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Stress and positive experiences of mothers and fathers of children with autism.

Adam D. Kayfitz
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Stress and Positive Experiences of Mothers and Fathers of Children with Autism

by

Adam D. Kayfitz, B.A.

A Thesis
Submitted to the Faculty of Graduate Studies and Research through Psychology
in Partial Fulfillment of the Requirements for
the Degree of Master of Arts at the
University of Windsor

Windsor, Ontario, Canada

2006

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ABSTRACT

The present study examined the similarities and differences in parenting stress and the positive experiences of mothers and fathers of school-aged children with autism as well as the correlates of these factors. Participants included 20 mother/father pairs raising children with autism (ages 5 to 11, M = 7.55). Parents completed measures of child challenging and adaptive behaviours, parental stress, childcare involvement, social support, and positive experiences of raising their children. Mothers reported significantly greater levels of child challenging behaviours, more involvement in childcare, and more positive experiences than fathers. Mothers' reports of child challenging and adaptive behaviours were significantly related to both mothers' and fathers' parenting stress. Mothers' childcare involvement was not related to any mother variables. Fathers' childcare involvement was positively related to satisfaction with fathers' social support. Mothers' and fathers' positive experiences were negatively related to parenting stress. Findings are discussed within a family systems context.
ACKNOWLEDGEMENTS

There are many important people to thank for the successful completion of this Master’s thesis. First, I would like express my gratitude to my thesis supervisor, Dr. Orr, who was instrumental throughout this process. Dr. Robert Orr taught me the process of making choices when conducting research. He taught me that research is never perfect and that we must make the best of the choices we make and be confident with these choices. I would also like to thank Dr. Orr’s supportive ear. There were many trying times throughout this process in which I experienced a great deal of uncertainty and stress. Dr. Orr calmly and patiently listened to my concerns and helped steer me in a positive direction.

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I would also like to acknowledge Dr Gragg’s contribution to the research process. She introduced me to the social support group and the Windsor autism community in which many of the research participants for this study were recruited. Her guidance in building relationships with research participants and conducting research that is useful to parents are lessons that I can carry with me in all of my future research endeavors.

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CHAPTER I

INTRODUCTION

The primary purpose of the present study was to examine the positive and negative experiences of mothers and fathers who raise a child with autism. This research studied mothers and fathers raising children with autism in terms of the amount of stress experienced in relation to three factors: the behavioural characteristics of the child, the amount of involvement in childcare, and the levels of stress experienced in their partners. Particular attention was paid to fathers’ experiences because fathers’ positive and negative experiences have been neglected in the literature. In addition to parental stress, this research also examined the positive aspects of raising a child with autism for both parents. Much of the literature focuses on the negative aspects, such as the stress experienced, and fails to acknowledge that parents may also be positively influenced by the experiences of raising their child. Thus, the present study investigated the positive factors associated with raising a child with autism, the similarities and differences in perceived experiences between mothers and fathers, and the relationship of positive experiences to parental stress.

Autism

Autism has been conceptualized as existing on a spectrum (Wing & Attwood, 1987). The diagnostic classifications of Autistic Disorder, Asperger’s Disorder, and Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS) have been collectively referred to as Autism Spectrum Disorders (ASD). Each disorder, while belonging to a larger phenotype, has its own specific diagnostic characteristics that distinguish it from other ASD diagnoses.
Autism is a pervasive developmental disorder characterized by impairments in social interaction, impairments in communication, and repetitive and stereotyped patterns of behaviour (American Psychiatric Association, 2000). The following paragraph outlines the social characteristics of autism. According to DSM-IV criteria, individuals with autism may have marked impairments in the use of nonverbal behaviours. For example, they may have difficulties using gaze, facial expressions, body postures, and gestures to regulate their social interaction. Individuals with autism may also fail to spontaneously seek to share their enjoyment, interests, or achievements with other people (e.g., by lack of showing, bringing, or pointing out objects of interest). Social and emotional reciprocity can also be impaired in these individuals. These impairments are reflected in responding inappropriately to what others say, making small talk, and giving an emotional response that is inappropriate for a particular situation (e.g., a laugh when someone tells sad story, or a frown when someone tells a happy story). Those with autism may also show little, or idiosyncratic interest in other people, and have difficulty forming developmentally appropriate peer relationships.

Individuals with autism also have difficulties in the area of communication (APA, 2000). According to the DSM-IV criteria, some individuals with autism experience a delay, or a total lack of the development of spoken language, without an attempt to compensate for this lack of development through the use of alternative modes of communication. The communication of individuals with autism who have adequate speech may be hindered by their inability to initiate and sustain conversations with others or by repetitive (e.g., echolalia), stereotyped, or idiosyncratic language. Additionally,
they may lack developmentally appropriate play skills and exhibit deficits in spontaneous and imaginative play.

Individuals with autism often display restrictive, repetitive, and stereotyped patterns of behaviours, interests, and activities (APA, 2000). According to DSM-IV criteria, those with autism are usually preoccupied with at least one stereotyped or restricted pattern of interest which is abnormal either in its intensity or focus (e.g., repetitive watching of a particular scene in a movie to the neglect of other scenes and other movies). They may adhere rigidly to nonfunctional rituals or routines. Stereotyped and repetitive motor mannerisms, such as hand and finger flapping, and complex whole-body movements, are common in individuals with autism. They may also have a preoccupation with parts of objects (e.g., the steering wheel of a toy car).

Most individuals with autism suffer from some type of intellectual impairment (Fombonne, 2003). Fombonne reported that approximately 30% of individuals with autism have a mild to moderate intellectual impairment, approximately 40% of individuals have a severe to profound intellectual impairment, and approximately 30% of individuals do not have any intellectual impairment although some of these individuals may have cognitive weaknesses which have an impact on their cognitive and intellectual functioning.

*Autism: Prevalence and Etiology*

Fombonne (2003) estimated that the prevalence of ASD is at least 27.5 to 60 cases per 10 000 cases, based on a systematic review of 32 studies between the years of 1966 and 2001. He estimated that the rate of Autism is 10/10 000, the rate of PDD-NOS is 15/10 000, and the rate of Asperger's Disorder is 2.5/10 000. Fombonne noted,
however, that the rate of ASD is likely an underestimate (the rate could be double) due to lack of cooperation from participants in epidemiological studies and to the relative insensitivity of screening devices. In his review, Rutter (2005) estimated that the prevalence rate for ASD is .5% of the general population or 30-60 cases per 10,000. The vast majority of individuals diagnosed with autism are male. The mean ratio of males to females diagnosed with autism is 4.3:1 (Fombonne, 2003).

There is good evidence to suggest that autism is a multifactorial disorder including a large genetic component, medical conditions, and prenatal influences (Rutter, 2005). However, an adequate understanding of the genetic and non-genetic causes has yet to be achieved.

The best established risk factor for ASD is genetic liability, the probability that a person will develop a disorder due to genetics (Rutter, 2005). Twin studies indicate a concordance rate of 60% in identical twins compared to a rate of 5% for fraternal twins. Rutter (2005) indicated that the probability that someone will develop an ASD due to genetics is 90%, the highest figure among all multifactorial childhood psychiatric disorders. He also reported that there are between 3 and 12 susceptibility genes for autism that work in combination with each other to cause the disorder. The exact location of these genes, however, has not been determined, although Rutter suggested that chromosomes 2 and 7 may be involved.

Medical conditions such as Cerebral Palsy, Fragile X Syndrome, Tuberous sclerosis, Phenylketonuria (PKU), Neurofibromatosis, Congenital rubella, and Down Syndrome have been found to have some association with autism in recent epidemiological studies (e.g., Howlin, Wing, & Gould, 1995; Hunt & Lindenbaum, 1984;
Smalley, Tanguay, Smith & Gutierrez, 1992). In a study assessing the background factors associated with males with Asperger’s Disorder, Cederlund and Gillberg (2004) found that 14% of males with Asperger’s Disorder also had a neurological disorder such as epilepsy, or a physical disorder.

While there are many medical conditions associated with autism the proportion of cases with autism that can be causally attributed to a known medical condition is low (Fombonne, 2003). In his review, Fombonne calculated that the median rate of cases with autism that can be attributed to at least one medical condition is 6.4%. Rutter (2005) estimated that no more than 10% of individuals with an ASD have some relevant somatic disease or disorder.

Since autism is viewed as a multifactorial disorder, it is important to look at non-genetic factors that might play a role in the etiology of autism. Isolated case reports have indicated that certain intrauterine infections and toxins (e.g., thalidomide use, cocaine or alcohol use, congenital infections) may play a causal role in ASD in individual cases (Folstein & Rosen-Sheidley, 2001; Medical Research Council, 2001). However, none of these have been prominent as causes in autism epidemiological studies (Rutter, 2005). There is also some evidence to suggest that birth complications may play a role in the etiology of autism. Bolton, Murphy, Macdonald, Whitlock, Pickles and Rutter (1997) found that birth complications are more likely to have occurred in individuals with autism than in their unaffected siblings or controls.

Definitions
Terms relevant to the proposed study will be defined here and the definitions will be used throughout the thesis. Relevant terms include: (a) challenging behaviours, (b) low adaptive behaviours, (c) parental involvement, and (d) stress.

Behaviours of children with autism that include high levels of aggression, irritability, social withdrawal, hyperactivity, noncompliance, stereotypical and repetitive behaviour, and inappropriate speech will be categorized in this study as challenging behaviours. Such behaviours have been labeled in previous literature as aberrant behaviours (Aman & Singh, 1986), and maladaptive behaviours (Tomanik, Harris, & Hawkins, 2004).

Behaviours such as low levels of personal self-sufficiency, community self-sufficiency, and personal and social responsibility (Nihira, Leland & Lambert, 1993) will be categorized as low adaptive behaviours in the present research study. Personal self-sufficiency refers to the ability of children to take care of themselves on a daily basis (e.g., bathing themselves, dressing themselves). Community self-sufficiency refers to the ability of children to communicate (e.g., use sentences) and interact with others (e.g., ability to ask others for help). Personal and social responsibility refers to the ability of children to self-direct their own behaviour and to participate in groups.

Parental involvement will be defined in the present study in a manner consistent with Roach, Orsmond, & Barratt (1999). They defined parental involvement in childcare as daily caregiving activities (e.g., dressing, feeding and bathing the child), recurring child-related tasks (e.g., transporting the child, arranging childcare, scheduling appointments for the child), and child socialization (e.g., playing with the child, disciplining the child). Their definition covers the multidimensional nature of caregiving.
The Concept of Stress

Lazarus and Folkman (1984) define psychological stress as "a relationship between the person and environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being" (p. 19). Thus, psychological stress refers to an individual's perception and evaluation of potential harm posed by environmental experiences, known as primary appraisal, and the resources available to the person to deal with the perceived harm, known as secondary appraisal (Cohen, Kessler, & Underwood-Gordon, 1995).

Appraisal is a construct that is different from perception or interpretation because it refers to the categorization and evaluation of stressors and their various dimensions with respect to the stressors' significance for well-being (Lazarus & Folkman, 1984). A person can appraise a situation or stimulus as either irrelevant, positive (e.g., a professional basketball player relishing the opportunity to take the final shot to win the game), or stressful (Monroe & Kelley, 1995). The way a person appraises a situation depends on two classes of antecedent conditions: perceived features of the stimulus situation, and the psychological characteristics of the individual (Cohen et al., 1995). Perceived features of the situation can include the imminence of a harmful confrontation, the intensity of the stimulus, the duration of the stimulus, and the controllability of the stimulus. Factors within the individual that can affect primary appraisal are beliefs about the self and the environment and personality dispositions. Differences in personal characteristics can help explain why individuals evaluate similar stressful situations differently (Walker, 2002).
According to Monroe & Kelley (1995), if a situation is appraised as stressful, there are at least three types of stressful appraisals: harm/loss, threat, and challenge. Harm/loss refers to situations in which some damage or loss has occurred to the individual. Threat refers to the anticipation of future damage or loss. Challenge refers to situations that present the possibility of growth or gain (Lazarus & Folkman, 1984).

After an appraisal of the environmental situation (primary appraisal), an individual must also determine if one has the necessary resources required to cope with the situation (secondary appraisal). Lazarus and Folkman (1984) describe secondary appraisal as: “a complex evaluative process that takes into account which coping options are available, the likelihood that a given coping option will accomplish what it is supposed to, and the likelihood that one can apply a particular strategy or set of strategies effectively” (p. 35). Some coping options can include fight/flight responses or thoughts and actions that reduce or relieve the emotional stress response (Cohen et al., 1995). If a person perceives that the environmental situation is stressful and that the environmental demands exceed her or his abilities to cope, the person will label her or his experiences as stressful. It is important to note that the processes of primary and secondary appraisal occur not only at the onset of the stressful event, but also during the course of the event (Cohen et al., 1995). One might initially feel she or he does not have the resources to cope with a stressful situation, but might later believe that she or he does. Alternatively, at the onset of a stressful situation one might believe she or he has the resources to cope, but then might believe she or he does not. Therefore, stress cannot be conceived in a static manner.
Lazarus and Folkman (1984) proposed a transactional model of stress, in which an individual encounters stressors, appraises the stressors, and responds. The response, in turn, influences the stressor which leads to a reappraisal of the stressor which leads to an evolving cycle of appraisals, responses, and alteration in stressors (Monroe & Kelley, 1995). This transactional model is useful in conceptualizing stress as a product of repeated interactions between the person and the person’s environment.

The Concept of Parental Stress

The focus of the current study was on parental stress, which has been conceptualized by Abidin (1995) as being composed of three components: child-related stress, parent-related stress, and situational/demographic life stress. According to Abidin, child-related stress refers to stress associated with the child’s level of adaptability, dependency and demandingness, distractibility, acceptability, reinforcement of parents, and mood. Parent-related stress refers to an impaired sense of competence in the parenting role, lack of social support, role restriction, depression, and conflict with one’s spouse. Situational life stress includes events such as changing jobs, moving, marriage, divorce, or death of a family member. While Abidin makes the distinction between child- and parent-related stress for his measure, Parenting Stress Index (PSI), it is not clear how distinct these two constructs are when generalized outside the context of the PSI. The terms parental/parenting stress will be used interchangeably when cited studies do not distinguish between child- and parent-related stress.

Measuring stress. Monroe and Kelley (1995) reviewed four common strategies used in the literature to measure stress appraisal: ad hoc single-item measures, multiple-item scales, life event scales, and investigator-based approaches. In the present study,
stress was measured using a multiple-item scale. Multiple-item scales can either measure a specific stressor and the associated appraisals, or measure appraisal as a response to the cumulative total of life stressors facing the individual.

Peacock & Wong (1990) developed The Stress Appraisal Measure (SAM). The SAM was designed to assess three dimensions of primary appraisal (threat, challenge, and centrality) and three dimensions of secondary appraisal (controllable-by-self, controllable-by-others, and controllable-by-anyone). Cohen, Kamarack, and Mermestein (1983) developed the Perceived Stress Scale (PSS) which is a 14-item scale designed to measure the degree to which individuals find their lives unpredictable, uncontrollable, and overloading.

