to deal with challenging behaviour. This made it difficult for parents to find services that met their needs. In the second theme parents' expressed behaviour concerns increased as their child grew. The increase in behaviour resulted in services that were once available to them no longer being available which limited their respite access. In the third and final theme parents' reported that having a child with increased behavioural needs led to respite being more stressful, as they either had to attend some programming with their child or were asked to pick their child up early. In this case the service was more inconvenient than beneficial. All three of these themes demonstrate barriers to respite services for parents. Therefore, child behavioural concerns are suggested as a primary influence on parents' choice of respite.

Results demonstrated parents of children with more behaviour concerns may use more formal respite than parents of children with less behaviour concerns. However, qualitative findings indicated child behaviour concerns were a barrier to respite access and influenced parent choice in what types of respite they used. These suggested parents of children with more behaviour concerns use more formal respite, but they may not be able to access as much respite as they would like or feel they need. This is important because parents of children with more behavioural concerns have been found to experience higher stress levels than their counterparts (Baker et al., 2002; Gupta 2007; Keetelar et al., 2008; Wulffaert et al., 2009). If these parents are not receiving enough supports to help mitigate this stress it can lead to adverse physical and emotional health for parents (Brehaut et al., 2004; Dumas et al., 1991; Gallagher, Phillips & Carroll, 2010; Oelfsen & Richardson, 2006).

This idea is also supported by the COR theory (Hobfoll, 1988, 1999). Parents of children who have disabilities and considerable behavioural needs are likely to use more

resources than parents of children with disabilities who have lesser behavioural needs. This follows from the notion that major life stress can have a significant impact on resource acquisition and protection. This means it would be harder for these parents to acquire the necessary additional resources to mitigate the stress. This is significant because the second corollary of the theory states those who lack resources are more vulnerable to resource loss, and that initial loss begets future loss which creates a negative cycle (Hobfoll, 1999). It was found through quantitative data analyses that parents who had children with higher behavioural needs used more formal respite. However, qualitative data analyses demonstrated parents wanted even more respite. These findings suggest, these parents are in a state of resource deficit, which as we know from the COR theory leads to increased stress (Hobfoll, 1988, 1999). As respite has been found to be a resource that can decrease parental stress, at least in the short term, (Meltzer & Bennett Johnson, 2004; Mullins, et al., 2002; Slavik Cowen & Reed, 2002), future research and practice should focus on programs specifically for children with high behavioural concerns. This is important as parents reported access to other existing programs is limited or providers were not trained to deal with challenging behaviour.

Limited research has been done in this area but one existing program in the United Kingdom operates numerous specialist services for disadvantaged children and families (McConkey et al., 2011). One of these services is respite specifically for families with children who have complex behavioural needs. Their model is focused on making respite as easy and rewarding experience for families as possible. This service has three inter-related components. First, families are allocated a number of overnight respite needs a year depending on the identified need. Respite is held in a home-like environment where children participate in an activity program, skill development, and receive behavioural supports. Second, the child is

provided with community support with a skilled worker within or outside of the home. The worker helps develop effective behaviour management strategies that can be passed onto families and promote social inclusion through participating in community activities. Third, they help with the transition to less intensive services. These services are designed to be scaffold away as the child and family become more able to manage difficult behaviors. The program is designed to act as early intervention rather than crisis support. This program is comprehensive, but no formal evaluations have been completed (McConkey, 2011). Despite the lack of evaluation this program is one of the first documented promising practices for supporting families of children with high behavioural needs. Given the results of this and other studies it would be important to consider respite models that include these elements to better support and provide for families.

Child Adaptive Needs and Respite Use

Another characteristic considered to influence parents' choice of respite were the child's adaptive needs. However, children who required a higher level of care were not found to use more or less formal or informal respite than their counterparts currently or in the past. This is important because it suggests parents do not choose respite based on their child's adaptive skills. On the other hand, child adaptive skills were discussed by two parents in the qualitative theme addressing respite options becoming limited as the child grows. Specifically, these parents found informal respite options became limited because family and friends were uncomfortable providing personal care for older children. This suggests maybe a relationship does exist between respite use and adaptive behaviour. Perhaps, families use less informal care and more formal care as a child gets older due to adaptive behaviour. This idea has been supported to some extent by previous research (Damaini, et al., 2004). Specifically, research

has found a greater severity of disability was more likely to lead to the use of formal respite supports.

This finding can also be considered under the lens of the COR theory (Hobfoll, 1988, 1999). One would assume similar to increased behavioural needs, increased adaptive needs would lead to decreased parental resources and increased stress. One may then expect parents to increase their respite use as a way to make up for these decreased resources. However, this finding was not supported. This suggests increased child adaptive behaviour needs do not take extra resources, or if parents do use extra resources to care for their child they use something other than respite.

The difference in findings between current and previous research, and what the COR theory suggests should be the result, may be due to the scales used to categorize adaptive ability. Specifically, in this study level of adaptive skills was measured by how many areas in which a child needed help (i.e., washing, dressing, toileting, eating and drinking, managing behaviour, occupying self, getting around/out and about, communication, sleeping, supervision). This did not take into account the level of help required in each of these areas. Parents may have rated their children as needing a help in all of the areas, but if the help they required was minimal they would be given the same rating as someone needing a large amount of help in the same number of areas. This was because reporting of child difficulties was not consistent enough to allow for this level of interpretation. Therefore, this likely did not truly represent the variation in child adaptive ability. Future research should consider using a standardized measure (e.g., Adaptive Behaviour Assessment Scale 2nd edition) which would allow for a better representation of the variation in adaptive behaviour. If a relationship between adaptive behaviour and respite use does exist, it would be important for service

providers and policy makers to understand it. For example, if parents with high adaptive needs children start using less informal respite and more formal respite as their children age service providers and policy makers can ensure there are adequate supports available for this population. Services tailored to this population may be important as some research has found a relationship between higher levels of parental stress and poor child developmental competence (Gupta, 2007), although this finding has been somewhat inconsistent (Ornstien Davis & Carter, 2008; Wulffaert et al., 2009). The relationship between parental stress and respite use will now be discussed.