The Parenting Stress Index – 3rd edition (PSI-III) is a multiple-item scale that has been widely used in research evaluating parenting stress with both a full and a short version. The full length PSI scale is composed of child-related stress, parent-related stress, and life stressor items. After an examination of the items (by the present author) in the context of the definitions of stress discussed earlier it appears the child domain reasonably matches the harm/loss aspect of primary appraisal. Many of the items in the child domain, which outline challenging behaviours and low adaptive behaviours such as the child wandering, being easily distracted, not smiling, crying etc., are followed by the qualifier “more than I expected.” This qualifier appears to imply that the child’s behaviour is different than the parents had expected and that an element of loss, perhaps of a “typical child”, has occurred to the parents that influence parents’ stress levels. Other items in the child domain, however, appear more as a symptom checklist than a measure of stress. For example, the items “My child appears disorganized and is easily distracted”
and "My child kicks a great deal when being dressed" do not measure aspects of appraisal. These items seem to assume that if the behaviours are present, they are stressful. However, as outlined in Stress Theory, for events to be stressful, they need to be appraised as such.

After an examination of the parent domain items (by the present author) in the context of the definitions of stress discussed earlier, it appears the parent domain is better at matching the harm/loss aspect of primary appraisal than the child domain. As with the child domain, many items in the parent domain use the qualifier "more than expected" or "which bothers me." Other items state that parents feel restricted in their life roles, feel depressed about their lives, and guilty about their parenting role. Thus, many of the items in the parent domain contain elements of harm/loss and aspects of their lives that are overwhelming.

The last section of the PSI measures the amount of life stress outside the parent-child relationship that the parent is currently experiencing, such as divorce, pregnancy, death of a family member, legal problems etc. The last section is similar to the life event scales outlined by Monroe and Kelley (1995). The Life Stress scale, however, is predicated primarily on the notion of change and does not adequately measure primary appraisal as defined above. The section lists events and asks respondents to indicate if the events occurred or did not occur in the family during the last 12 months. Although most of the listed events can be stressful, the occurrences of the events in and of themselves are not stressful unless appraised as such.

In summary, the PSI in most circumstances adequately measures the harm/loss aspect of primary appraisal. The PSI, however, does not attempt to assess secondary
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appraisal. At the present time, there do not appear to be any excellent measures of secondary appraisal of parental stress. In the future, measures that combine primary and secondary appraisal of parenting stress need to be created. Despite this limitation, the PSI has been a useful measure for assessing levels of stress in parents of children with developmental disabilities and parents of children with autism.

The following sections outline the correlates of stress in these two populations. First, the correlates of stress in mothers of children with developmental disabilities are outlined because they are the most studied group and yield the most information in stress research. Then, the correlates of stress in mothers of children with autism, fathers of children with developmental disabilities, and fathers of children with autism that have been reported in the research literature are reviewed.

Correlates of Stress in Mothers of Children with Developmental Disabilities

The following discussion focuses on child and family variables that have been shown to be associated with parenting stress for mothers of children with developmental disabilities. The discussion then focuses on the association between child challenging behaviours and low adaptive behaviours and parenting stress in mothers of children with developmental disabilities, variables which are also the focus of the present study.

The literature yields inconsistent findings regarding the associations of demographic and family variables and mothers’ parental stress. There is some evidence to suggest that raising a younger child, having a lower socioeconomic status (SES), more financial problems, and a weaker marital relationship are associated with higher levels of mothers’ parental stress (Sloper, Knussen, Turner, & Cunnigham, 1991; Walker, 2002). Others, however, have found that demographic and family variables, such mothers’ age,
the age of the child, number of siblings, SES, and number of years married are not associated with mothers' parenting stress (Hauser-Cram, Warfield, Shonkoff, & Krauss 2001; Roach et al., 1999; Walker, 2002).

The level of social support received by mothers appears to have a more reliable association with maternal stress than demographic or family variables. There appears to be a general consensus that the more social support mothers receive, the less parenting stress they experience (Hauser-Cram, et al., 2001; Sloper et al., 1991; Walker, 2002).

Child characteristics have also been shown to be associated with parenting stress in mothers. For example, mothers tend to experience more stress when their children have lower Intellectual Quotients (IQ) and academic abilities (Sloper et al., 1991). Hauser-Cram et al. (2001) found that disability status (e.g., a Down Syndrome diagnosis) was associated with child-related stress. Child characteristics such as challenging behaviours and low adaptive behaviours have also been shown to be associated with child- and parent-related stress for mothers of children with developmental disabilities.

Sloper et al. (1991) found that higher levels of child challenging behaviours and lower levels of child self-sufficiency were associated with greater parenting stress in mothers of children with developmental disabilities. Likewise, Hauser-Cram et al. (2001) found that higher levels of challenging behaviours and lower levels of adaptive behaviour in children with developmental disabilities were associated with greater levels of child- and parent-related stress in mothers. Similarly, Weiss, Sullivan, and Diamond (2003) found that child behaviours such as excessive hugging, hyperactivity, and problematic self-injurious behaviours, that not necessarily aggressive towards others, were associated with greater levels of child-related stress. They also found that lower levels of child
personal/social responsibility were associated with greater parent-related stress for mothers. Thus, there is fairly consistent evidence that greater levels of child challenging behaviours and lower levels of adaptive behaviours are related to greater levels of parenting stress in mothers of children with developmental disabilities. It is noteworthy, however, that individual differences in mothers' personality may influence the amount of stress experienced. For example, Sloper et al. (1991) found that the degree of neuroticism in mothers of children with developmental disabilities was correlated with the level of parenting stress experienced over and above the stress experienced by challenging behaviours.

**Correlates of Stress in Mothers of Children with Autism**

The levels of stress of mothers of children with autism have been shown to be related to their psychological well-being, and the developmental progress of the child. Wolf, Noh, Fisman, and Speechley (1989) found that mothers of children with autism experienced higher levels of depression when they reported higher levels of child-related stress. Also, Hastings (2003) found that the more stress experienced by mothers of children with autism, the greater levels of depression and anxiety they experienced.

Robbins, Dunlap, and Plienis (1991) assessed the relationship between parenting stress in mothers of children with autism and child progress on various developmental domains one year after participation in a family intervention program. The primary goal of the intervention program was to establish an organized, consistent, and intensive program for each child within her or his home. Children and their parents received approximately five hours per week of individualized intervention, based on the principals of applied behaviour analysis, over the course of a three-month period. The children were
assessed one year following the termination of the program on language, social, cognitive, self-help, and gross- and fine-motor skills. Parenting stress in mothers was also assessed one year following the termination of the intervention program. Robbins et al. found an inverse relationship between the levels of parenting stress in mothers and child improvement in the various developmental domains. Thus, mothers who experienced more stress had children who showed less improvement as a result of the program than mothers who were less stressed. They concluded that family adaptations, such as the reduction of parenting stress, may be associated with child developmental progress.

As with the literature on the correlates of stress in mothers of children with developmental disabilities, there are mixed results for demographic factors in terms of their correlates of stress in mothers of children with autism. Variables that may influence parenting stress in mothers of children with autism include child characteristics, such as age, gender, and cognitive functioning, as well as demographic and family variables, such as family size, income, and social support (Bouma & Schweitzer, 1990; Gray & Holden, 1992; Sharpley, Bitsika & Efremidis, 1997).

Some studies have found that mothers of older children with autism are likely to be more depressed and stressed than those with younger children (Gray & Holden, 1992; Konstantareas & Homatidis, 1989), while other studies have not found such a relationship (Koegel, Schreibman, Loos, Dirlich-Wihelm, Dunlap, Robbins, & Plienis, 1992; Sharpley et al., 1997; Tomanik et al., 2004).

Tomanik et al., (2004) found that gender and family variables such as maternal age, ethnicity, education, marital status, and SES were not associated with parental stress in mothers of children with autism. Koegel et al. (1992) found that the stress profiles of
mothers of children with autism were similar in spite of different child characteristics, such as child’s age or cognitive functioning. They also found that parents of children with autism reported greater stress than parents of typically developing children, regardless of their children’s ages or levels of cognitive functioning.

Sharpley et al., (1997) found that, like mothers of children with developmental disabilities, mothers of children with autism had lower daily levels of stress, and less frequently felt stressed beyond their limits if they had access to support from other family members such as grandparents, aunts, uncles, and siblings. Sharpley et al. also found that mothers who had higher levels of social support felt more confident in handling their children’s major difficulties. Also, mothers who perceived the assisting member of the family as having expertise and knowledge about autism felt even more confident in their own parenting abilities.

Previous research has indicated that challenging behaviours and low adaptive behaviours of children with autism are related to parental stress in mothers of children with autism (Hastings, 2003; Lecavalier, Leone, & Wiltz, 2006; Tomanik et al., 2004). Tomanik et al. found that the more challenging behaviours children exhibited, the lower the level of adaptive behaviours they exhibited. They also found that mothers of children with autism reported more parent-related stress when their children were more irritable, lethargic, socially withdrawn, hyperactive and noncompliant (challenging behaviours), unable to take care of themselves, and unable to communicate or interact with others (low adaptive behaviours). Lecavalier et al (2006) also found a significant relationship between child challenging behaviours and parenting stress in mothers of children with autism. They found, however, that overall levels of adaptive behaviours were not related
to total parenting stress scores on the Parenting Stress Index – Short Form (PSI-SF).

Therefore, it appears that low levels of adaptive behaviour might have more of an impact on aspects of parent-related stress such as parental competence and role restriction than on total stress. This might be the case because mothers typically view their children’s difficulties, such as difficulties feeding or dressing independently, or being able to self-direct their own behaviour, as failures on the mothers’ part (Milgram & Atzil, 1988). Such feelings of parental incompetence are consistent with aspects of parent-related stress.

**Summary of Common Triggers of Stress for Mothers**

There does not appear to be conclusive evidence that any particular demographic or family variable is consistently related to parenting stress in mothers of children with developmental disabilities or autism. Some studies have found that child variables such as age (Gray & Holden, 1992; Walker, 2002), group status (Hauser-Cram et al., 2001) and cognitive functioning (Sloper et al., 1991) and family variables such as SES and strength of the marital relationship (Sloper et al., 1991) are related to parenting stress in mothers. However, the majority of the research literature suggests that demographic variables such as the age of the child, gender, group status, and cognitive functioning, and family variables such as SES, number of siblings, family size and number of years married are not consistently related to mothers’ parenting stress (Hauser-Cram et al., 2001; Koegel et al., 1992; Roach et al., 1999; Sharpley et al., 1997; Tomanik et al., 2004; Walker, 2002).

Social support, however, does appear to be a variable consistently associated with mothers’ parenting stress. Mothers who receive social support from family members such
as grandparents tend to experience less maternal stress (Hauser-Cram et al., 2001; Sharpley et al., 1997; Sloper et al., 1991; Walker, 2002). Social support is thought to provide a person with the psychological resources to maintain mental and emotional health (Caplan, 1974).

Child challenging behaviours and low adaptive behaviours are also consistently associated with mothers’ parenting stress. Child challenging behaviours and lower levels of adaptive behaviours exhibited by children with developmental disabilities and autism are strongly associated with parenting stress in mothers (Hastings, 2003; Hauser-Cram et al., 2001; Lecavalier et al., 2006; Sloper et al., 1991; Tomanik et al., 2004; Weiss et al., 2003) although low levels of adaptive behaviour might be more related to parent-related stress than to total stress for mothers of children with autism (Lecavalier et al., 2006; Tomanik et al., 2004).

A comparison of mothers of children with developmental disabilities and mothers of children with autism indicates that for both groups, stress levels are influenced by similar factors. However, mothers of children with autism tend to experience greater levels of parenting stress than mothers of children with developmental disabilities (Dumas, Wolf, Fisman, & Culligan, 1991; Holroyd & McArthur, 1976; Kasari & Sigman, 1997; Wolf et al., 1989).

Correlates of Stress in Fathers of Children with Developmental Disabilities

Fathers have been studied less than mothers and thus there is less information regarding the correlates of stress in fathers of children with developmental disabilities. There is evidence to suggest, however, that financial problems, the child’s group status, IQ, and gender might be related to parenting stress in fathers of children with
developmental disabilities. The financial problems associated with raising a child with a
developmental disability are a source of stress for fathers (Sloper et al., 1991). Roach et
al. (1999) found that raising a child with a developmental disability is more stressful for
fathers than raising a typically developing child. However, Hauser-Cram et al. (2001) did
not find such an association. The child’s intellectual functioning has also been found to
be associated with levels of child- and parent-related stress for fathers of children with
developmental disabilities (i.e., the lower the IQ, the greater parenting stress experienced
by fathers; Weiss et al., 2003). In terms of gender, Hauser-Cram et al. (2001) found that
fathers of girls reported a steeper increase in parenting stress during the early childhood
period (i.e. increases in stress levels experienced quickly over a period of time) whereas
fathers of boys reported a more gradual increase in parenting stress during both early and
middle childhood (i.e. increases in stress levels experience more gradually and less
severely over time). This finding indicates that fathers of girls with developmental
disabilities might experience more initial stress than fathers of boys with developmental
disabilities during these time periods.

Child challenging behaviours and low adaptive behaviours have also been shown
to be associated with fathers’ parenting stress. For example, Hauser-Cram et al. (2001)
found that higher levels of challenging behaviours were associated with increases in
child-related stress on the Parenting Stress Index. This finding is not surprising given the
overlap of the child domain of the PSI and challenging behavioural checklists. Hauser-
Cram et al. (2001), however, did not find a relationship between child challenging
behaviours and parent-related stress in fathers of children with developmental disabilities.
Sloper et al. (1991) found, however, that the more challenging behaviours exhibited by
children the more parenting stress fathers reported. However, when challenging
behaviours, neuroticism, and the quality of the marital relationship were entered into a
multiple regression equation predicting parenting stress, only neuroticism and the quality
of the marital relationship predicted fathers’ parenting stress. Weiss et al. (2003) found
that that low levels of personal and social responsibility for the children (adaptive
behaviour) were significant predictors of both child- and parent-related stress for fathers.
Similarly, Sloper et al. found an association between low levels of child self-sufficiency
and fathers’ parenting stress. Low levels of mastery motivation (the child’s persistence on
problem posing tasks) have also been shown to be associated with increases in parent-
related stress for fathers (Hauser-Cram, 2001).

Correlates of Stress in Fathers of Children with Autism

There is little research into the correlates of stress in fathers of children with
autism. However, like mothers, there is some evidence to suggest that the level of stress
felt by fathers of children with autism is related to their psychological well-being. For
example, parenting stress in fathers of children with autism has been shown to be
associated with depression and anxiety although not to the same degree as it is for

There is also some evidence to suggest fathers of sons with autism report
parenthood to be more stressful than fathers raising a girl with autism (Rodrigue,
and disruption of family planning than fathers raising typically developing children
(Rodrigue et al., 1992).
Dumas et al., (1991) and Wolf et al., (1989) reported that fathers of children with autism experience greater parenting stress than fathers of children with developmental disabilities. Children with autism reciprocate their fathers’ attempts to communicate and play less than children with developmental disabilities which might explain group differences in stress. An exception to this finding was discovered by Rodrigue et al. (1992). Rodrigue et al. found that fathers of children with autism, and fathers of children with Down Syndrome did not differ significantly in the degree to which they felt frustrated, anxious, and poorly motivated in the parenting role (aspects of parent-related stress), but that their degree of parenting efficacy and satisfaction were within the normal range. The authors noted that the fathers in their study might have been a select few who were comfortable in their roles of raising a child with autism or a Down Syndrome. In addition, fathers who felt less confident in the parenting role might not have participated.

The extent to which child challenging behaviours are related to parenting stress in fathers of children with autism is not clear. For example, Hastings (2003) found a significant association between child challenging behaviours and parenting stress in fathers. However, when maternal mental health was controlled for, child challenging behaviours were no longer associated with fathers’ parenting stress.

*Summary of Common Triggers of Stress for Fathers*

The gender of the children and financial consequences of raising children with developmental disabilities or autism appear to be consistent sources of stress for fathers. It is somewhat unclear, however, if fathers’ parenting stress is increased as a result of raising girls (Hauser-Cram et al., 2001) or boys (Rodrigue et al., 1992). It is clearer, however, that the financial consequences of raising children with autism or children with
developmental disabilities are associated with parenting stress for fathers (Rodrigue et al., 1992; Sloper et al., 1991).

It is also not clear to what degree child challenging behaviours and low adaptive behaviours are associated with fathers' parenting stress levels. There is evidence that child challenging behaviours and low adaptive behaviours are sources of parental stress for fathers of children with developmental disabilities (Hauser-Cram et al., 2001; Sloper et al., 1991; Weiss et al., 2003), although Sloper et al. (1991) did not find that fathers' parental stress could be predicted by child challenging behaviours. Similarly, Hastings (2003) found that for fathers of children with autism, child challenging behaviours did not predict parental stress levels when maternal mental health was controlled for. Also, there does not appear to be any information regarding the association of low adaptive behaviours and parenting stress for fathers of children with autism.

Comparison of Mothers' and Fathers' Stress

There is some evidence to suggest that mothers of children with developmental disabilities and of children with autism experience more parenting stress than fathers (Moes, Koegel, Schreibman & Loos, 1992; Sharpley et al., 1997; Sloper et al., 1991). Others, however, have found similar levels of parenting stress for mothers and fathers. Hauser-Cram et al. (2001) found that mothers' and fathers' parent-related stress scores were similar when parents' children with developmental disabilities were 10 years of age. Also, Hastings (2003) found no significant difference in the total stress scores between mothers and fathers of children with autism. Regardless of the level of parenting stress, there appears to be differences between mothers and fathers in the correlates of the
parenting stress. Thus, mothers' and fathers' parental stress might be influenced by different aspects of their children's disabilities.

Parental stress in both fathers of children with autism and fathers of children with developmental disabilities is more related than parental stress in mothers to financial burdens, children's group status (i.e. the type of disability), children's intellectual level, and children's gender (Hauser-Cram et al., 2001; Rodrigue et al., 1992; Sloper et al., 1991; Weiss et al., 2003). Parental stress in both mothers of children with autism and mothers of children with developmental disabilities is more related to child challenging behaviours and low adaptive behaviours than is parental stress in fathers (Hastings, 2003; Hauser-Cram et al., 2001; Sloper et al., 1991; Tomanik et al., 2004; Weiss et al., 2003).

The Influence of Parental Involvement in Childcare

The differential influence of child challenging behaviours and low adaptive behaviours on mothers' and fathers' parenting stress might be a function of the amount of parental involvement in childcare. Mothers of typically developing children and children with disabilities (e.g., Autism, Down Syndrome, Cerebral Palsy) usually spend more time caregiving and assume more responsibility for child socialization than do fathers (Heller, Hsieh, & Rowitz, 1997; Lamb, 1997; Roach et al., 1999; Rodrigue, Morgan, & Geffken, 1990; Young & Roopnarine, 1994). Roach et al. (1999) found an association between the amount of maternal involvement childcare for children with developmental disabilities and parent-related stress. Mothers of children with developmental disabilities who were more involved in daily caregiving, child-related tasks, and child socialization perceived more difficulties with aspects of parent-related stress such as health, role restriction, and spousal support, than mothers who were less involved in childcare. Researchers have
suggested that child challenging behaviours and low adaptive behaviours are more stressful for mothers than fathers because such child behaviours pull for more maternal involvement (Hastings, 2003; Rodrigue et al., 1992; Sloper et al., 1991; Tomanik et al., 2004). Milgram and Atzil (1988) found that mothers, who are typically the primary caregivers, view their child's difficulties as failures on the mothers' part.

Fathers, on the other hand, might experience less parent-related stress than mothers because fathers are less involved (Rodrigue et al., 1992). Hawkins, Christiansen, Pond-Sargent, and Hill (1993) explained that the differences in involvement in childcare might be due to differential socialization and to different developmental trajectories that mothers and fathers follow after the birth of a child. They explained that from infancy, girls are socialized to caregive whereas boys are socialized to be strong. Also, it might be easier for women to change their inner psychological world and adjust to the role of parent than men because women may have more biological preparation, such as the time the baby spends in the mother's womb. Caring for a child by fathers might be limited by the child's activity level, employment, financial concerns, societal attitudes about men's roles, and some women's ambivalence about "making room" for fathers participation in childcare. An interesting gender difference is that when fathers of children with developmental disabilities are more involved in childcare they experience less parent-related stress and more parental competence than when they are less involved (Roach et al., 1999).

Higher levels of involvement of fathers of children with autism in childcare might serve several functions such as reducing the amount of maternal involvement in childcare, enhancing fathers' parental competence, and lowering parenting stress in
fathers. These factors might be associated with a reduction in parental stress for both mothers and fathers. General Systems Theory assumes that the feelings and actions of each member of a marriage dyad will influence the feelings and actions of the other member (Hecker, Mims, & Boughner, 2003). For example, Hastings (2003) found that the level of depression and anxiety reported by fathers of children with autism was related to levels of parenting stress in the fathers’ wives. Hastings also found that maternal depression was related to parenting stress in the mothers’ husbands. Also, Roach et al. (1999) found that mothers and fathers of children with developmental disabilities total stress was related to each others’ stress levels. Thus, greater parent-related stress for mothers was associated with more parent-related stress for fathers. They also found that greater parent-related stress for fathers was associated with greater parent-related stress for mothers in the areas of parental competence, isolation, depression, and spousal support. Therefore, if greater father involvement in childcare is associated with a reduction in fathers’ parent-related stress, and there is an interdependence between the stress of mothers and fathers, then mothers’ stress might also be lower.

Paternal involvement in childcare might even be viewed as a form of social support for mothers. As previously stated, social support is associated with a reduction in mothers’ parenting stress (Sharpley et al., 1997) and helps to decrease the parental burden. Social support is usually conceptualized as help from grandparents, aunts, uncles, siblings, friends, and professionals, yet it may be appropriate to also include help from fathers, as they are typically less involved in childcare.

Parenting a child with autism is stressful. Examining the correlates of stress is important so that interventions can be put in place to alleviate some of the stress parents
of children with autism experience. However, raising children with autism provides unique opportunities to parents, some of which are positive. To fully understand the complex nature of raising a child with autism and the full range of parental experiences, it is important to look at the other end of the continuum, the positive aspects of raising a child with autism.

The Positive Aspects of Raising a Child with a Disability

Much of the literature on parents of children with disabilities focuses on the negative aspects of raising a child with autism such as parental stress. Helf and Glidden (1998) reviewed research on families of children with developmental disabilities from the 1970’s, 1980’s, and 1990’s. They found that much of the literature focused on the negative rather than positive aspects of raising a child with a developmental disability. They stated that researchers still emphasize negative responses as much as they did 20 years ago. A review of the literature would suggest that raising children with disabilities is a negative experience for parents. However, if only negatively phrased questions are asked, it is unlikely that positive responses will be revealed (Antonovsky, 1993). It is equally important and useful to examine the positive aspects of raising a child with autism if one is to achieve an accurate understanding of the complexities of such a process.

Hastings and Taunt (2002) reviewed five descriptive studies of parents’ positive perceptions of raising children with disabilities. Despite different samples and methodologies, they found a good level of agreement in terms of the key issues identified by parents. They summarized 14 positive themes that emerged in at least two of the five reviewed studies:
1. Pleasure/satisfaction in providing care for the child
2. Child is a source of joy/happiness
3. Sense of accomplishment in doing one’s best for the child
4. Sharing love with the child
5. Child providing a challenge or opportunity to learn and develop
6. Strengthening family and/or marriage
7. Giving a new or increased sense of purpose in life
8. Leading to the development of new skills, abilities, or new career opportunities
9. Becoming a better person (more compassionate, less selfish, more tolerant)
10. Increasing personal strength or confidence
11. Expanding social and community networks
12. Increasing spirituality
13. Changes in one’s perspective on life (e.g., clarified what is important in life, more aware of the future)
14. Making the most of each day, living life at a slower pace

The aforementioned list of positive perceptions of raising a child with a disability has been categorized by some in terms of personal growth, improved relations with others, and changes in philosophical or spiritual values (Scorgie & Sobsey, 2000). Positive perceptions have also been categorized as positive feelings towards the child, positive impact upon the respondent, and positive impact upon the family (Behr, Murphy, & Summers, 1992).

There are several theories to explain the reported positive perceptions of raising a child with a disability. Some of these theories view the positive aspects parents
experience as a resource factor. The Family Adjustment and Adaptation Model (FAAM) outlines processes by which families try to restore the balance between the demands and capabilities of children with disabilities in an attempt to minimize parenting stress (Patterson, 1988, 1989, 1993). According to the model, parents may focus on the positive aspects of their children and emphasize the growth of the self and family while paying less attention to the limitations of the children.

Family schema, a concept that is congruent with the FAAM, is the shared beliefs, meanings, and values a family develops in order to cope or adapt to any situation. Family schemas are used as filters through which all experiences, good and stressful are evaluated (McCubbin, Thompson, Thompson, & McCubbin, 1993). A positive outlook toward raising a child with a disability might be part of a family schema that is used to restore the balance and to cope and adapt to raising such a child (Hastings & Taunt, 2002).

Different coping strategies, such as reframing, are associated with more positive perceptions of a child with a disability. Reframing occurs when individuals positively reframe events to make them more manageable (McCubbin, Olson, & Larsen, 1991). Hastings, Allen, McDermott, and Still (2002) found that reframing was associated with perceptions of a positive impact of the child itself (happiness/fulfillment) and on the family in general (strengthening family closeness). Reframing coping was also associated with personal growth and maturity of the mother. Certain coping strategies, such as reframing or problem-focused coping, might also be related to positive affect. Positive affect may bolster psychological and physical resources during stress, act as a buffer to the physiological consequences of stress, and protect against depression (Folkman &
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Moskowitz, 2000). Therefore, it would seem important to study the positive perceptions of raising a child with a disability if positive perceptions are viewed as a resource factor when coping and if they are related to positive affect.

There might be a problem, however, with viewing the positive aspects of raising a child with a disability as a resource factor when coping. Coping implies that individuals find ways to go on with their lives (Scorgie & Sobsey, 2000). It is possible that coping can be viewed as a defense mechanism. Such a view may have negative connotations and may imply that having a child with a disability is not “normal” and is a disruption to “normal” life that must someway be recaptured. It might also suggest that parents’ positive experiences may seem as an artificial way to get “back to normal.” However, Stainton and Besser (1998) suggested that the positive changes described by parents are real and meaningful and “not simply a defense or coping mechanism” (p.68). Perhaps a positive way to state the impact of a child with a disability on a family is to call it a transformative experience (Palus, 1993). Palus (1993) defined a transformative experience as “a life event and its outcome, such that the event is given a central role within a self-narrative in causing, catalyzing, or symbolizing substantial, lasting psychological change” (p.40). He described transformative changes as involving two phases: initial disequilibrium (such as the birth of a child with a disability) and reorganization. Therefore, the way things were usually done is interrupted or even completely abandoned (Beck, 1999) and a new way of acting is substituted. A transformative experience can cause an individual to move forward and to change an individual for the better, whereas coping can imply a way to return to the past and may not necessarily promote the growth of the person.
Summary of the Literature

A review of the literature suggests that it is unclear if mothers' and fathers' levels of parenting stress differ as there is some research indicating that there are differences and other research indicating no differences. It is clearer, however, that the correlates of parenting stress are generally different. Fathers' parenting stress appears to be influenced by financial burdens, children's group status (i.e., the type of disability), children's intellectual levels, and children's gender. The influence of child challenging and low adaptive behaviours on fathers' parenting stress has been less researched. While there is some evidence that child challenging behaviours are related to fathers' parenting stress, there is no information regarding the influence of low adaptive behaviours on fathers' parenting stress. Mothers' parenting stress, however, is consistently related child challenging and low adaptive behaviours. In addition, greater levels of social support is related to lower levels of parenting stress for mothers of children with autism.

A review of the literature also reveals that mothers of children with autism are more involved in childcare than fathers. Research in a developmental disability population suggests that mothers experience greater parenting stress when they are more involved in childcare. Fathers of children with developmental disabilities, however, appear to experience less parenting stress when more involved in childcare. There is no information regarding these associations for parents of children with autism.

Although much of the literature focuses on the negative aspects of raising a child with autism, there is evidence that parents of children with autism also have positive experiences. While research into these positive experiences is limited there is some research to suggest that parents who use reframing coping are better able to have more
positive experiences raising their children. Theories also suggest that parents of children with disabilities may also cope with some of the stresses associated with raising their children by attending more to the strengths than to the limitations of their children.

The Present Study

The overall purpose of the present study was to examine both the stressful and the positive experiences of mothers and fathers who raise children with autism. More specifically, the present study focused on five outcomes.

The first was to examine the relationship between child challenging behaviours, low adaptive behaviours, and parental stress in mothers and fathers of children with autism. Although there is general agreement that child challenging behaviours are associated with parenting stress for mothers of children with developmental disabilities and autism (Hauser-Cram et al., 2001; Lecavalier et al., 2006; Tomanik et al., 2004) there is less agreement about the impact child challenging behaviours have on fathers’ parenting stress levels, especially on fathers of children with autism. The study of children’s low adaptive behaviours in relation to parenting stress in autism is also sparse. There are a number of studies investigating this relationship for parents of children with developmental disabilities. Tomanik et al. (2004), however, was one of the first to examine the relationship between low adaptive behaviours and parenting stress in mothers of autism. There does not appear to be any research regarding the association between children’s low adaptive behaviours and parenting stress for fathers of children with autism.

A second focus of the present study was to examine the role that parental involvement in childcare had in the occurrence of parental stress. There appear to be
gender differences in the association between parental involvement and parental stress for parents of children with developmental disabilities. Greater maternal involvement is associated with greater parenting stress for mothers of these children while greater paternal involvement is associated with less parenting stress for fathers of these children (Roach et al., 1999). Research on the relationship between parental involvement in childcare and parental stress is lacking for parents of children with autism. Maternal involvement in childcare might also mediate the relationship between child challenging and low adaptive behaviours and mothers’ parenting stress, but this has not been tested. It is known that child challenging and low adaptive behaviours are related to parenting stress in mothers (Tomanik et al., 2004), and that maternal involvement is associated with mothers’ parenting stress (Roach et al., 1999). However, it is unknown if child challenging and low adaptive behaviours are related to the amount of maternal involvement in childcare.

A third focus was to examine the role of involvement in childcare for fathers of children with autism and the levels of parenting stress experienced in the fathers’ spouses. Paternal involvement in childcare might serve several functions such as decreasing maternal involvement in childcare, enhancing paternal competence, and lowering fathers’ parenting stress. No research has yet looked at whether mothers are less involved in childcare when fathers are more involved in childcare. Roach et al. (1999) found that greater paternal involvement in childcare, for fathers of children with developmental disabilities, was associated with less parenting stress in fathers. In addition the total stress experienced by one partner in a marriage influenced the amount of total stress experienced by the other partner in the marriage. Thus, a relatively lower
level of parenting stress in fathers should be associated with relatively lower level of parenting stress in mothers. What remains unclear is if mothers’ parenting stress will be lower because they spend less time involved in childcare when their husbands are more involved in childcare.