Parental Stress Levels and Respite Use

This study examined parental stress and its potential relationship with the use of formal and informal respite. However, similar to child adaptive skills and respite use, no relationship was found between parental stress and the amount of formal or informal respite used currently or in the past. That is, parents experiencing high levels of stress were not found to use more or less formal or informal respite supports than parents experiencing lower levels of stress. Parents' respite use does not appear to be influenced by their stress levels. However, given the small sample size of this study (i.e., $n = 26$), there may have not been enough power to find a difference, if one existed.

Qualitatively, parents reported stress as a barrier to respite use. Specifically, respite was reported to be more stressful than stress relieving. This was further expressed through three subthemes, the guilt of leaving their child at respite, respite as too much of a hassle to organize, and parents feeling like a *bother* to those they asked for respite supports. Subthemes appeared to be reference to particular kinds of respite. For example, families felt guilty leaving their child at formal respite services and felt formal respite services were a hassle to organize.

However, parents felt like a bother when they asked for informal respite supports from family and friends. This suggested both formal and informal respite supports created stress for parents. That said, while quantitatively no relationship was found between type of respite use and existing parental stress levels there does appear to be some relationship between respite use and parental stress. That is, parents may use less respite than they require because it creates stress. This is an important consideration because if respite creates stress it becomes counterproductive. Respite is designed to provide caregivers with a break and decrease their stress. In a controlled setting this was found to be the case (Mullins, et al., 2002). However, if in an uncontrolled setting respite induces stress then it defeats respite's purpose.

According to the COR theory, parental stress levels should impact parents' respite use given formal and/or informal respite is a commonly used social support resource for parents of children with disabilities. Respite use should be affected, as resource acquisition is greatly impacted by stress (Hobfoll, 1998). Therefore, parents of children who have disabilities and are experiencing more stress should have difficulty acquiring more resources. Further, as the second corollary notes, resource loss begets further resource loss, and parents who scored higher on the stress scale may not have the resources to access more respite (Hobfoll, 1998). Parents experiencing less stress should be more able to access further resources. However, perhaps no difference was found because these parents did not feel they needed more resources or found alternative resources. As the qualitative findings demonstrated, accessing respite as a resource takes significant resources. Perhaps parents have chosen to access less resource intensive supports for their children.

Practically, it will be important to ensure obtaining access to respite is not a stressful experience since some aspects of respite have been found by current and previous research to

be stressful for parents (Damiani, et al., 2004; Doig, et al., 2004; Grant & Whittell, 2000; MacDonald & Callery, 2004; Neufeld, et al., 2001). Chan and colleagues (2012) discussed the entire experience of accessing respite should be stress free from the moment the parent decides they need respite, to finding respite, and to being provided respite. Additional influences on respite choice found through qualitative analyses are now discussed.

Other Influences on Respite Choice

Three of the six qualitative themes found in this study have been previously discussed as they supported quantitative results. The remaining three themes to consider include: financial restrictions, child comfort, and limited options or not knowing what respite services are available to them. Financial restrictions were discussed by a number of parents as a barrier or influence on their formal respite use. Parents expressed formal respite services were expensive, funding was difficult to access, and there were often competing priorities (e.g., therapy) that also required a financial investment. These findings suggested parents may not be getting an adequate amount of respite services or may not use respite at all. Inherent in parents saying they do not use services because they are too expensive is the implication that they want to use services but they are too expensive. Understanding this as a barrier to respite access is important, because parents of children with disabilities experience greater levels of stress than parents of children without disabilities (Brehaut et al., 2004; Can Child, 2003; Raina et al., 2004). As respite can act as a support to mitigate this stress it is important that barriers to access respite are removed. If parents feel respite is financially restrictive this suggests a need for new funding models and access procedures so parents can obtain the services they need to raise their child.

This theme has also been identified in the literature. Financial restrictions, such as limited funding availability and being unable to afford the out of pocket costs for respite were reported by Resch and colleagues (2010). However, their study not only discussed financial restrictions for obtaining respite but for a variety of services (e.g., therapy, other health related services). It is important to note this was an American study, in which parents would be required to cover more medical costs than their Canadian counterparts. However, similar points were made in a Canadian study by Doig and colleagues (2009). They reported the ability to pay for care was an essential condition to its use. Similar to parents in this study, there was a lack of consistency in how respite was paid for or funding was obtained. Financial restrictions are a common theme influencing formal respite service use. This consistency throughout the literature suggests that respite funding models may need to be reexamined and expanded. This is supported by a family-centred care model. Specifically, Chan and colleagues (2012) propose funding flexibility so families can use funding in the way that best suits their needs.

Parents also reported their child's comfort with the respite type chosen, be it formal or informal, was important to their decision making. In essence, parents want to know when they leave their children will be well cared for and accepted. This demonstrates respite needs to be more than just a break for the parents but also a positive experience for the child. Some parents specifically expressed choosing respite because of specific programming and socialization opportunities it provides for their child. Other parents reported they were unable to leave their child at respite overnight because it caused too much distress for their child. These findings demonstrated when parents choose respite types their child's unique needs are important considerations. This finding provides further support for family-centred care which involves the family in choosing and shaping the respite services they receive. A family-centred model

would make it easier for parents to find respite that suited their child's unique needs. This is important because if parents are aware their child is not comfortable at respite it is unlikely the parents are getting a break. If parents are not getting a break, it in essence defeats the purpose of respite.

The need for respite to be a positive experience has previously been reported (Doig, et al., 2009; McConkey, Truesdale, & Conliffe, 2004). For example, parents will not use respite types their children do not like (Doig, et al., 2009). Researchers have also reported the child should not only be comfortable with the respite service used but they should gain from the experience. For example, respite provides the child with the opportunity to interact with others and experience different activities. Therefore, when designing a respite service or model it is important to consider the unique needs of individual children and families. In addition, it should provide opportunities for the child such as socialization or skill building. Future research should consider what makes respite a positive experience for the child, so strengths-based services can be developed.

Parents also felt respite options were subject to restrictive criteria and parents were often unsure where to access respite services. This demonstrates there is a need for more respite. Specifically, services that are tailored to particular needs such as challenging behaviour or limited adaptive skills are needed. In addition, better advertising of existing respite services may help parents understanding of what services are currently available. Restrictive criteria and lack of respite knowledge may also suggest the need for a more coordinated system. Perhaps a solution would have all families wishing to access respite directed to a central respite database or a respite coordinator. If parents can easily access services it might increase uptake which may lead to increased awareness of how limited or ineffective current services are.

Removing the barriers to this resource may also increase its effectiveness in replenishing the resources parents use for their children ultimately decreasing stress. Therefore, respite services should have one access point all parents go through in order to limit the amount of disconnected services and reduce overall hassle (Merriman & Canavan, 2007). This is important because it would help to ensure parents are able to access services if they need them hopefully reducing undue additional stress caused by the system.

Limitations

A number of limitations could be identified in this study. First, this study had a small sample size since only 26 parents of children with disabilities were recruited as participants. Despite extensive recruitment efforts within Saskatchewan, and opening the study to include participants from Ontario and Manitoba, the sample size for this study was smaller than expected (i.e., originally sought 110 participants). This resulted in an inability to complete the originally planned logistic regression that would have been used to determine if child behaviour, child adaptive ability, and parental stress were predictors of parental respite use. Alternatively, non-parametric Mann Whitney U tests and correlations were used to determine if these characteristics and respite use were related. The smaller sample size restricted the types of analysis that could be done, in addition to limiting generalizability. In order to increase sample size in future studies researchers could consider using tokens of appreciation to increase participation. For example, offering incentives that are relevant to participants such as having all participants names go into a draw for pre-paid respite services. Another suggestion for an increasing parental participation would be partnering with specific community agencies (e.g., Saskatchewan Association for Community Living), and developing the survey together. This partnership may help community agencies feel more invested in helping to more actively

recruit participants. Future research may also consider using a wider age range, as parents of children with disabilities often care for their children beyond childhood and adolescence into adulthood.

Second, the characteristics of child behavioural concerns and child adaptive skills may have been better measured using standardized measures (e.g., Behaviour Assessment System for Children 2nd edition (Reynolds & Kamphaus, 2004); Adaptive Behaviour Assessment System 2nd edition (Harrison & Oakland, 2003). Future research examining these concepts may wish to use these types of measures. Measures that provide more detailed information on child behaviour would have allowed for a more detailed analysis of how behaviour and adaptive skills were related to respite use. For example, the ABAS-2 has a number of subscales (e.g., practical, conceptual, community skills, self-care, social) that would have allowed for a better understanding of which specific adaptive skills were important to the type of respite use. In addition, it would have helped to improve the validity and reliability of the measurement of the child's adaptive skills and behaviour.

Third, categorizing the continuous variables of adaptive behaviour, behavioural challenges, and parental stress levels in the way that was chosen may have lead to an inability to detect differences between the groups. Specifically, the chosen categories may not have been the best representation of the data. For example, parental scores on the stress scale were split into two categories at the midpoint. Dichotomizing the groups may not have captured the true variability of the data. Future research should consider keeping these variables as continuous or bearing in mind the possibility of grouping information into more than two or three categories.

Finally, parents who reported the hours of use for day and overnight summer camp (hours in an average month) as respite were inconsistently reported. Specifically, some parents averaged out the hours used per month while others reported the hours used for the whole year. Assurances of how the parents reported the hours they used summer camp respite for could not be made, therefore this data was unable to be used. Future research may consider collecting this information by average hours used per year, and then converting the hours reported to hours per month. Controlling for these limitations will allow future research to build on this research's initial findings.

Conclusion

This study aimed to discover the types of respite parents were using, and if formal and informal respite usage were related to parental stress levels, child behavioural concerns, or child adaptive behaviour. A better understanding of respite use, and the reasons parents use respite, will allow service providers (e.g., group respite homes, respite caseworkers, government agencies) and policy makers to provide better respite programming for families and children. Specifically, understanding respite usage will allow providers and policy makers to create and tailor services to individual families. This is important because, as is known from the COR theory, parents' ability to deal with the stress that comes from parenting a child with a disability will be related to the resources they have at their disposal. Each family will have their own set of resource needs and so respite should be flexible to fill families' resource gaps. That way, improved respite services can result in a decrease of parenting stress and mitigate adverse stress effects for both parents and children.

Parents reported using a range of respite both in type and hours of use in an average month. A tentative relationship between formal respite use and child behavioural concerns was

found, in that respite use was greater for parents of children with high behavioural concerns than for parents of children with low behavioural concerns. However, despite this relationship parents often reported a lack of respite resources in terms of providers trained in specific disorders and behaviour. That is, as children aged, fewer formal and informal respite options were available to them. Other influences for parental use of respite found included: financial, child comfort, the idea that respite was more stressful than stress relieving, and limited options or knowledge of options. Service providers, program developers, and policy makers should be aware of these influences, since understanding these findings will allow for the provision of better respite services, with the hope of improving the quality of life for both children and their parents.

Implications for Practice

Parents of children with developmental disabilities experience higher levels of stress than parents of typically developing children (Brehaut et al., 2004; Britner et al., 2003; CanChild, 2003; Raina et al., 2004; Wulffaert et al., 2009). As prolonged parental stress can lead to negative and child and parent outcomes (Brehaut, et al., 2004; Schormans, 2002) effective respite services to support parents in raising children with developmental disabilities are key. Despite a small sample size, the results from this study have practical implications for respite practice.

This study showed variation between parents, in the number of respite services they use and the number of hours for which they were used. This suggested respite use is individualized to a family and their particular circumstance. Finding ways to provide respite to families in ways that suit their individual needs is important, as respite has been found to reduce parental stress in the short term and psychological distress in the long term (Mullins, et al., 2002; Slavik

Cowen, & Reed, 2002). If respite services can be individualized to families, respite use may be more effective and lead to a greater decrease in parental stress. Therefore, respite services should move away from the current *one size fits all* model, to a model of family-centred care which has been identified as a best practice (e.g., Merriman & Canavan, 2007). In essence this means respite should be viewed as a partnership with the family. This partnership builds on family resources and social networks, potentially removing the burden of care and stigma experienced by the family (e.g., Chan et al., 2012). The focus of services should be on restoring and regenerating family well-being and resilience which in turn can facilitate positive family adaptation (e.g., Chan et al., 2012). Qualitative findings demonstrated multiple themes that influenced respite use including: a need for trained, credible providers, more respite options for youth, financial assistance, increased awareness of available services, and easier access. All of these are important considerations for respite service providers and policy makers to consider when developing respite programs and policies. That is, if respite services suit family needs, are accessible, and financially feasible families are more likely to use respite and gain the benefits it can provide.