Given that the present thesis was concerned with multiple factors associated with parenting stress (i.e. child challenging and adaptive behaviours, and parental involvement), the fourth focus of this thesis was to also examine the impact that social support had on parental stress. Previous research indicates that social support is negatively related to parenting stress for mothers (Hauser-Cram et al., 2001; Sharpley et al., 1997; Sloper et al., 1991; Walker, 2002). It would seem important to examine how social support changes the potential impact that child challenging and adaptive behaviours, and parental involvement variables may have on parenting stress. While the relationship between social support and parenting stress is well researched for mothers, there is no information regarding this relationship for fathers.

The present study also examined the positive experiences of parents who raise children autism. This was studied in three contexts. The first was to examine the similarities and differences between mothers and fathers in the positive experiences of raising school-aged children with autism. The second was to examine the relationship between the positive experiences parents reported and the amount of parental involvement in childcare. The third was to examine the relationship between the positive experiences of raising a child with autism and parental stress. The study of the positive aspects of the child is a relatively new way of looking at disabilities for researchers and there is currently only a small information database.
One of the few studies examining the similarities and differences between mothers and fathers of school-aged children with intellectual disabilities, some of whom had children with autism, found that mothers generally reported more positive experiences than fathers (Hastings, Beck, & Hill, 2005). Hastings et al (2005) found that mothers, more than fathers, reported that their children were a source of strength and family closeness (e.g., mothers became more accepting of things, adjusted to unchangeable things, and had greater sensitivity to family issues), expanded social networks, and a source of learning as they responded to their children’s challenges (e.g., increased awareness of people with disabilities, greater understanding of people who are different, and greater compassion). Fathers, however, reported more than mothers that their children were a source of pride (e.g., proud of the abilities of their children) and cooperation (e.g., children help around the house; children are helpful to other family members). Thus, it appears that mothers and fathers experience the positive aspects of raising children with intellectual disabilities differently, just as mothers and fathers view the sources of stress differently. The positive impact that children with autism alone have on their parents have not been studied extensively. There appears to be only one study that examined the similarities and differences between parents in the positive experiences of raising children with autism. Similar to their previous findings in an intellectual disability population (Hastings et al., 2005), Hastings et al. (2005) found that mothers of preschool children with autism reported more positive experiences than fathers. The present study sought to replicate and expand the findings of Hastings et al (2005) and Hastings et al (2005) using parents of school-aged children, all of whom were diagnosed with autism.
Hastings et al. (2005) suggested that mothers might have more positive experiences raising their children than fathers because they spend more time caring and interacting with their children, allowing them the opportunity to observe the positive aspects of their children more often. Indeed, mothers of typically developing children and children with disabilities (e.g., Autism, Down Syndrome, Cerebral Palsy) usually spend more time caregiving and assume more responsibility for child socialization than do fathers (Heller et al., 1997; Roach, et al., 1999; Rodrigue et al., 1990; Young & Roopnarine, 1994). Because mothers are also more likely to have the opportunity to experience negative aspects of their children they may also experience greater parenting stress when they are more involved in childcare (Roach et al., 1999). The present study examined whether parents would have more or fewer positive experiences of their children when they were more involved in childcare. It is also possible that exposure to more positive experiences might be related to reduced levels of parenting stress.

Thus, the present study also examined the relationship between the positive experiences parents had and the levels of parenting stress they reported. Hastings et al. (2005) found that positive affect (measured by participants agreeing to adjectives such as excited, strong, enthusiastic) was positively related to mothers’ and fathers’ reported positive experiences. Positive affect may bolster psychological and physical resources during stress, act as a buffer to the physiological consequences of stress, and protect against depression (Folkman & Moskowitz, 2000). Support for this was found by Hastings et al (2005) who concluded that mothers, but not fathers, of children with intellectual disabilities experienced less parental stress when they reported more positive
experiences of raising their children. The present study further examined this finding with parents of school-aged children with autism.

The following is an elaboration of the specific aims and/or hypotheses of the present study. Many of the research goals concerning fathers were exploratory in nature due to the lack of knowledge concerning fathers' stress:

_Hypotheses and Research Goals_

**Research goal 1.** To examine the similarities and differences between mothers' and fathers' levels of parenting stress and perceptions of their children's levels of challenging behaviours and adaptive behaviours.

_Hypothesis 1._ Researchers have found that mothers of children with autism reported more parenting stress when they reported higher levels of child challenging behaviours (Hastings, 2003; Lecavalier, et al., 2006; Tomanik et al., 2004) and lower levels of adaptive behaviours in their children (Tomanik et al., 2004). Hypothesis: _Greater levels of child challenging behaviours and lower levels of adaptive behaviours will be associated with higher parenting stress levels in mothers of children with autism._

**Research goal 2.** To examine the role that child challenging behaviours and low adaptive behaviours have on parenting stress in fathers.

_Hypothesis 2._ Researchers have found that mothers of children from a variety of populations are more involved in childcare activities than fathers (Heller et al., 1997; Lamb, 1997; Roach et al, 1999; Rodrigue et al., 1990; Young & Roopnarine, 1994). Hypothesis: _Mothers of children with autism will report greater involvement in childcare, such as spending more days per week involved in daily caregiving activities, reporting_
greater levels of responsibility for general child-related tasks, and reporting greater levels of responsibility for child socialization than fathers.

Hypothesis 3. Researchers have found that child challenging behaviours and low adaptive behaviours are related to parenting stress in mothers (Lecavalier et al., 2006; Tomanik et al., 2004). Roach et al. (1999) found that mothers who spent more time in childcare experienced more parental stress. Several researchers have suggested, but not tested the hypothesis that mothers will spend more time involved in childcare when they report their children to have higher levels of challenging behaviours and lower levels of adaptive behaviour (Hastings, 2003; Rodrigue et al., 1992; Sloper et al., 1991; Tomanik et al., 2004). Hypothesis: Maternal involvement in childcare will mediate the relationship between child challenging behaviours and low adaptive behaviours and parenting stress in mothers of children with autism. More specifically (a) higher levels of child challenging behaviours and lower levels of adaptive behaviours in children with autism will be associated with higher levels of parenting stress in mothers of children with autism, and (b) higher levels of child challenging behaviours and lower levels of adaptive behaviour will be associated with greater levels of maternal involvement in childcare. Therefore, greater maternal involvement in childcare will be associated with greater levels of parenting stress for mothers of children with autism.

Hypothesis 4. Roach et al. (1999) found that fathers of children with developmental disabilities experienced less parenting stress when they were more involved in childcare. Hypothesis: Greater paternal involvement in childcare will be associated with lower levels of parenting stress in fathers of children with autism.
Hypothesis 5. Roach et al. (1999) found that fathers who were more involved in childcare experienced lower levels of parenting stress. Thoughts, feelings, and actions, of one partner in a marriage (i.e., fathers) are likely to influence the thoughts, feelings, and actions of the other partner in a marriage (i.e., mothers; Hecker et al., 2003). Hypothesis: 

Paternal involvement in childcare will moderate the relationship between maternal involvement in childcare and parenting stress in mothers of children with autism, such that greater paternal involvement in childcare will be associated with lower levels of maternal involvement in childcare and lower parenting stress in mothers.

Hypothesis 6. Roach et al. (1999) found a positive relationship between the total stress scores for mothers and fathers of children with developmental disabilities. Hypothesis: There will be a positive association between parenting stress in mothers and fathers of children with autism, such that higher levels of parenting stress in mothers will be associated with higher levels of parenting stress in fathers.

Research goal 3. To examine the differences between mothers’ and fathers’ number of social supports and their satisfaction with social supports.

Hypothesis 7. There is consistent evidence across developmental disability and autism populations that increased levels of social support are related to decreased levels of stress for mothers. (Hauser-Cram et al., 2001; Sharpley et al., 1997; Sloper et al., 1991; Walker, 2002). Hypothesis: Greater involvement and satisfaction with social support will be associated with lower levels of parenting stress in mothers of children with autism.

Children with autism will report more positive aspects of raising their children than will fathers.

Hypothesis 9. Hastings et al. (2005) suggested that mothers might have more positive experiences raising their children than fathers because they spend more time caring and interacting with their children, allowing them the opportunity to observe the positive aspects of their children more often. Hypothesis: Mothers who report greater levels of childcare involvement will also report more positive aspects of raising their children.

Hypothesis 10. Certain coping strategies, such as reframing, are associated with parents reporting positive aspects of their children with developmental disabilities (Hastings et al., 2002) and may also be related to positive affect. Positive affect can increase psychological resources during stress (Folkman & Moskowitz 2000). Hastings et al (2005) found that mothers, but not fathers, of children with intellectual disabilities, some of which had children with autism, experienced lower levels of parenting stress when they experienced more positive aspects of their children. Hypothesis: Mothers, but not fathers, who report more positive aspects of raising their children with autism will report lower levels of parenting stress.
CHAPTER II

METHOD

Participants

Participants included 20 mother/father pairs. The participants were raising children ranging in age from 5 to 12 with one of the following DSM-IV Autism Spectrum Disorder (ASD) diagnoses: Autistic Disorder, Asperger’s Disorder, or Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS). Demographic information for parents is presented in Table 1. The mean age for fathers was 3.70 years older than the mean age for mothers. Only 75% of the fathers and 85% of the mothers endorsed (by responding to an open-ended question) belonging to a particular cultural group. The majority of the fathers (55%) and the mothers (70%), however, identified themselves as either being Caucasian or Canadian. Seventy-five percent of the fathers and 100% of mothers had at least some university education. In terms of employment, the majority of fathers (90%) full-time employment while 35% of the mothers were in full-time employment. Of the 14 mothers who had either a University or College degree or a post graduate degree, only five were employed full-time with all three who had a post graduate degree in full-time employment. While there was some discrepancy between partners regarding total family income, 65% of the fathers and 60% of the mothers reported family incomes of at least $70,000. The average number of children (including children with autism) that the mother/father pairs raised was 2.4 ($SD = .94$).

There were 20 children with an Autism Spectrum Disorder. Demographic information for the children is presented in Table 2. The majority of children were
Table 1.
Mother and Father Demographic Information

<table>
<thead>
<tr>
<th>Variable</th>
<th>Father frequency (%)</th>
<th>Mother frequency (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age in years</td>
<td></td>
<td></td>
</tr>
<tr>
<td>$M$ 42.45</td>
<td>38.75</td>
<td></td>
</tr>
<tr>
<td>$SD$ 6.70</td>
<td>5.75</td>
<td></td>
</tr>
<tr>
<td>Range 34-58</td>
<td>30-49</td>
<td></td>
</tr>
<tr>
<td>Cultural group</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Asian 1 (5)</td>
<td>1 (5)</td>
<td></td>
</tr>
<tr>
<td>British 1 (5)</td>
<td>1 (5)</td>
<td></td>
</tr>
<tr>
<td>Canadian 7 (35)</td>
<td>7 (35)</td>
<td></td>
</tr>
<tr>
<td>Christian 0 (0)</td>
<td>1 (5)</td>
<td></td>
</tr>
<tr>
<td>Caucasian 4 (20)</td>
<td>7 (35)</td>
<td></td>
</tr>
<tr>
<td>Francophone 1 (5)</td>
<td>0 (0)</td>
<td></td>
</tr>
<tr>
<td>Italian 1 (5)</td>
<td>0 (0)</td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Some High School 2 (10)</td>
<td>0 (0)</td>
<td></td>
</tr>
<tr>
<td>High-School diploma 2 (10)</td>
<td>0 (0)</td>
<td></td>
</tr>
<tr>
<td>Technical school 1 (5)</td>
<td>0 (0)</td>
<td></td>
</tr>
<tr>
<td>Some college/some university 7 (35)</td>
<td>5 (25)</td>
<td></td>
</tr>
<tr>
<td>University degree or college degree 7 (35)</td>
<td>11 (55)</td>
<td></td>
</tr>
<tr>
<td>Post graduate degree 1 (5)</td>
<td>3 (15)</td>
<td></td>
</tr>
</tbody>
</table>
Table 1 (cont.)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Father frequency (%)</th>
<th>Mother frequency (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Employment status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unemployed</td>
<td>1 (5)</td>
<td>7 (35)</td>
</tr>
<tr>
<td>Part time</td>
<td>1 (5)</td>
<td>6 (30)</td>
</tr>
<tr>
<td>Full time</td>
<td>18 (90)</td>
<td>7 (35)</td>
</tr>
<tr>
<td><strong>Family Income</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>35 000-50 000</td>
<td>2 (10)</td>
<td>1 (5)</td>
</tr>
<tr>
<td>50 000-70 000</td>
<td>5 (25)</td>
<td>7 (35)</td>
</tr>
<tr>
<td>70 000-100 000</td>
<td>5 (25)</td>
<td>5 (25)</td>
</tr>
<tr>
<td>Over 100 000</td>
<td>8 (40)</td>
<td>7 (35)</td>
</tr>
</tbody>
</table>
Table 2.
Child Demographic Information

<table>
<thead>
<tr>
<th>Variable</th>
<th>Frequency (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>16 (80)</td>
</tr>
<tr>
<td>Female</td>
<td>4 (20)</td>
</tr>
<tr>
<td><strong>Age in years</strong></td>
<td></td>
</tr>
<tr>
<td>M</td>
<td>7.55</td>
</tr>
<tr>
<td>SD</td>
<td>2.35</td>
</tr>
<tr>
<td>Range</td>
<td>5-11</td>
</tr>
<tr>
<td><strong>Mother reported DSM-IV diagnosis</strong></td>
<td></td>
</tr>
<tr>
<td>Autistic disorder</td>
<td>15 (75)</td>
</tr>
<tr>
<td>Asperger's disorder</td>
<td>1 (5)</td>
</tr>
<tr>
<td>PDD-NOS</td>
<td>4 (20)</td>
</tr>
<tr>
<td><strong>Source for Diagnosis</strong></td>
<td></td>
</tr>
<tr>
<td>Psychologist</td>
<td>13 (65)</td>
</tr>
<tr>
<td>Psychiatrist</td>
<td>2 (10)</td>
</tr>
<tr>
<td>Pediatricist</td>
<td>1 (5)</td>
</tr>
<tr>
<td>Developmental pediatrician</td>
<td>4 (20)</td>
</tr>
</tbody>
</table>

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male (80%). Mothers’ reports of their children’s diagnosis revealed that that majority of the children were diagnosed with Autistic Disorder (75%). The majority of children as reported by their parents were diagnosed by a psychologist (65%).

**Measures**

Participants were asked to fill out multiple questionnaires. The questionnaires included a demographic information sheet designed by the author. Parenting stress was measured through the Parenting Stress Index—Short-Form. Adaptive behaviours and child challenging behaviours were assessed through the Inventory for Client and Agency Planning (ICAP). Parental involvement was assessed though the Parental Involvement Scale—Revised. Social Support was assessed through the Social Support Questionnaire-6. Finally, the positive aspects of raising a child with autism were assessed through the Positive Contributions Survey. Measures that were created or that are freely available through public access are presented the appendices.

**Demographic questionnaire** (see Appendix A). Participants were asked to complete a demographic questionnaire on parent, child, and family characteristics. Parent characteristics included gender, age, culture/ethnicity, level of education, and employment status. Child characteristics included gender, age, DSM-IV diagnosis, and source of the diagnosis. Family characteristics included number of other children, ages of all children, and family income.