Care for children with disabilities should move to an integrated system that includes a continuum of services to mitigate barriers. An integrated system of providing respite would be responsive to the changing needs of families and service users over time (Chan et al., 2012; Merriman & Canavan, 2007). Additional training needs to be given to service providers, specifically in how to manage challenging externalizing behaviours, as this was mentioned by parents in this study as a training need. This should include how to implement a behaviour support program, and support and respond to the stress of caregivers (e.g., Chan et al., 2012). Future respite practice should also consider better funding models to assist families. This is

important because parents reported that financial restrictions and requirements were a barrier to respite use. Parents found respite was expensive, and funding was difficult to access. New funding models should provide families with an appropriate amount of funding for the respite supports that would be most beneficial for them. For example, a flexible funding model would allow families to use funds in a way that best suits their individual needs. Under this model families may choose to fly in a family member or friend to care for the child rather than accessing residential respite (e.g., Chan et al., 2012). All of these changes can be considered in the context of a family centred model. The family should work with the service providers and policy makers to inform decisions about the services and supports the family will receive (Law, et al., 2003).

This study also found that parents of children with more behavioural needs used more hours of formal respite care in the past, and were using more hours of formal respite presently than parents of children with less behavioural concerns. Qualitatively, parents reported current respite services for children with challenging behaviour are inadequate in terms of availability and training. These findings suggest parents of children with behavioural concerns are using more respite, and yet still do not feel adequately supported. This is a concern because parents of children with more behavioural needs have been reported to experience higher levels of parenting stress than parents of children with less behavioural needs (e.g., Baker et al., 2002; Gupta, 2007; Keetelaar et al., 2008; Ornstein Davis & Carter, 2007; Wulfaert et al., 2009). Services specifically for children with challenging behaviour need to be developed to support parents who have been found to experience higher levels of parenting stress in order to decrease said stress.

Little research has been done to examine the style and nature of respite best suited to families of children with challenging behaviour (e.g., McConkey et al., 2011). This is an important population to consider as parents reported as their child becomes physically larger and more challenging behaviorally there are less supports available to them. Further, parents expressed that there are a lack of service providers who are trained to deal with challenging behaviour. As an answer to this concern an agency in the United Kingdom has developed a model respite program designed specifically for families of these children (McConkey et al., 2011). This program includes overnight respite allocation, community support with a skilled worker, and transition support to less intensive services. While it has yet to be formally evaluated, this program is a promising respite practice for children with challenging behaviours. It is imperative that practices specific to this population continue to be developed and evaluated to ensure parents are receiving necessary and appropriate supports. This is important because parents of children with more challenging behaviours have been found to experience higher levels of stress than their counterparts (e.g., Baker et al., 2002; Gupta, 2007; Keetelaar et al., 2008; Ornstein Davis & Carter, 2007; Wulfaert et al., 2009).

Implications for Future Research

Future research is needed to further explore the preliminary finding that respite use and behaviour are related. A larger sample size would allow for the use of stronger statistical methods which may lead to a definitive significant result. In addition, it may be helpful to use a standardized measure of behaviour to allow for more descriptive findings and for better comparisons across studies. Given child behaviour is often discussed in the literature as both a facilitator and barrier to respite access, better understanding this relationship may lead to stronger programming for these children.

Stress in parents of children with disabilities is complex as outlined in the aforementioned models of stress (e.g., Double ABCX model). The use of Conservation of Resources Theory (Hobfoll, 1988, 1998) to interpret the relationship between stress and respite use may have been too simplistic given the complexity of models based on other theories of stress (e.g., Double ABCX model). Future researchers may wish to consider investigating the role of other variables that may influence the complex relationship of stress in parents such as finances, parent role (e.g., mothers, fathers), social support, and parental coping skills.

The qualitative information from parents in this study explored: (1) a lack of qualified, credible, trusted providers, (2) child's comfort level, (3) available respite options become limited as a child grows, (4) restricted respite options and knowledge of availability, (5) financial restrictions and requirements, and (6) respite as more stressful than stress relieving. The information given by parents was rich and descriptive. However, most of the feedback was criticisms of respite services. While this information is valuable future studies could encourage parents to also comment on the positive and constructive aspects of respite services. Therefore, future research may want to run focus groups or individual parent interviews to gain the perspective of what currently works well in respite, and what could be done better taking a solution-focused perspective. Parents understand better than anyone what works and what will work and can provide valuable positive information to this field.

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APPENDIX A

LETTER OF INVITATION TO COMMUNITY AGENCIES

LETTER OF INVITATION TO COMMUNITY AGENCIES

Date

Dear _____,

RE: Permission to Survey Agency Clients for Master's Research Project

I am a master's student in the Department of Educational Psychology and Special Education at the University of Saskatchewan under the supervision of Dr. Laureen McIntyre. As part of the requirements for the completion of my master's degree, I am conducting research to identify relationships between use of respite types and parental stress, child behaviour and child adaptive skills. This information may help to identify future needs for respite programming and services which in turn could help to ensure caregivers are receiving assistance that is most suited for their individual situation. There are no known risks of this research study. However, while reflecting on past emotional reactions in order to answer survey questions, it is possible that participants will experience a negative emotional reaction. Participants will be informed about crisis counselling available through the Saskatchewan HealthLine, Manitoba Clinic Crisis Line and Distress Centres Ontario. The project is entitled, *Exploring parental stress, child behaviour and adaptive characteristics as predictors of parental choice of respite*.

I am requesting your assistance in participant recruitment. I hope to have your agency e-mail a letter of invitation and survey link to your clients to invite them to participate in my research study. Participants will be invited to voluntarily participate by completing a 20 minute web-based survey examining parental/caregiver stress, child behaviour and adaptive skills and informal and formal respite service use. These raw scores will serve as the data used in statistical analyses on which the results and discussion of this study will be based. Participants will have access to the completed study through the University of Saskatchewan Electronic Theses and Dissertations service (<http://library2.usask.ca/etd>). I would like to conduct the survey during May/June 2013.

The information gathered from clients who participate in this study will be used for my thesis, scientific publications, and presentations to professionals, parents and educators. The confidentiality of all information gathered from participants will be ensured. The surveys are anonymous and I will have no access to information linking data to particular individuals or agencies. Due to the anonymous nature of the study, participants will not be able to withdraw data once it is submitted. Please find enclosed copies of all correspondence to participants. If you require further information, please feel free to contact me by phone at (613) 695-4003 or by e-mail at tam792@mail.usask.ca.

This research project has been approved on ethical grounds by the University of Saskatchewan Research Ethics Board. Any questions regarding your rights as a participant may be addressed to that committee through the Research Ethics Office ethics.office@usask.ca (306) 966-2975. Out of town participants may call toll free (888) 966-2975. I look forward to hearing from you.

Kind Regards,

Tara McFadden
Masters Candidate
Department of Educational Psychology and Special Education
University of Saskatchewan

APPENDIX B
PARTICIPANT INFORMATION LETTER

PARTICIPANT INFORMATION LETTER

Tara McFadden
Masters Candidate
#206-218 Viewmount Drive
Ottawa, ON
K2E 7X5

Date

Dear Participant,

I am a master's student in the Department of Educational Psychology and Special Education at the University of Saskatchewan under the supervision of Dr. Laureen McIntyre. As part of the requirements for the completion of my master's degree, I am conducting research to identify relationships between use of respite types and parental stress, child behaviour and child adaptive skills. This information may help to identify future needs for respite programming and services which in turn could help to ensure caregivers are receiving assistance that is most suited for their individual situation. The project is entitled, *Exploring parental stress, child behaviour and adaptive characteristics as predictors of parental choice of respite*.

Caregivers of children with diagnosed developmental disabilities within the age range of 6-18 who have previously and/or currently have accessed respite services are invited to participate in this survey. Please note that for the purposes of this study respite includes both formal and informal (help from family or friends) types. The survey will take approximately **20 minutes** to complete. The raw scores from this survey will serve as the data used in the statistical analyses on which the results and discussion of this study will be based. There are no known risks associated with this research study. However, while reflecting on personal stressors in order to answer survey questions it is possible that participants will experience a negative emotional reaction. Saskatchewan: If this occurs during your completion of this survey please call the Saskatchewan HealthLine at 1-877-800-0002 to speak to a Registered Psychiatric Nurse or Social Worker. Manitoba: If this occurs during your completion of this survey please call the Klinik Crisis Line at 1-888-322-3019 to speak to a trained counsellor. Ontario: If this occurs during your completion of the survey please contact your local Distress Center at (insert number for appropriate area, dependent on what area the agency forwarding the letter is located in) to speak to a trained counsellor.

The information gathered from those who participate in this study will be used for my thesis, scientific publications and presentations to professionals and caregivers. The confidentiality of all information gathered from participants will be ensured. All responses obtained from you will remain confidential. The survey is anonymous. **Please note that because the survey is anonymous, it will impossible to withdraw your data once the survey has been submitted.** I will not have access to any personal information that can connect survey data to individual participants. Participation in this survey is completely voluntary.

Your cooperation in completing this portion of my project would be greatly appreciated.

If you are interested in participating, please read the attached Consent Information Form for further information, and then click on the link below to complete the survey. This research project has been approved on ethical grounds by the University of Saskatchewan Research Ethics Board. Any questions regarding your rights as a participant may be addressed to that committee through the Research Ethics Office ethics.office@usask.ca (306) 966-2975. Out of town participants may call toll free (888) 966-2975.

If you have any questions or concerns about this study, please contact me by email at tam792@mail.usask.ca, or at my home phone number (613) 695-4003. You may also contact my research supervisor by e-mail at laureen.mcintyre@usask.ca for more information. If after participating in this study you are interested in the results, a brief executive summary will be available upon request.

Thank you, in advance, for your consideration and cooperation in participating in this project.

Kind regards,

Tara McFadden, B.A.
Masters Candidate
Department of Educational Psychology and Special Education
University of Saskatchewan

APPENDIX C
RECRUITMENT POSTER



Department of Educational Psychology and Special Education
Participants needed for a research study:
“Exploring parental stress, child behaviour and adaptive characteristics as predictors of parental choice of respite”

We are looking for participants who are parents of children with developmental disabilities between the ages of 6 and 18 to take part in a study of predictors of parental choice of respite.

As a participant in this study you will be asked to complete a computer based survey that will ask about your informal and formal respite use, parental stress, and details about your child’s needs.

Your participation will take approximately 20 minutes of your time.
For more information and to volunteer for this study please follow this link:
https://usaskssrl.qualtrics.com/SE/?SID=SV_8dzACqNt6VDXbdX

If you have any questions about this study please contact:
Tara McFadden at 613-695-4003 or *tam792@mail.usask.ca*

This research is conducted under the direction of Dr. Laureen McIntyre, Department of Educational Psychology and Special Education and has been approved on ethical grounds by the University of Saskatchewan Research Ethics Board.

APPENDIX D

CONSENT, ADAPTED RESPITE INFORMATION QUESTIONNAIRE AND

PARENTAL STRESS SURVEY

2012-06W Parental Stress Index Study

Questionnaire for Parents of Children with Developmental Disabilities

Introduction

INTRO1.

Welcome to this unique research opportunity!

Please answer all questions as fully as possible. If you are unable to answer a question you are free to move on to the next question. Your answers are confidential to yourself, the research author and her supervisor. If you have more than one child with a developmental disability, then you will be asked to complete a questionnaire for each child.

You will first be presented with a participation consent information form. Please fully review this form before you continue in the survey.

INTRO2.

Participant Consent Information Form

Title of Study

Exploring parental stress, child behaviour and adaptive characteristics as predictors of parental choice of respite.