**Parenting Stress Index—Short-Form.** The Parenting Stress Index—Short-Form (PSI-SF) consists of 36 items derived from the Parenting Stress Index (PSI; Abidin, 1995). Because of the number of measures parents were asked to complete in this study the Parenting Stress Index—Short Form (PSI-SF) instead of the full length PSI because the
PSI-SF take only 10 minutes to complete and has good psychometric properties. The PSI-SF is composed of three scales: Parental Distress (PD), Difficult Child Characteristics (DC), and Dysfunctional Parent-Child Interaction (P-CDI). The PD subscale measures parents' low sense of competence in the parenting role, lack of social support, role-restriction, depression, and conflict with one's spouse. A sample item from the PD subscale is: "I feel trapped by my responsibilities as a parent." The DC subscale measures characteristics of the child that make him/her easy or difficult to manage. A sample item from the DC subscale is: "I feel that my child is very moody and easily upset." The P-CDI subscale measures parents' failed expectations of their children, and non-reinforcing interactions with their children. A sample item from the P-CDI subscale is: "My child rarely does things for me that make me feel good." The PSI-SF uses a combination of five-point Likert type items (strongly disagree to strongly agree), and fixed five-point scale items. Total stress scores, comprised of the above three subscales, range from 36 to 180 with higher scores indicating greater parenting stress. High total stress scores are considered to be at or above the 90th percentile (raw score greater than or equal to 90). Given that aspects of the child domain corresponding to the DC and P-CDI subscales of the PSI-SF can be considered more as symptom checklists than measuring the appraisal of stressful events or behaviours, the present study only included scores from the PD subscale in the analyses even though parents completed the entire PSI-SF. Raw scores from the PD subscale range from 12 to 60 with higher scores indicating more stress related to the parenting role. As with the Total Score, scores are converted to percentiles in which percentiles at or above the 90th percentile (raw score greater than or equal to 36)
are indicative of high parenting stress. Only raw scores on the PD subscale were used in the analyses.

The PSI-SF is strongly correlated with the full length PSI. It has been reported that the PSI-SF correlates as high as .94 with total stress scores from the full length PSI (Abidin, 1995). Scores on the PD subscale of the PSI-SF have been reported to correlate as high as .92 with the parent domain from the full length PSI (Abidin, 1995). Abidin also reported that scores on DC and P-CDI subscales of the PSI-SF correlated .87 and .73 respectively with the child domain from the full length PSI (Abidin, 1995).

The test-retest reliability for the PSI-SF has been reported to be: .84 for total stress, .85 for PD, .78 for DC, and .68 for P-CDI. The internal consistency coefficients have been reported to be .91 for total stress, .87 for PD, .85 for DC, and .80 for P-CDI (Abidin, 1995).

**Inventory for Client and Agency Planning (ICAP).** The ICAP is designed to assess adaptive behaviour skills and problem behaviours (defined as child challenging behaviours in the thesis) for individuals who have developmental disabilities and who are between the ages of 3 months and 44 years (Bruininks, Hill, Weatherman, & Woodcock, 1986). The test was normed on 1764 individuals in 40 communities throughout the United States who were thought to be representative of the population makeup of the USA in terms of gender, race, occupation, region, and urbanization. There were roughly equal numbers of individuals in early childhood (3 months through 5 years), childhood (6 through 12 years), and adolescent-adult (13 years through 44 years) age ranges in the normative sample.
The Adaptive Behaviour scale contains 77 adaptive behaviour items organized into four broad domains: Motor Skills, Social and Communication Skills, Personal Living Skills, and Community Living Skills. Each item is a statement of a task. Within each of the four adaptive behaviour domains, each item/task increases in difficulty along a typical developmental continuum. The Motor Skills domain (18 items) assesses gross- and fine-motor skills. Sample items include: “Picks up small objects with one hand” and “Turns knob or handle and opens a door.” The Social and Communication Skills domain (19 items) assesses skills in social interaction, language comprehension, and language expression. Sample items include: “Makes sounds or gestures to get attention” and “Speaks in three- or four-word sentences.” The Personal Living Skills domain (21 items) assesses eating and meal preparation, toileting, dressing, personal self-care, and domestic skills. Sample items include: “Swallows soft foods” and “Puts on T-shirt or pullover shirt, although it may be on backward.” The Community Living Skills domain (19 items) assesses levels of independence in areas essential to successful community adjustment such as punctuality, knowledge of money and value, and work skills. Sample items include: “Finds toys or objects that are always kept in the same place” and “Crosses nearby residential streets, roads, and unmarked intersections alone.” The scale uses a four-point Likert type scale. A score of zero indicates the individual never or rarely performs that task even if asked. A score of one indicates the individual does the task, but not well, or one quarter of the time, but may need to be asked. A score of two indicates the individual does the task fairly well, or three quarters of the time, but may need to be asked. A score of three indicates the individual does the task very well, always or almost always without being asked. Raw scores from each of the four domains range from 0-63.
Raw scores from each of the four domains are then converted to a domain score, which is a score on a \( w \) scale in which there is equidistance between each score. A Broad Adaptive Behaviour (BAB) score is calculated by summing the four domain scores and dividing by 4. Difference scores are then calculated for each of the four domains and the BAB domain by subtracting the average domain score for the age group the child is being compared to from the child’s obtained domain score. Positive difference scores indicate the child has adaptive behaviour skills above a typically developing same age group. Negative difference scores indicate the child has adaptive behaviour skills below a typically developing same age group. Difference scores are then converted to standard scores which range from \(<1\) to \(198\). Higher standard scores indicate greater levels of adaptive behaviour. A standard score of 100 (SD=15) would place a child in the Average range.

Please see Table 3 for a listing of all the internal consistency coefficients for early childhood and childhood. Median internal consistency values for the four domains and the BAB domain range from .54 to .88 for early childhood and .50 to .85 for childhood (Bruininks et al., 1986). Test-retest reliability was conducted on a 6 to 8 year-old sample, and a 10 to 11 year-old sample (see Table 4). Test-retest reliabilities for the four domains and the broad independence domain range from .69 to .96 in the younger sample, and .52 to .84 in the older sample.

The Adaptive Behavior scale has been shown to have construct validity after a number of studies in which scores of individuals with mild to severe intellectual disabilities, individuals with learning disabilities, and with behavioural disorders were compared to their typically developing same age counterparts. For example, typically
Table 3.

Internal Consistency Coefficients for the ICAP Domain Scores

<table>
<thead>
<tr>
<th>Adaptive behaviour domains</th>
<th>Early Childhood</th>
<th>Childhood</th>
</tr>
</thead>
<tbody>
<tr>
<td>Motor Skills</td>
<td>.70</td>
<td>.50</td>
</tr>
<tr>
<td>Social and Communication Skills</td>
<td>.84</td>
<td>.69</td>
</tr>
<tr>
<td>Personal Living Skills</td>
<td>.76</td>
<td>.73</td>
</tr>
<tr>
<td>Community Living Skills</td>
<td>.54</td>
<td>.70</td>
</tr>
<tr>
<td>Broad Independence</td>
<td>.88</td>
<td>.85</td>
</tr>
</tbody>
</table>
Table 4.

Test-retest Coefficients for the ICAP

<table>
<thead>
<tr>
<th>Score</th>
<th>6-8 years</th>
<th>10-11 years</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Adaptive Behaviour</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Motor Skills</td>
<td>.69</td>
<td>.52</td>
</tr>
<tr>
<td>Social and Communication Skills</td>
<td>.81</td>
<td>.77</td>
</tr>
<tr>
<td>Personal Living Skills</td>
<td>.87</td>
<td>.79</td>
</tr>
<tr>
<td>Community Living Skills</td>
<td>.96</td>
<td>.84</td>
</tr>
<tr>
<td>Broad Adaptive Behaviour</td>
<td>.92</td>
<td>.84</td>
</tr>
<tr>
<td><strong>Maladaptive Behaviour Indices</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Internalized Maladaptive Index</td>
<td>.90</td>
<td>.74</td>
</tr>
<tr>
<td>Asocial Maladaptive Index</td>
<td>.84</td>
<td>.69</td>
</tr>
<tr>
<td>Externalized Maladaptive Index</td>
<td>.76</td>
<td>.84</td>
</tr>
<tr>
<td>General Maladaptive Index</td>
<td>.83</td>
<td>.88</td>
</tr>
</tbody>
</table>
developing children, as predicted, had significantly greater adaptive skills than children with mild or moderate to severe intellectual disabilities (Bruininks et al., 1986). In addition there were no differences found, as predicted, in any of the adaptive behaviour domains between children with learning disabilities and typically developing children, or between adolescents with behaviour disorders and typically developing children (Bruininks et al., 1986). These results provide evidence for the construct validity of the adaptive behaviour scales because the scales differentiate between groups we expect to differ, and do not differentiate between groups that are not expected to differ in adaptive behaviour.

The Problem Behaviour scale assesses the level of frequency and severity of eight broad categories of problem (challenging) behaviours. The scale provides examples of behaviours that are typical of that class of behaviours. The problem behaviour categories are grouped into three indexes: Internalized Problems, Asocial Problems, and Externalized Problems: Internalized Problems include: (a) Hurtful to Self (e.g., hitting self, biting self), (b) Unusual or Repetitive Habits (e.g., rocking, twirling fingers), and (c) Withdrawal or Inattentive Behaviour (e.g., showing little interest in activities, keeping away from other people). Asocial problems include: (a) Socially Offensive Behaviour (e.g., using vulgar language, touching others too much), and (b) Uncooperative Behavior (e.g., refusing to obey, refusing to share with others). Externalized problems include: (a) Hurtful to Others (e.g., hits and kicks others), (b) Destructive to Property (e.g., deliberately breaks, defaces, or destroys things), and (c) Disruptive Behaviour (e.g., interferes with others by clinging, pestering, crying without reason). The eight categories of behaviour also create a general problem behaviour index. The respondent provides a
description of the single most serious problem within each of the eight categories of
behaviour and then rates the frequency of the behaviour from 1 (less than once a month)
to 5 (one or more times an hour) and the severity of the behaviour from 1 (slightly
serious, a mild problem) to 4 (to extremely serious, a critical problem). If a particular
behaviour category does not apply (i.e., the child does not exhibit such a class of
behaviours), parents indicate that the frequency of the behaviour is zero (never) and the
severity is zero (not serious).

Within each of the four indices, raw scores for both frequency and severity are
converted into part scores and then summed. These scores are then summed with an age-
adjustment factor and subtracted from 100 to yield the Internalized Maladaptive Index
(IMI), Asocial Maladaptive Index (AMI), Externalized Maladaptive Index (EMI), and
General Maladaptive Index (GMI). Scores range from +10 to -70 with negative scores
indicating greater levels of problem behaviour. The index scores are based on a scale
similar to the decibel loss scale used to describe the extent of hearing impairment. Scores
ranging from +10 to -10 are considered Normal, from -11 to -20 Marginally Serious,
from -21 to -30 Moderately Serious, from -31 to -40 Serious, -41 and below Very
Serious. In order to eliminate negative numbers a constant of 50 was added by the
researcher to each score. With the constant added scores ranged from 4 (most
challenging) to 51 (least challenging).

Test-retest reliability for the Maladaptive Behaviour Indices was conducted on a 6
to 8 year-old sample, and a 10 to 11 year-old sample (see Table 4). Test-retest reliabilities
ranged from .76 to .92 in the younger sample, and from .69 to .89 in the older sample.
The Maladaptive Behaviour Indices have been shown to have construct validity through a number of studies in which scores of individuals with moderate to severe intellectual disabilities, and with behaviour disorders were compared to their typically developing same-aged counterparts. For example, adolescents with a moderate to severe intellectual impairment and adolescents and children with a moderate behaviour disorder had significantly greater negative maladaptive behaviour scores than their typically developing same aged peers (Bruininks et al., 1986).

The Parental Involvement Scale-Revised (see Appendix B). The Parental Involvement Scale-Revised (PIS) is a 20-item questionnaire designed to assess various aspects of parental involvement in childcare. The questionnaire is a revised version of the questionnaire used by Roach et al. (1999). The questionnaire is comprised of three subscales: The Daily Caregiving scale (DC), The Child-Related Tasks scale (CRT), and The Child Socialization scale (CS). The scale also gives participants an open-ended question to explain additional aspects of their role as caregivers.

The Daily Caregiving scale (DC) measures daily activities performed by parents including, dressing, feeding, bathing, putting child to bed, and reading. Parents indicate the number of days per week (0-7) that they are involved in each of these activities with their children. The total range of scores is between 0 and 35 with higher scores indicating greater daily caregiving (Roach et al., 1999). The total score is then converted to a mean and ranges from 0-7 with higher scores indicating greater number of days per week involved in daily activities.

The Child-Related Tasks scale (CRT) includes a list of eight general child-related tasks that parents might perform including: transporting child, arranging childcare,
shopping for clothes, shopping for toys, scheduling appointments, taking child to appointments, paperwork, and caring for a sick child. Parents indicate on a five-point scale the level of responsibility of each parent for each task (mother always responsible, mother usually responsible, mother and father equally responsible, father usually responsible, father always responsible). When mothers are the respondents the scale ranges from 1 (fathers always responsible) to 5 (mothers always responsible). The total score ranges from 8-40 with higher scores indicating perceptions of greater maternal involvement in child-related tasks. When fathers are the respondents the scale is reverse scored so that the scale ranges from 1 (mothers always responsible) to 5 (fathers always responsible). Total scores range from 8-40 with higher scores indicating perceptions of greater paternal involvement in child-related tasks (Roach et al., 1999). In both cases, a mean score out of 5 (ranging from 1-5) was calculated with higher scores indicating greater involvement in child-related tasks.

The Child Socialization scale (CS) includes a list of six parenting responsibilities: play partner for quiet activities, active play partner, partner on social outings, nurturer, teacher, and disciplinarian. The same response scale as the CRT is used. Like the CRT scale, responses for fathers were reverse scored. Total scores range from 6-30 with higher scores indicating perceptions of greater parental involvement in child socialization (Roach et al., 1999). Like the CRT scale, a mean score out of 5 (ranging from 1-5) was calculated with higher scores indicating a greater level of involvement in child socialization.

A total parental involvement composite was calculated for the overall assessment of parental involvement. First the mean score out of 7 for the DC scale was converted to a
mean score of 5 (ranging from 0-5) by multiplying each score by a constant of .71. This new score was added to the mean scores of the CRT scale and the CS scale. Thus, a total composite ranging from 2-15 was created with higher scores indicating greater levels of overall parental involvement.

A Parental Involvement Composite (PIC) was also created by the author of the thesis for both mothers and fathers to determine the level of agreement between parents’ reports of their levels of childcare involvement. To create the composite, fathers’ scores on the CRT and CS scales were un-reversed. The means out of 5 for each scale were calculated. Fathers’ PIC was created by summing the means of the un-reversed CRT and CS scales for fathers. Mothers’ scores on the CRT and CS remained unchanged. Mothers’ PIC was created by summing the means of the CRT and CS scales. Scores on both PIC’s ranged from 2-10. For fathers, higher scores indicate fathers’ reports that their wives are more involved in childcare. For mothers, higher scores indicate mothers’ reports of being more involved in childcare.