Researcher and Supervisor:

Tara McFadden, Master of Education candidate, Department of Educational Psychology and Special Education, University of Saskatchewan,

E-mail: tam792@mail.usask.ca

Home Telephone: (613) 695-4003

Dr. Laureen McIntyre, Associate Professor, Department of Educational Psychology and Special Education, University of Saskatchewan,

Email: laureen.mcintyre@usask.ca

Office Telephone: (306) 966-5266

Purpose of the Study

The purpose of the study is to explore the relationship between choice of respite type and parental stress, child behaviour and child adaptive skills as perceived by Saskatchewan, Manitoba and Ontario caregivers of children with disabilities.

Specifically, this study will investigate two primary research questions:

1. What respite services are families with children who have disabilities using?
2. Do parental stress levels, severity of disability, and severity of behavioural challenge predict the types of respite used by families?

Data from this investigation will provide information about relationships between the types of respite caregivers choose and particular child and parent characteristics. Exploration of these relationships will help identify what types of respite parents are using and why, which can help inform future respite resource development.

As a participant in this study:

1. You are provided with an invitational letter to participate that provides project information, contact information and research procedures.
2. It is possible that you may experience a negative emotional reaction as a result of participating. If this occurs and you are in Saskatchewan you may contact the Saskatchewan HealthLine at 1-877-800-0002 to speak to a Registered Psychiatric Nurse or Social Worker. If you are in Manitoba you may contact the Klinik Crisis Line at 1-888-322-3019 to speak to a trained counsellor. If you are in Ontario please contact Connex Ontario at 1-866-531-2600 to speak to a referral and information specialist who can provide supportive listening and direct you to the appropriate distress line if required. The above services can provide you with crisis counselling or with information about counselling resources in your community.
3. You are asked to complete the web-based Participant Survey Form that may take 20 minutes to complete by clicking the forward button below. Data will be kept confidential. Researchers will only have access to anonymous information. Due to this it will not be possible to withdraw your data once submitted. The raw scores from the survey will serve as the data used in the statistical analyses on which the results and discussion of this study will be based. The researcher intends to begin data analysis by July 15, 2013.

If you have any questions concerning the study, please feel free to contact the researcher at the number provided. The University of Saskatchewan Behavioural Research Ethics Board (Beh-REB) approved this study on ethical grounds on September 13, 2012. Any questions regarding your rights as a participant maybe addressed to that committee through the Research Ethics Office (966-2084). Participants from outside of Saskatoon may call the Research Ethics Office collect. Participants interested in the results of the study will receive an executive summary upon request by contacting the researcher by phone or e-mail. You can access the complete study through the University of Saskatchewan Library Electronic Theses and Dissertations service (<http://library2.usask.ca/etd>).

By completing the survey you indicate the following:

1. I have read and understood the description above.
2. I have been provided with contact information to have any questions addressed.
3. I consent to participate in the study described above.

INTRO3.

We would like to start by asking you a few questions about your family.

Do you have any children between the ages of 6 and 18 that have a developmental disability?

1. Yes
2. No (**TERMINATE**)

INTRO4.

How many children do you have with a developmental disability? *Please enter the number of children below.*

INTRO5.

Please select your province.

INSERT PROVINCE LIST – TERMINATE IF SASKATCHEWAN, ONTARIO, OR MANITOBA IS NOT SELECTED

INTROA.

You will now be asked a series of questions for each child that you have with a developmental disability. If you have one child with a developmental disability, then you will answer the series of questions one time.

Main Questionnaire

Section A: Your Family

A1. What is your relationship to the child?

1. Mother
2. Father
3. Step-mother
4. Step-father
5. Grandparent
6. Aunt
7. Uncle
8. Legal guardian
9. Other (please specify)

A2. What is the child's age? _____

PROGRAMMING NOTE: AGES MUST BE BETWEEN 6 AND 18

A3. Please select the child's gender.

1. Male
2. Female

A4. What is your child's diagnosis and associated difficulties?

A5. Does your child need help in any of the following areas? Select all that apply.

1. Washing
2. Dressing
3. Toileting
4. Eating and Drinking (including dietary issues)
5. Managing his/her behaviour
6. Occupying self
7. Getting around/going out and about
8. Communication
9. Other (please specify)
10. None (**SKIP TO A6**)

ASK A5a-i FOR EACH OPTION SELECTED IN A5:

A5a. You indicated that your child needs help Washing. Please describe the help needed.

A5b. You indicated that your child needs help Dressing. Please describe the help needed.

A5c. You indicated that your child needs help Toileting. Please describe the help needed.

A5d. You indicated that your child needs help Eating and Drinking (including dietary issues). Please describe the help needed.

A5e. You indicated that your child needs help Managing his/her behaviour. Please describe the help needed.

A5f. You indicated that your child needs help Occupying self. Please describe the help needed.

A5g. You indicated that your child needs help Getting around/going out and about. Please describe the help needed.

A5h. You indicated that your child needs help Communication. Please describe the help needed.

A5i. You indicated that your child needs help <ENTER OTHER TEXT RESPONSE>. Please describe the help needed.

A6. Does your child require constant supervision?

1. Yes
2. No

IF A6=YES:

A6a. Please describe how your child requires constant supervision.

A7. Does your child have sleep difficulties?

1. Yes
2. No

IF A7=YES:

A7a. Please describe your child’s sleep difficulties.

A8. Please indicate how often your child exhibits the behaviour listed below.

	<u>Often</u>	<u>Sometimes</u>	<u>Seldom</u>	<u>Never</u>
	<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>
1. Easily distracted	1	2	3	4
2. Physically aggressive towards others	1	2	3	4
3. Verbally aggressive towards others	1	2	3	4
4. Self-injurious	1	2	3	4
5. Impatient	1	2	3	4
6. Easily adapts to new situations	1	2	3	4
7. Loses control over emotions	1	2	3	4
8. Appears to be in his or her “own world”	1	2	3	4

Section B: Respite Care Services

Next, we would like to ask you about respite care services.

Respite care has been defined as “a service whose main function is to relieve the parent/family/primary caregiver for a specific period of time while facilitating a positive and rewarding experience for the child with a disability or chronic illness”. This can include formal respite by a trained care provider or informal respite by a friend or family member.

The following section will ask questions regarding your respite care experiences.

B1. In an average month, which of the following **informal** respite services do you **currently** use?

1. Your other children
2. The child's grandparents
3. Other relatives
4. Neighbours
5. Friends
6. Other (please specify)
7. I do not use informal respite services

ASK B1A FOR EACH OPTION SELECTED IN B1. IF B1=7, SKIP TO B2.

B1a. In an average month, how many **hours** do you **currently** use the following informal respite services?

1. Your other children _____
2. The child's grandparents _____
3. Other relatives _____
4. Neighbours _____
5. Friends _____
6. <INSERT OTHER SPECIFIED RESPONSE> _____

B2. In an average month, which of the following **formal** respite services do you **currently** use?

1. A residential treatment facility
2. Group day care
3. Group respite facility
4. Day summer camp
5. Overnight summer camp
6. Trained individual respite worker in your home
7. Untrained individual respite worker in your home (babysitter)
8. Other (please specify)
9. I do not use informal respite services

ASK B2A FOR EACH OPTION SELECTED IN B2. IF B2=8, SKIP TO B3.

B2a. In an average month, how many **hours** do you **currently** use the following formal respite services?

1. A residential treatment facility _____
2. Group day care _____
3. Group respite facility _____
4. Day summer camp _____
5. Overnight summer camp _____
6. Trained individual respite worker in your home _____
7. Untrained individual respite worker in your home (babysitter) _____
8. <INSERT OTHER SPECIFIED RESPONSE> _____

ASK B3 IF THERE ARE NOT ANY RESPITE SERVICES SELECTED IN B1 OR B2.

B3. Why are you not currently using any respite care services? Please provide as many reasons as you wish.

B4. Which of the following **informal** respite services have you used in the **past**?

1. Your other children
2. The child's grandparents
3. Other relatives
4. Neighbours
5. Friends
6. Other (please specify)
7. I did not use informal respite services

ASK B4A FOR EACH OPTION SELECTED IN B4. IF B4=7, SKIP TO B5.

B4a. In an average month, how many **hours** did you use informal respite services in the **past**?

1. Your other children _____
2. The child's grandparents _____
3. Other relatives _____
4. Neighbours _____
5. Friends _____
6. <INSERT OTHER SPECIFIED RESPONSE> _____

B5. Which of the following **formal** respite services have you used in the **past**?

1. A residential treatment facility
2. Group day care
3. Group respite facility
4. Day summer camp

5. Overnight summer camp
6. Trained individual respite worker in your home
7. Untrained individual respite worker in your home (babysitter)
8. Other (please specify)
9. I did not use informal respite services

ASK B5A FOR EACH OPTION SELECTED IN B5. IF B5=8, SKIP TO B6.

B5a. In an average month, how many hours did you use the following as formal respite services in the **past**?

1. A residential treatment facility _____
2. Group day care _____
3. Group respite facility _____
4. Day summer camp _____
5. Overnight summer camp _____
6. Trained individual respite worker in your home _____
7. Untrained individual respite worker in your home (babysitter) _____
8. <INSERT OTHER SPECIFIED RESPONSE> _____

ASK B6 IF USED RESPITE SERVICES IN PAST, BUT NO LONGER USING IT.

B6. Why you are no longer using respite services you have used in the past? Please provide as many reasons as you wish.

ASK B7 IF CURRENTLY USING OR USED RESPITE SERVICES IN THE PAST.

B7. What factors have influenced the types of respite you chose?

B8. Do you feel that respite options for your child are limited as a result of behavioural challenges?

1. Yes
2. No

ASK B8a IF B8 IS YES

B8a. Please explain why you feel that respite options for your child are limited as a result of behavioural challenges.

B9. Do you feel that respite options for your child are limited as a result of level of your child's cognitive and self-care abilities?

1. Yes
2. No

ASK B9a IF B9 IS YES

B9a. Please explain why you feel that respite options for your child are limited as a result of level of your child's cognitive and self-care abilities.

B10. If there is anything else you wish to add please do so below. _____

Section C: Parental Stress Scale

C1. The following statements describe feelings and perceptions about the experience of being a parent. Think of each of the items in terms of how your relationship with your child or children typically is. Please indicate the degree to which you agree or disagree with each of the following items.

1 = Strongly disagree 2 = Disagree 3 = Undecided 4 = Agree 5 = Strongly agree

- ___ 1. I am happy in my role as a parent.
- ___ 2. There is little or nothing I wouldn't do for my child(ren) if it was necessary.
- ___ 3. Caring for my child(ren) sometimes takes more time and energy than I have to give.
- ___ 4. I sometimes worry whether I am doing enough for my child(ren).
- ___ 5. I feel close to my child(ren).
- ___ 6. I enjoy spending time with my child(ren).
- ___ 7. My child(ren) is an important source of affection for me.
- ___ 8. Having child(ren) gives me a more certain and optimistic view for the future.
- ___ 9. The major source of stress in my life is my child(ren).
- ___ 10. Having child(ren) leaves little time and flexibility in my life.
- ___ 11. Having child(ren) has been a financial burden.
- ___ 12. It is difficult to balance different responsibilities because of my child(ren).
- ___ 13. The behavior of my child(ren) is often embarrassing or stressful to me.
- ___ 14. If I had it to do over again, I might decide not to have child(ren).
- ___ 15. I feel overwhelmed by the responsibility of being a parent.

___ 16. Having child(ren) has meant having too few choices and too little control over my life.

___ 17. I am satisfied as a parent.

___ 18. I find my child(ren) enjoyable.

C2. How many adults live in your household?

1. 1
2. 2
3. 3
4. 4
5. 5
6. 6 or more

C3. How many children under 18 years of age live in your household?

1. 1
2. 2
3. 3
4. 4
5. 5
6. 6 or more

CONCLUSION:

Thank you very much for taking your time to complete this questionnaire.

PROGRAMMING NOTE:

Scoring

To compute the parental stress score, items 1, 2, 5, 6, 7, 8, 17, and 18 should be reverse scored as follows: (1=5) (2=4) (3=3) (4=2) (5=1). The item scores are then summed.