**Social Support Questionnaire-6 (see Appendix C).** The Social Support Questionnaire-6 (SSQ6; Sarason, Sarason, Shearin, & Pierce, 1987) is a six-item subset of the 27-item SSQ (Sarason, Levine, Basham, & Sarason, 1983) that measures participants’ number of social supports and satisfaction with social supports. Participants are asked to list the number of people they can count on for support, from 0 to 9, in a variety of situations. Participants are asked who they can count on to a) distract them from their worries, b) help them feel more relaxed, c) accept them, d) care for them, e) make them feel better, and f) console them, when the participants are under stress or upset. The Number scale (N scale) is comprised of the mean number of people across the
six questions. The N scale ranges from 0 to 9 with higher scores indicating greater number of social supports. After each of the six questions, participants are asked how satisfied they are with the social support they receive under the various situations, from 1 (very dissatisfied) to 6 (very satisfied). The Satisfaction scale (S scale) is comprised of the mean satisfaction of support across the six questions. The S scale ranges from 1 to 6 with higher scores indicating greater satisfaction with social support. The N and S scales have been shown to have only modest correlations ranging from .34 to .58 (Sarason et al., 1983; Sarason et al., 1987) indicating that both aspects of social support, while related, represent different dimensions of the general concept.

The internal consistency of the N and S scales, based on three undergraduate samples ranged from .90 to .93, indicating a high degree of internal reliability of both scales (Sarason et al., 1987). The test-retest reliability for the N and S scales measured over a four-week interval is .90 and .83 respectively (Sarason, 1983).

Sarason et al (1987) established support for the construct validity of the SSQ6. They found a high level of consistency between the SSQ6 and the SSQ even when the six questions from the SSQ6 were removed from the SSQ. Across three undergraduate samples the correlation between SSQ6 N scale and SSQ N scale ranged from .95 to .97 and from .95 to .96 for the SSQ6 S and SSQ S scale indicating a high level of construct validity. The SSQ6 is also negatively related to measures of anxiety, depression, and loneliness indicating that a greater amount of social support is related to lower levels of anxiety, depression, and loneliness as predicted in the literature. Sarason et al (1983) found that neither the N scale nor the S scale correlated with a measure of social desirability.
Positive Contributions Survey. The Positive Contributions Survey (PCS) is composed of 50 Likert-type questions assessing the positive contributions of a family member with a disability. The PCS is one of four subscales from the Kansas Inventory of Parental Perceptions (KIPP – Behr et al., 1992). This measure is available online (http://www.beachcenter.org/Books%5CFullPublications%5CPDF%5CKIPP.pdf). The construction of the scale was composed of three phases: parental interviews, exploratory factor analysis, and a validation study to explore the reliability and validity of the instrument. The PCS was the first scale of its kind to empirically measure and validate parents' positive perceptions of raising a child with a disability. Factor, reliability, and validity information was obtained from a sample of 1,262 respondents from 34 states in the USA. The most frequently reported child diagnosis was mental retardation (65%). The most frequently reported child level of disability was mild or moderate (61%). However, 39% of the reported levels of disability were severe or profound.

The PCS yields nine factors in which the child is a source of: (a) learning through experience with special problems in life (e.g., increased awareness of people with disabilities, increased sensitivity: seven items), (b) happiness and fulfillment (e.g., fun to be around, cheers me up: six items), (c) strength and family closeness (e.g., I am more accepting of things, family has become closer: seven items), (d) understanding of life’s purpose (e.g., everyone has a purpose in life, confirms my faith in God: four items), (e) awareness about future issues (e.g., realize importance of planning for family future: three items), (f) personal growth and maturity (e.g., learned to control temper, I am a more responsible person: seven items), (g) expanded social network (e.g., circle of friends is larger, met some of my best friends: five items), (h) career/job growth (e.g.,
gives new perspective to my job, gives inspiration to improve my job skills: four items),
(i) pride and cooperation (e.g., help around the house, helpful to other family members:
seven items). Respondents answer the 50 statements on a 1 (strongly disagree) to 4
(strongly agree) scale with scores ranging from 50-200. Higher scores are associated with
parents' stronger positive perceptions of their children with a disability.

The internal consistency coefficients for the Positive Contributions factors range
from.56 to.86 with a mean coefficient of.77 (see Table 5). Test-retest reliability
coefficients for the Positive Contributions factors range from .30 to .74 with a mean
coefficient of .56 (see Table 5). The relative instability of this measure appears to reflect
the changeable nature of perceptions of daily experiences, emotions, and moods (Behr et

There is some evidence for the construct validity of the PCS obtained from Behr’s
et al. (1992) validation study. For example, scores on the Strength and Family Closeness
factor were significantly positively correlated with scores on the Family APGAR ($r =
.30). The Family APGAR (Smilkstein, 1988) is a measure of family social support and
functioning. Thus, respondents who reported that their children with a disability
contributed to the family’s sense of strength and closeness also reported greater
satisfaction with their families functioning. Also, scores on the Understanding Life’s
Purpose factor were significantly positively correlated with scores on the Special Purpose
factor ($r = .32; a factor from the Causal Attributions subscale of the KIPP). Thus, those
who reported that their children contributed to a greater understanding of life’s purpose
and had increased religious faith, were more likely to attribute the children’s disabilities
to God’s will or to some special purpose.
Table 5.
Reliability Coefficients for the Positive Contributions Factors

<table>
<thead>
<tr>
<th>Factors</th>
<th>Internal Consistency</th>
<th>Test-Retest</th>
</tr>
</thead>
<tbody>
<tr>
<td>Learning through Experience with Special Problems</td>
<td>.80</td>
<td>.57</td>
</tr>
<tr>
<td>Happiness and Fulfillment</td>
<td>.85</td>
<td>.61</td>
</tr>
<tr>
<td>Strength and Family Closeness</td>
<td>.86</td>
<td>.30</td>
</tr>
<tr>
<td>Understanding of Life's Purpose</td>
<td>.62</td>
<td>.61</td>
</tr>
<tr>
<td>Awareness about Future Issues</td>
<td>.56</td>
<td>.52</td>
</tr>
<tr>
<td>Personal Growth and Maturity</td>
<td>.84</td>
<td>.56</td>
</tr>
<tr>
<td>Expanded Social Network</td>
<td>.76</td>
<td>.64</td>
</tr>
<tr>
<td>Career/job Growth</td>
<td>.78</td>
<td>.50</td>
</tr>
<tr>
<td>Pride and Cooperation</td>
<td>.85</td>
<td>.74</td>
</tr>
</tbody>
</table>
Procedure

Before participants were recruited, Research Ethics Board (REB) approval was obtained. The REB board approved that the present research was of minimal risk to participants. Participants were recruited from parent support groups in Windsor, Richmond Hill, Pickering, and Ottawa, Ontario. Parents of children with autism were also recruited from social skills groups for children with autism in Toronto. The primary author attended such groups in person and described the details of the study and what was required for participation. Participants were also obtained through recruitment flyers sent to parents in various newsletters and from speech-language pathologists. Typically the researcher made first contact with mothers at social support and social skills groups or the mothers contacted the researcher after viewing the flyers posted on the internet. Very few fathers made first contact with the researcher and very few fathers attended social support groups. Thus, mothers who agreed to participate played a central role in recruiting their husbands to also participate.

Families (i.e., married couples) who agreed to participate were given/mailed two identical research packages; one for mothers and one for fathers. Included in the research packages were an informed consent information sheet (see Appendix D), the questionnaires consisting of the various measures described, and a list of community resources. The informed consent outlined that the purpose of the study was to achieve a greater understanding of mothers’ and fathers’ parenting stress and the positive experiences of raising their children with autism. The informed consent also outlined the time commitment of the study (approximately 45 minutes to 60 minutes) and the
procedures for parents to follow. Mothers and fathers were asked to complete the questionnaires on their own and were asked not to discuss any of the answers with each other until after they mailed the questionnaires back to the researcher in separate, self-addressed, postage-paid envelopes. The list of community resources was provided to parents so they could call various community agencies if they were experiencing any uncomfortable feelings through participation in the study, or uncomfortable feelings deriving from their life in general.

Families who agreed were sent reminder emails or given reminder phone calls which also provided the opportunity for participants to ask questions about the research. Thus, some participants chose to remain anonymous while others who wanted reminders were guaranteed confidentiality. Of the 49 questionnaires handed out, 20 were returned resulting in a 40.82% response rate.

Participants were provided feedback in three ways. First, the primary researcher provided oral feedback to the social support group in Windsor in which many of the families were recruited. Second, a two-page written feedback about the results and implications of the study, as well as practical recommendations to help with parents’ stress levels were posted on an Internet website at the University of Windsor designated for autism research. Third, participants who provide their email addresses in the recruitment phase of the study were emailed the written feedback.
CHAPTER III

RESULTS

Analyses Related to Demographics

Before the main statistical analyses were conducted, several analyses exploring demographic variables were conducted to clarify the characteristics of the sample. There were three phases to these analyses. The first phase explored gender differences between mothers' and fathers' age, level of education, and employment status. The second phase explored relations between parent, child, and family demographic variables and parental distress. These associations were explored separately for mothers and for fathers. The third phase explored relations between parent, child, and family demographic variables and positive experiences. These associations were explored separately for mothers and for fathers.

Demographic gender differences. See Table 1 for demographic frequencies of parent age, level of education, and employment status. An independent sample t-test was conducted to compare mothers' and fathers' age. There were no significant differences between mothers' age (M = 38.75, SD = 5.75) and fathers' age (M = 42.45, SD = 6.70), $t(38) = 1.87, p = .07$. A chi-square was conducted to compare mothers' and fathers' level of education. Mothers and fathers did not significantly differ in their education level, $\chi^2(5) = 5.56, p = .35$. A chi-square was also conducted to compare mothers' and fathers' employment status. There were significant differences between mothers' and fathers' employment status, $\chi^2(2) = 12.91, p = .002$. An examination of Table 1 reveals that there were significantly more unemployed mothers (35%) than fathers (5%), significantly more
part-time employed mothers (30%) than fathers (5%), and significantly more full-time employed fathers (90%) than mothers (35%).

_Father variables and parental distress._ Relations between parent (age, level of education, and employment status), child (age, DSM-IV diagnosis), and family (number of other children, and family income) demographic variables and parental distress were explored. These associations were explored with one-way ANOVA’s (for categorical variables such as level of education, employment status, and family income) and correlations (for continuous variables such as parental age, child age, and number of children). Demographic frequencies for parent, family, and child variables are presented in Table 1 and Table 2. Means and standard deviations for fathers’ parental distress scores as a function of education and family income are presented in Table 6. For fathers, there were no significant correlations found between parental distress and parental age \((r = .21, p = .38)\), child age \((r = .40, p = .08)\), or number of other children \((r = -.16, p = .50)\). A one-way ANOVA was conducted to explore the differences between parental distress as a function of fathers’ level of education. Due to insufficient cell sizes data were recoded from the original set of six education options (see Table 1) to three education options (no college/university, some college/university, college/university degree). No significant differences were found between fathers’ parental distress scores and level of education, \(F(2, 17) = .37, p = .70\). A one-way ANOVA was also conducted to explore the differences between parental distress as a function of fathers’ reports of family income. No significant differences were found, \(F(3, 16) = 1.83, p = .18\).

_Mother variables and parental distress._ Demographic frequencies for parent, family, and child variables are presented in Table 1 and Table 2. Means and standard
Table 6.
Means, Standard Deviations, and Cell Sizes for Fathers’ Demographic Variables as a Function of Parental Distress and Positive Experiences

<table>
<thead>
<tr>
<th>Variable</th>
<th>$n$</th>
<th>Parental Distress$^a$</th>
<th>Positive Experiences$^b$</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td>$M(SD)$</td>
<td>$M(SD)$</td>
</tr>
<tr>
<td>No College/University</td>
<td>5</td>
<td>32.60(12.12)</td>
<td>124.00(6.40)</td>
</tr>
<tr>
<td>Some College/University</td>
<td>7</td>
<td>31.57(7.21)</td>
<td>133.14(22.84)</td>
</tr>
<tr>
<td>College/University Degree</td>
<td>8</td>
<td>28.88(6.15)</td>
<td>138.50(14.49)</td>
</tr>
<tr>
<td><strong>Family Income</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>$35000-$50000</td>
<td>2</td>
<td>42.50(16.26)</td>
<td>131.50(21.92)</td>
</tr>
<tr>
<td>$50000-$70000</td>
<td>5</td>
<td>29.00(3.39)</td>
<td>125.80(5.54)</td>
</tr>
<tr>
<td>$70000-$100000</td>
<td>5</td>
<td>29.2(3.27)</td>
<td>144.80(19.88)</td>
</tr>
<tr>
<td>Over $100000</td>
<td>8</td>
<td>29.88(7.99)</td>
<td>130.50(17.80)</td>
</tr>
</tbody>
</table>

$^a$ = Parenting Stress Index – Short Form, Parental Distress; $^b$ = Positive Contributions Survey, Total Score
deviations for mothers’ parental distress scores as a function of education, employment status, and family income are presented in Table 7. For mothers, there were no significant correlations found between parental distress and parental age \((r = .32, p = .17)\), child age \((r = .01, p = .98)\), or number of other children \((r = -.22, p = .36)\). A one-way ANOVA was conducted to explore the differences between parental distress as a function of mothers’ level of education. There was a significant difference between education level and parental distress, \(F(2, 17) = 3.95, p = .04\). A Tukey test revealed that mothers with a post graduate degree had significantly less distress than mothers with some college/university. A one-way ANOVA was conducted to explore the differences between parental distress as a function of mothers’ employment status. No significant differences were found, \(F(2, 17) = .08, p = .92\). A one-way ANOVA was also conducted to explore the differences between parental distress as a function of mothers’ reports of family income. No significant differences were found, \(F(2, 17) = .32, p = .73\).

**Father variables and positive experiences.** Relations between parent (age, level of education, and employment status), child (age, DSM-IV diagnosis), and family (number of other children, and family income) demographic variables and positive experience scores were also explored. These associations were explored with one-way ANOVA’s (for categorical variables such as level of education, employment status, and family income) and correlations (for continuous variables such as parental age, child age, and number of children). Demographic frequencies for parent, family, and child variables are presented in Table 1 and Table 2. Means and standard deviations for fathers’ positive experience scores as a function of education and family income are presented in Table 6. For fathers, there were no significant correlations found between positive experience
Table 7.

Means, Standard deviations, and Cell Sizes for Mothers’ Demographic Variables as a Function of Parental Distress and Positive Experiences

<table>
<thead>
<tr>
<th>Variable</th>
<th>Parental Distress(^a)</th>
<th>Positive Experiences(^b)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(M(SD,n))</td>
<td>(M(SD,n))</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Some college/University</td>
<td>36.33(7.87, 6)</td>
<td>141.00(17.99, 6)</td>
</tr>
<tr>
<td>College/University Degree</td>
<td>32.73(9.31, 11)</td>
<td>144.40(20.90, 10)</td>
</tr>
<tr>
<td>Post Graduate Degree</td>
<td>19.33(7.57, 3)</td>
<td>152.33(21.50, 3)</td>
</tr>
<tr>
<td><strong>Employment Status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unemployed</td>
<td>33.00(8.83, 7)</td>
<td>141.67(19.47, 6)</td>
</tr>
<tr>
<td>Part-time</td>
<td>31.67(8.09, 6)</td>
<td>151.67(19.77, 6)</td>
</tr>
<tr>
<td>Full-time</td>
<td>30.71(13.39, 7)</td>
<td>141.00(20.17, 7)</td>
</tr>
<tr>
<td><strong>Family Income</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>$35000-$70000</td>
<td>34.00(9.10, 8)</td>
<td>151.86(17.54, 7)</td>
</tr>
<tr>
<td>$70000-$100000</td>
<td>31.00(5.34, 5)</td>
<td>135.00(15.28, 5)</td>
</tr>
<tr>
<td>Over $100000</td>
<td>29.86(13.70, 7)</td>
<td>144.14(22.80, 7)</td>
</tr>
</tbody>
</table>

\(^a\) = Parenting Stress Index – Short Form, Parental Distress; \(^b\) = Positive Contributions

Survey Total Score
scores and parental age ($r = .03, p = .89$), child age ($r = -.05, p = .83$), or number of other children ($r = .01, p = .98$). A one-way ANOVA was conducted to explore the differences between positive experience scores as a function of fathers' level of education. No significant differences were found between fathers' parental distress scores and level of education, $F(2, 17) = 1.15, p = .34$. A one-way ANOVA was also conducted to explore the differences between positive experience scores as a function of fathers' reports of family income. No significant differences were found, $F(3, 16) = 1.22, p = .33$.