Parental Stress Scale Reference: Berry, J. O., & Jones, W. H. (1995). The Parental Stress Scale: Initial psychometric evidence. *Journal of Social and Personal Relationships*, 12, 463-472.

Respite Information Survey adapted from Preece, D. & Jordan, R. (2007). Short breaks services for children with Autistic Spectrum Disorders: Factors Associated with service use and non-use. *Journal of Autism and Developmental Disabilities*, 37, 374-385.

APPENDIX E
ORIGINAL RESPITE QUESTIONNAIRE

FINAL COPY OF QUESTIONNAIRE USED IN SURVEY

QUESTIONNAIRE FOR PARENTS OF CHILDREN AND YOUNG PEOPLE WITH AUTISTIC SPECTRUM DISORDER

Please answer all questions as fully as possible. Your answers are confidential to yourself and the research worker. If you have more than one child with autistic spectrum disorder, please complete a questionnaire for each child: you can get another questionnaire from [address here].

Section 1: Your Family

1. Child's date of birth:.....
2. Child's sex: Male Female (*please delete as necessary*)
3. Child's diagnosis:.....
4. School attended:.....

5. Please can you say what your ethnic origins are by ticking the appropriate boxes below. (We need to know this information in order to find out how acceptable respite care services are to people from minority ethnic groups).

	Child's mother	Child's father
Black, Afro-Caribbean origin		
Black, African origin		
Black, Asian origin		
Black, Other (please specify)		
White, European origin		
White, Other (please specify)		

6. Members of your household

Please fill in the table below, allowing one line for every person who lives in your house.

Person No.	Relationship to child	Age	Occupation	Full/part-time
1				
2				
3				
4				
5				
6				

7				
8				
9				
10				

7. Please can you say if your child needs help in the following areas. Please tick the appropriate boxes and describe the help s/he needs.

	Yes	No	Describe help needed
Washing			
Dressing			
Toileting			
Eating and drinking (including dietary issues)			
Managing his/her behaviour			
Occupying self			
Getting around / going out and about			
Communicating			
Does s/he need constant supervision?			
Does s/he have sleep difficulties?			

8. What is your child's behaviour like most of the time? Please describe.

.....

.....

9. Do any of the following people help to look after your child? Please tick as many boxes as necessary.

Your partner	<input type="checkbox"/>	Neighbours	<input type="checkbox"/>
Your other child(ren)	<input type="checkbox"/>	Friends	<input type="checkbox"/>
The child's grandparents	<input type="checkbox"/>	Other people	<input type="checkbox"/>
Other relatives	<input type="checkbox"/>	If other, please give details	

10. Is this a satisfactory arrangement for you? Please tick

Yes	<input type="checkbox"/>
No	<input type="checkbox"/>

11. Does your child stay away from home overnight without you? Please tick.

Frequently	<input type="checkbox"/>
Sometimes	<input type="checkbox"/>
Rarely/never	<input type="checkbox"/>

12. If so, where does your child usually stay? (e.g. with relatives, respite care service, school trips)

.....

Section 2. Short break (respite care) services

13. Do you currently have a social worker? Please tick.

Yes	<input type="checkbox"/>
No	<input type="checkbox"/>

14. Has anyone ever suggested that you might use 'respite care' services? Please tick.

Yes	<input type="checkbox"/>
No	<input type="checkbox"/>

15. If yes, what person (e.g. another parent, teacher, social worker, etc)

.....

16. Where would you go to find out more about 'respite care' services?

.....

17. Do you feel the need for 'respite care' at the moment?

Mother		Father	
Yes		Yes	
No		No	

18. Which, if any, 'respite care' services are you using at present. Please tick as many boxes as necessary.

A residential home	
A residential (boarding) school	Weekly
	Termly
	Other
A family-based scheme	
A sitting service	
A childminder	
Domiciliary care (home help)	
Play group	
Holiday playschemes	
Sessional worker/befriending	
Other (please say what)	
None at all	

19. If you are not using any 'respite care' services, please say why not. Give as many reasons as you wish.

.....

.....

20. Which, if any, 'respite care' services have you used in the past. Please tick as many boxes as necessary.

A residential home	
A residential (boarding) school	Weekly
	Termly
	Other
A family-based scheme	
A sitting service	
A childminder	
Domiciliary care (home help)	
Play group	
Holiday playschemes	
Sessional worker/befriending	
Other (please say what)	
None at all	

21. If you have used a 'respite care' service in the past, please say why you are no longer doing so?

.....

Section 3: Future Needs

22. Do you think you may need 'respite care' in the foreseeable future? Please tick.

Yes	
No	

23. If yes, how much help do you expect to need in the next 12 months? Please indicate both how often and how long you would prefer the breaks to be (e.g. one evening per fortnight, one weekend a month, etc).

.....

.....

24. What, if any, benefits do you think your family might gain from using 'respite care' services?

.....

Section 4: General Attitude to 'Respite Care'

25. Please tick the box which most closely reflects your view on each of the following statements.

	Strongly agree	Agree	Not sure	Disagree	Strongly disagree
Using respite care services emphasises the difference between disabled children and others					
Respite care can prevent children being received into long-term care					
Parents should always be responsible for looking after their own children					
Respite care can improve a child's skills and abilities					
Respite care is only useful if it includes overnight breaks					
There is not enough information available about respite care services					
The needs of children with autistic spectrum disorder can be met within general respite services					

26. If there is anything you wish to add, please do so below.

.....
.....
.....
.....
.....
.....
.....
.....

27. The researcher is hoping to follow up this survey by conducting a number of interviews about 'respite care' with parents of children with autistic spectrum disorders and with brothers and sisters. If you or your children would be willing to take part in this next stage of the research, please indicate below and fill in the contact details.

	Yes	No
I/we would be willing to be interviewed		
My/our child(ren) are willing to be interviewed, and I/we give consent for this		

Age of child with autistic spectrum disorder, if to be interviewed.....
Child's verbal ability.....

Number of brothers and sisters willing to be interviewed (if applicable).....

Age(s).....

Contact name.....

Address.....

.....
.....
.....

Telephone number.....

Thank you very much for taking the time to complete this questionnaire.
Please return it in the stamped/addressed envelope provided to:

[1st author's name & address here]