**Mother variables and positive experiences.** Demographic frequencies for parent, family, and child variables are presented in Table 1 and Table 2. Means and standard deviations for mothers' positive experience scores as a function of education, employment status, and family income are presented in Table 7. For mothers, there were no significant correlations found between positive experience scores and parental age ($r = -.09, p = .71$), child age ($r = -.06, p = .80$), or number of other children ($r = -.02, p = .94$). A one-way ANOVA was conducted to explore the differences between positive experience scores as a function of mothers' level of education. No significant differences were found, $F(2, 16) = .32, p = .73$. A one-way ANOVA was conducted to explore the differences between positive experience scores as a function of mothers' employment status. No significant differences were found, $F(2, 16) = .56, p = .58$. A one-way ANOVA was also conducted to explore the differences between positive experience scores as a function of mothers' reports of family income. No significant differences were found, $F(2, 16) = .13, p = .35$.

ANOVA's for fathers' employment status and mothers' and fathers' reports of their children's diagnosis were not conducted due to the disproportionate number of fathers in
full-time work, and the disproportionate number of children diagnosed with Autistic Disorder. The unequal distribution of responses to each cell in these two variables made ANOVA's unreliable. In such cases a visual inspection of the data was used. There appeared to be no consistent pattern between fathers' employment status, mothers' and fathers' reports of child diagnosis, and parental distress or positive experiences when descriptive analyses were used.

Summary of Demographic Findings

Results indicated that mothers and fathers did not differ with respects to their age or their level of education. There were, however, significantly more full-time employed fathers than mothers. There was only one significant relationship between demographic variables and parental distress or positive experiences. Mothers with a post graduate degree reported significantly less stress than mothers with some college/university. This finding warrants further follow-up, but will not be addressed in subsequent analyses.

Analyses of Main Dependent Variables

The means and standard deviations for the measures described in the method section, the PSI-SF (Parental Distress raw score), ICAP (Broad Adaptive Behaviour Index standard score and General Maladaptive Index), PIS (Total Involvement), SSQ (mean number and mean satisfaction), and PCS are presented in Table 8 and 9. Analyses will be presented in a manner consistent with the research goals and hypotheses outlined in the introduction section of this thesis following a discussion of the relevant statistical assumptions.

Assumptions. When checking the assumptions of normality and absence of outliers, mother’s total parental involvement had a kurtosis level of 7.13 which is outside the
Table 8.

Comparison of Mean Scores on the PSI-SF, PIS, ICAP, and Social Support Scales for Mothers and Fathers

<table>
<thead>
<tr>
<th>Measure</th>
<th>Mothers</th>
<th>Fathers</th>
<th>t</th>
</tr>
</thead>
<tbody>
<tr>
<td>PSI-SF Parental Distress</td>
<td>31.8 (9.97)</td>
<td>30.75 (7.99)</td>
<td>0.52</td>
</tr>
<tr>
<td>GMI</td>
<td>24.72 (13.62)</td>
<td>31.39 (11.43)</td>
<td>-2.41*</td>
</tr>
<tr>
<td>BABI</td>
<td>58.55 (30.07)</td>
<td>60.65 (24.07)</td>
<td>-0.58</td>
</tr>
<tr>
<td>PIS Total Involvement</td>
<td>11.38 (1.39)</td>
<td>7.72 (1.53)</td>
<td>7.56**</td>
</tr>
<tr>
<td>SSQ6 Number of Supports</td>
<td>3.50 (1.87)</td>
<td>2.19 (1.47)</td>
<td>4.73**</td>
</tr>
<tr>
<td>SSQ6 Satisfied with Support</td>
<td>4.76 (1.18)</td>
<td>4.78 (0.87)</td>
<td>-0.06</td>
</tr>
</tbody>
</table>


*p < .05, **p < .001.
Table 9.
Comparison of PCS Scores for Mothers and Fathers

<table>
<thead>
<tr>
<th>PCS¹ scale</th>
<th>Mothers</th>
<th>Fathers</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Learning Through Experience of Special Problems</td>
<td>23.52 (3.06)</td>
<td>21.42 (2.91)</td>
<td>.06</td>
</tr>
<tr>
<td>Source of Happiness and Fulfillment</td>
<td>19.05 (3.84)</td>
<td>18.63 (2.18)</td>
<td>.62</td>
</tr>
<tr>
<td>Source of Strength and Family Closeness</td>
<td>22.26 (3.40)</td>
<td>19.95 (3.50)</td>
<td>.03*</td>
</tr>
<tr>
<td>Understanding Life’s Purpose</td>
<td>11.84 (2.14)</td>
<td>10.37 (2.45)</td>
<td>.07</td>
</tr>
<tr>
<td>Awareness About Future Issues</td>
<td>9.11 (1.24)</td>
<td>7.79 (1.62)</td>
<td>.002*</td>
</tr>
<tr>
<td>Personal Growth and Maturity</td>
<td>19.26 (4.52)</td>
<td>17.32 (3.58)</td>
<td>.19</td>
</tr>
<tr>
<td>Expanded Social Network</td>
<td>13.74 (3.51)</td>
<td>11.00 (3.00)</td>
<td>.01*</td>
</tr>
<tr>
<td>Career/Job Growth</td>
<td>10.74 (2.75)</td>
<td>9.63 (2.72)</td>
<td>.18</td>
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<tr>
<td>Source of Pride and Cooperation</td>
<td>15.32 (4.42)</td>
<td>16.95 (3.42)</td>
<td>.17</td>
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<tr>
<td>PCS total score</td>
<td>144.58 (19.34)</td>
<td>133.05 (17.34)</td>
<td>.05</td>
</tr>
</tbody>
</table>

¹n = 19, "= Positive Contributions Survey

*p < .05, **p < .001
recommended range (-2 to 2) indicating a non-normal distribution. Given that this was the only variable with normality issues, and that t-tests are generally robust to violations of normality, this variable was not transformed. A number of outliers were also revealed. These included one father’s parental distress score (an extreme high score), one mother’s total parental involvement score (an extreme low score), one mother’s mean social support satisfaction score (an extreme low score), and one father’s mean social support satisfaction score (an extreme low score). Individual review of each of these cases indicated that they were all reasonable cases and meaningful data. Inclusion of these data points indicates the diverse nature of the participant’s experiences. In addition, the results to follow this discussion were similar when these data points were excluded from analyses.

Research goal 1: Gender differences. The first research goal was to examine differences between mothers’ and fathers’ parental distress and reports of child challenging and adaptive behaviours. Means, standard deviations, and t-values for mothers and fathers on the PD subscale of the PSI-SF, General Maladaptive Index of the ICAP and Broad Adaptive Behaviour Index of the ICAP are presented in Table 8. This research goal was examined using paired sample t-tests. There was no significant difference in the amount of parental distress (PD raw scores) experienced by parents. However, 30% of mothers and 15% of fathers reported clinically significant levels of parental distress (PD raw score equal or greater than 36). Mothers reported significantly lower GMI scores (i.e., more child challenging behaviours) than fathers. Whereas 45% of mothers rated their children’s challenging behaviours as either Serious or Very Serious, only 22% of fathers rated their children’s challenging behaviours as Serious or Very
Stress and positive experiences 72

Serious. Despite such a difference there was positive correlation between mothers’ and fathers’ GMI scores, \( r(16) = .58, p < .05 \). Mothers’ and fathers’ BABI scores, however, were not significantly different. Mothers’ reports of their children’s adaptive behaviours were significantly positively correlated with fathers’ reports of their children’s adaptive behaviours, \( r(18) = .83, p < .001 \). The mean BABI standard scores that mothers and fathers reported placed their children’s behaviours in the Extremely Low range of functioning. This indicates that the adaptive functioning of these children with autism is significantly lower than typically developing children.

Hypothesis 1: Child behaviours and mothers’ parental distress. It was predicted that greater levels of child challenging behaviours and lower levels of adaptive behaviours would be associated with higher parenting distress levels for mothers. Pearson correlations (Table 10) were conducted to examine this hypothesis. Mothers’ reports of their children’s challenging (GMI scores) and adaptive behaviours (BABI scores) were significantly associated with mothers’ parental distress scores (PD scores), \( r(18) = -.50, p < .05 \); \( r(18) = -.45, p < .05 \) respectively. Specifically, greater levels of child challenging behaviours (lower scores on GMI), and lower levels of child adaptive behaviours were associated with higher levels of mothers’ parental distress.

Research goal 2: Child behaviours and fathers’ parental distress. This research goal paralleled hypothesis 1. The second research goal was to examine the role of child challenging behaviours and low adaptive behaviours on parenting distress in fathers. Pearson correlations (Table 10) were conducted to examine this goal. Fathers’ reports of child challenging behaviours (GMI scores) were significantly associated with fathers’
Table 10.

Correlations between Child, Maternal, and Paternal Variables

<table>
<thead>
<tr>
<th>Variable</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
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<th>10</th>
<th>11</th>
<th>12</th>
<th>13</th>
<th>14</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. GMI&lt;sup&gt;a&lt;/sup&gt; (M)</td>
<td>.58*</td>
<td>.65**</td>
<td>.40</td>
<td>-50*</td>
<td>-.60**</td>
<td>.09</td>
<td>.04</td>
<td>.25</td>
<td>.47*</td>
<td>.39</td>
<td>.55*</td>
<td>.11</td>
<td>.43</td>
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<td>2. GMI (F)</td>
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<td>.16</td>
<td>-.35</td>
<td>-.47*</td>
<td>.48*</td>
<td>-.27</td>
<td>.10</td>
<td>.22</td>
<td>.48*</td>
<td>.46</td>
<td>.23</td>
<td>.23</td>
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<tr>
<td>3. BABI&lt;sup&gt;b&lt;/sup&gt; (M)</td>
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<td>.83***</td>
<td>-.45*</td>
<td>-.26</td>
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<tr>
<td>4. BABI (F)</td>
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<td>-.29</td>
<td>-.36</td>
<td>-.31</td>
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<tr>
<td>5. PSI-SF-PD&lt;sup&gt;c&lt;/sup&gt; (M)</td>
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<td>.52*</td>
<td>-.09</td>
<td>-.33</td>
<td>-.52*</td>
<td>-.46*</td>
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<tr>
<td>6. PSI-SF-PD (F)</td>
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<td>-.43</td>
<td>-.41</td>
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<td>7. PIS&lt;sup&gt;d&lt;/sup&gt; (M)</td>
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<td>8. PIS (F)</td>
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<td>9. PCS&lt;sup&gt;e&lt;/sup&gt; (M)</td>
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<td>10. PCS (F)</td>
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<tr>
<td>11. SSQ6-N scale&lt;sup&gt;f&lt;/sup&gt; (M)</td>
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<td>12. SSQ6-N scale (F)</td>
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<td>13. SSQ6-S scale(^{(e)}) (M)</td>
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<td>.23</td>
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<td>14. SSQ6-S scale (F)</td>
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</table>

M = mother rating, F = Father rating. \(^{(a)}\) = General Maladaptive Index (child challenging behaviours). \(^{(b)}\) = Broad Adaptive Behaviour Index (low adaptive behaviours). \(^{(c)}\) = Parenting Stress Index Short Form – Parental Distress. \(^{(d)}\) = Parental Involvement Scale. \(^{(e)}\) = Positive Contributions Survey (positive experiences). \(^{(f)}\) = Social Support Questionnaire Scale-6-Number scale. \(^{(g)}\) = Social Support Questionnaire Scale-6-Satisfaction Scale.

\(*p < .05, **p < .01, ***p < .001\)
parental distress scores (PD scores), $r(16) = -.47, p < .05$. Thus, fathers' reported significantly less parental distress when they reported higher GMI scores (i.e., lower levels of challenging behaviours). Fathers' reports of child adaptive behaviours (BABI scores) were not significantly associated with fathers' parental distress.

*Inter-parent correlations of child behaviours and parental distress.* Fathers' PD raw scores were compared to mothers' reports of GMI scores and BABI scores. Fathers' parental distress (PD scores) was significantly negatively related to mothers' reports of child challenging behaviours (GMI scores), $r(18) = -.60, p < .01$, and adaptive behaviours (BABI scores), $r(18) = -.47, p < .05$. Thus, fathers reported less parental distress when mothers' reported less severe child challenging behaviours and greater levels of child adaptive behaviours. Mothers' PD raw scores were compared to fathers' GMI scores and BABI scores. No significant correlations were found.

*Hypothesis 2: Childcare involvement.* It was predicted that mothers would report greater levels of parental involvement in childcare than fathers. Means, standard deviations, and $t$-values for mothers and fathers on the total PIS scale are presented in Table 8. This hypothesis was examined by using paired sample $t$-tests. Mothers reported significantly greater levels of involvement (i.e., higher PIS scores) in childcare than fathers. Mothers' and Fathers' PIC were correlated to determine the level of agreement between parents' reports of childcare involvement. There was a significant relationship between fathers' and mothers' reports of childcare involvement, $r(18) = .75, p < .001$, indicating that mothers' and fathers' had a high level of agreement when reporting levels of childcare involvement. Therefore, both mothers and fathers agreed that mothers were more involved in childcare than fathers.
**Hypothesis 3: Mothers’ involvement, child behaviours, and parental distress.** It was predicted that maternal involvement in childcare would mediate the relationship between child challenging and adaptive behaviours and mothers’ parental distress. The small sample size excluded the possibility of conducting regression analysis to test this mediational hypothesis. Thus, this hypothesis was examined using Pearson correlations (Table 10). As previously reported, in hypothesis 1, child challenging behaviour scores on the GMI (higher scores = less severe challenging behaviours), and adaptive behaviour standard scores on the BABI were negatively related to mothers’ parental distress. Mothers’ reports of their parental involvement (PIS scores), however, were not associated with either measure of their children’s behaviours (challenging or adaptive behaviours) or to mothers’ parental distress. Fathers’ reports of child challenging behaviour scores on the GMI (higher scores = less severe challenging behaviours) were positively correlated with mothers’ parental involvement scores on the PIS, $r(16) = .48$, $p <.05$ (see Table 10). Thus, mothers reported greater levels of childcare involvement when fathers reported lower levels of child challenging behaviours.

**Hypothesis 4: Fathers’ involvement and parenting distress.** It was predicted that greater levels of fathers’ involvement in childcare would be related to lower levels of fathers’ parenting distress. This hypothesis was examined with Pearson correlations (Table 10). There was a trend approaching significance indicating that parental involvement in childcare (PIS scores) was negatively related to parental distress (PD scores) for fathers $r(18) = -.44$, $p =.055$. Thus, there was a trend for fathers to experience less parental distress when they were more involved in childcare.
Hypothesis 5: Fathers’ and mothers’ childcare involvement. It was predicted that greater levels of childcare involvement by fathers would be related to lower levels of childcare involvement for mothers and lower levels of parenting distress for mothers. This hypothesis was examined using Pearson correlations (Table 10). No significant relationships between fathers’ level of childcare involvement and either mothers’ childcare involvement or mothers’ parental distress were found.

Hypothesis 6: Mothers’ and fathers’ parental distress. It was predicted that there would be a positive association between mothers’ and fathers’ levels of parenting distress. This hypothesis was conducted using Pearson correlations (Table 10). There was a significant positive correlation between mothers’ and fathers’ parental distress (PD scores), $r(18) = .52, p < .05$. Thus, greater levels of parental distress as reported by mothers were associated with greater levels of parental distress as reported by fathers.

Research goal 3: Gender differences in social support. The third research goal was to examine the differences between mothers’ and fathers’ number of social supports and satisfaction with social support. Means, standard deviations, and $t$-scores for number of supports on the SSQ and satisfaction with supports on the SSQ are presented in Table 8. This research goal was examined using paired sample $t$-tests. Mothers reported a significantly higher number of social supports than fathers, but not greater satisfaction with their social supports. In addition, there was a significant positive correlation between mothers’ and fathers’ number of social supports, $r(18) = .75, p < .01$ (see Table 10).

Hypothesis 7: Mothers’ parental distress and social support. It was predicted that there would be a negative relationship between mothers’ parenting distress and the number of social supports, and a negative relationship between mothers’ parenting
distress and their satisfaction with social supports. This hypothesis was examined using Pearson correlations (Table 10). No significant relationships were found for mothers. For fathers, there was a significant negative correlation between satisfaction with social support and their levels of parental distress, $r(17) = -.79, p < .001$. Thus, fathers' experienced significantly less parental distress when they reported they were more satisfied with their social supports.

**Hypothesis 8: Gender differences in positive experiences.** It was predicted that mothers would report more positive experiences of raising their children than fathers. Means, standard deviations, and $p$ values for mothers and fathers on the nine subscales of the PCS as well as the total PCS score are presented in Table 9. This hypothesis was examined using paired sample $t$-tests. Mothers reported that their children were significantly more a source of a) strength and family closeness, b) awareness about future issues, c) expanded social network, and d) total positive experiences than fathers. In addition, there were non-significant trends suggesting that mothers reported their children were more a source of learning through experience of special problems ($p = .06$), and understanding life’s purpose ($p = .07$) than fathers. Due to the increased possibility of type 1 error due to multiple comparisons, a more conservative approach was taken by using the revised Bonferonni correction. Thus, the most significant difference between mothers and fathers was tested at $p = .005$ (.05/10 comparisons), the second most significant difference was tested at $p = .0055$ (.05/9 remaining comparisons) and so forth. Using the revised Bonferonni correction, none of the previous differences between mothers and fathers remained significant.
Hypothesis 9: Mothers' positive experiences and childcare involvement. It was predicted that mothers would report greater levels of positive experiences when they reported greater levels of involvement in childcare. This hypothesis was examined using Pearson correlations (Table 10). No significant relationship between mothers’ childcare involvement (PIS scores) and positive experiences (PCS scores) were found.

Hypothesis 10: Parenting distress and positive experiences. It was predicted that there would be a negative relationship between parenting distress and positive experiences for mothers, but not fathers. This hypothesis was examined with Pearson correlations (Table 10). For mothers, there was a significant negative correlation between parental distress (PD scores) and total positive experiences (total PSC scores), \( r(17) = - .52, p < .05 \). For fathers, there was a non-significant trend \( (p = .055) \) that parental distress was negatively related to positive experiences. Mothers’ parental distress was also significantly negatively correlated with fathers’ positive experiences, \( r(17) = -.46, p < .05 \). Thus, mothers reported less parental distress when fathers reported more positive experiences. Fathers’ reports of parental distress, however, were not related to mothers’ reports of positive experiences.

There was also one significant correlation between child challenging behaviours (GMI scores) and parents’ positive experiences (total PCS scores; see Table 10). Fathers’ reports of their positive experiences were significantly positively correlated with mothers’ reports of their children’s challenging behaviours \( r(18) = .47, p < .05 \). Thus, fathers reported more positive experiences when mothers reported their children had less challenging behaviours (higher score = less challenging behaviours). Fathers’ reports of their children’s challenging behaviours were not related to mothers’ positive experiences.
Also, children's adaptive behaviours were not related to either mothers' or fathers' positive experiences.

**Additional social support analyses.** A number of additional significant correlations between parental involvement (PIS scores), child challenging behaviours (GMI scores), and social support were found (Table 10). Fathers' reports of their satisfaction with social support were significantly positively related to fathers' level of childcare involvement, $r(17) = .60, p < .01$. Mothers' reports of their children's challenging behaviours (higher scores = less challenging behaviours) were significantly positively related to fathers' number of social supports, $r(18) = .55, p < .05$. Fathers' reports of their children's challenging behaviours (higher scores = less challenging behaviours) were also significantly positively related to mothers' number of social supports, $r(16) = .48, p < .05$. Thus, both mothers' and fathers' reported having more social supports when their partner reported lower levels of child challenging behaviours.

**Additional Gender and Age Analyses**

Additional analyses were performed to examine if mothers' and fathers' reports of parental distress, child challenging and adaptive behaviours, parental involvement, social support, and positive experiences were related to child gender, child age, and parent age. Means and standard deviations for mothers' and fathers' reports of the dependent variables described above as a function of child gender are presented in Table 11. Correlations between mothers' and fathers' reports of the dependent variables described above and child age are presented in Table 12. Correlations between mothers' and fathers' reports of the dependent variables described above and parent age are described in Table 13.
Table 11.
Mothers’ and Fathers’ Scores on Dependent Variables as a Function of Child Gender

<table>
<thead>
<tr>
<th>Child Gender</th>
<th>Mothers</th>
<th>Fathers</th>
<th>Mothers</th>
<th>Fathers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Measure</td>
<td>M(SD)</td>
<td>M(SD)</td>
<td>M(SD)</td>
<td>M(SD)</td>
</tr>
<tr>
<td>PSI-SF&lt;sup&gt;a&lt;/sup&gt; Parental Distress</td>
<td>33.75(8.80)</td>
<td>24.00(11.84)</td>
<td>30.25(6.23)</td>
<td>32.75(14.27)</td>
</tr>
<tr>
<td>GMI&lt;sup&gt;b&lt;/sup&gt;</td>
<td>21.75(11.90)</td>
<td>29.50(20.68)</td>
<td>30.2(10.36)</td>
<td>37.33(17.21)</td>
</tr>
<tr>
<td>BABI&lt;sup&gt;c&lt;/sup&gt;</td>
<td>56.63(27.30)</td>
<td>66.25(43.60)</td>
<td>58.88(19.27)</td>
<td>67.75(41.56)</td>
</tr>
<tr>
<td>PIS&lt;sup&gt;d&lt;/sup&gt; Total Involvement</td>
<td>11.25(1.52)</td>
<td>11.92(.45)</td>
<td>7.85(1.61)</td>
<td>7.19(1.20)</td>
</tr>
<tr>
<td>SSQ6&lt;sup&gt;e&lt;/sup&gt; Number of supports</td>
<td>3.57(1.74)</td>
<td>3.21(2.65)</td>
<td>2.21(1.50)</td>
<td>2.08(1.58)</td>
</tr>
<tr>
<td>SSQ6 Satisfied with Supports</td>
<td>4.77(1.20)</td>
<td>4.88(1.12)</td>
<td>4.93(.67)</td>
<td>4.21(1.36)</td>
</tr>
<tr>
<td>PCS&lt;sup&gt;f&lt;/sup&gt; total score</td>
<td>145.20(18.35)</td>
<td>142.25(25.75)</td>
<td>131.75(17.35)</td>
<td>138.00(16.06)</td>
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</tbody>
</table>

<sup>a</sup> = Parenting Stress Index – Short Form. <sup>b</sup> = General Maladaptive Index. <sup>c</sup> = Broad Adaptive Behaviour Index. <sup>d</sup> = Parental Involvement Scale. <sup>e</sup> = Social Support Questionnaire-6. <sup>f</sup> = Positive Contributions Survey.
Table 12.
Correlations of Child Age and Dependent Variables as a Function of Parent Gender

<table>
<thead>
<tr>
<th>Measure</th>
<th>Mothers (Child Age)</th>
<th>Fathers (Child Age)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>r</td>
<td>p</td>
</tr>
<tr>
<td>PSI-SF&lt;sup&gt;a&lt;/sup&gt; Parental Distress</td>
<td>.01</td>
<td>.98</td>
</tr>
<tr>
<td>GMI&lt;sup&gt;b&lt;/sup&gt;</td>
<td>-.40</td>
<td>.08</td>
</tr>
<tr>
<td>BABI&lt;sup&gt;c&lt;/sup&gt;</td>
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<td>.10</td>
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<td>.18</td>
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<tr>
<td>PCS&lt;sup&gt;f&lt;/sup&gt; total score</td>
<td>-.06</td>
<td>.80</td>
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<sup>a</sup> = Parenting Stress Index – Short Form. <sup>b</sup> = General Maladaptive Index. <sup>c</sup> = Broad Adaptive Behaviour Index. <sup>d</sup> = Parental Involvement Scale. <sup>e</sup> = Social Support Questionnaire-6. <sup>f</sup> = Positive Contributions Survey.
Table 13.
Correlations of Parent Age and Dependent Variables as a Function of Parent Gender

<table>
<thead>
<tr>
<th>Measure</th>
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<th>Fathers' Age</th>
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<td>r</td>
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<tr>
<td>PSI-SF&lt;sup&gt;a&lt;/sup&gt; Parental Distress</td>
<td>.32</td>
<td>.17</td>
</tr>
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<td>GMI&lt;sup&gt;b&lt;/sup&gt;</td>
<td>-.04</td>
<td>.87</td>
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<td>BABI&lt;sup&gt;c&lt;/sup&gt;</td>
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<tr>
<td>PIS&lt;sup&gt;d&lt;/sup&gt; Total Involvement</td>
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<td>.77</td>
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<td>SSQ6&lt;sup&gt;e&lt;/sup&gt; Number of Supports</td>
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<td>.73</td>
</tr>
<tr>
<td>SSQ6 Satisfied with Supports</td>
<td>.11</td>
<td>.65</td>
</tr>
<tr>
<td>PCS&lt;sup&gt;f&lt;/sup&gt; total score</td>
<td>-.09</td>
<td>.70</td>
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<sup>a</sup> = Parenting Stress Index - Short Form. <sup>b</sup> = General Maladaptive Index. <sup>c</sup> = Broad Adaptive Behaviour. <sup>d</sup> = Parental Involvement Scale. <sup>e</sup> = Social Support Questionnaire-6. <sup>f</sup> = Positive Contributions Survey.
**Child gender.** Exploratory analyses were conducted to examine if mothers’ and fathers’ reports of the dependent variables in this study differed by child gender. Because there were 16 male children, and only four female children (see Table 2), statistical comparisons would be unreliable. Thus, only descriptive data is provided (see Table 11). As a note of caution, girls in the present study tended to have less severe forms of autism than boys as 50% of girls were diagnosed with either Asperger’s Disorder or PDD-NOS, compared to 18.3% of boys diagnosed with Aspergers’ Disorder or PDD-NOS. Mothers’ mean score for Parental Distress was 10 points higher for mothers of boys than mothers of girls. Mothers’ mean score for the GMI was 8 points lower (lower = more severe challenging behaviours) for mothers of boys than mothers of girls. Mothers’ mean BABI score was 10 points lower for mothers of boys than mothers of girls. Fathers’ mean GMI score was 7 points lower (lower = more severe challenging behaviours) for fathers of boys than fathers of girls. Fathers’ mean BABI score was 9 points lower for fathers of boys than fathers of girls. Therefore, mothers and fathers tended to rate sons as having more severe challenging behaviours and less adaptive behaviours than daughters. These trends need further exploration in future research with larger sample sizes to draw any conclusions regarding child gender differences.

**Child age.** Relations between mothers’ and fathers reports’ of the dependent variables and child age were explored with Pearson correlations (see Table 12). No significant relationships were found.

**Parent age.** Relations between mothers’ and fathers’ reports of the dependent variables and parental age were explored with Pearson correlations (see Table 12). No significant correlations were found.
CHAPTER IV

DISCUSSION

The present study examined the associations between child challenging and adaptive behaviours, parental involvement in childcare, and levels of social support on parenting stress of both mothers and fathers of school-aged children with autism. In addition, the present study examined the positive experiences of parents raising children with autism as well as factors related to these positive experiences. This study fills a gap in the research on parenting stress and autism, and was unique because of the inclusion of fathers, who are typically not represented in the literature on parenting stress. The inclusion of fathers allowed for family-based evaluations of the similarities and differences experienced by mothers and fathers raising the same child.

A goal of the present research was to evaluate the similarities and differences between mothers and fathers in terms of their perceptions of their children’s levels of challenging and adaptive behaviours (which has not been extensively examined in the literature to date) and their levels of parenting stress (parental distress). Mothers’ and fathers’ reports of their children’s adaptive behaviours were similar, while their reports of their children’s challenging behaviours were not. Even though both mothers’ and fathers’ reports of each of these variables were positively correlated, mothers reported significantly greater levels of child challenging behaviours than did fathers. These results highlight the different experiences of parents raising the same child. Parents may have reported a similar level of a composite measure of their children’s motor, social and communication, personal living, and community living skills, because these may be relatively objective measures of children’s behaviours. It would seem unlikely that
children would be able to clean their room or be able to ask for directions from one parent but not another. It can be noted that while mothers’ and fathers’ reports of their children’s challenging behaviours were positively related, the absolute level of severity was different. Thus, parents’ experiences of their children’s challenging behaviours might be more subjective than their experiences of their children’s adaptive behaviours. For example, fathers might not view certain behaviours of their children as problematic or challenging as do mothers. Hawkins et al (1993) note that males are typically socialized to act assertively and instrumentally, while females are socialized to act more expressively and with more concern about relationships. Therefore, challenging behaviours (e.g., hurting others, destroying property) displayed by males (the majority of children in this study were male) may not be rated by fathers as severely as by mothers because these behaviours may be seen as more typical for males. Mothers might also be more sensitive to their children’s internalized difficulties (e.g., withdrawal) than fathers and thus perceive these difficulties as a greater problem or more challenging than do fathers. In support of this assumption, 45% of mothers rated their children’s challenging behaviours as either Serious or Very Serious while only 22% of fathers rated their children’s challenging behaviours as Serious or Very Serious.

There was no significant difference between mothers’ and fathers’ reports of their levels of parental distress in terms of their competence in the parenting role, role restriction, depression, or conflict with one’s spouse. These results are consistent with some of the literature on parents of children with autism and developmental disabilities (Hastings, 2003; Hauser-Cram et al., 2001), but inconsistent with other literature (Moes et al., 1992; Sharpley et al., 1997; Sloper et al., 1991). Even though levels of parental
distress are similar, it is still necessary to determine if the levels of distress are related to other variables in the same way for mothers and fathers. The present study examined whether the correlates of parenting distress were similar for mothers and fathers.

Other than maternal education, no other maternal or paternal demographic factors were related to parenting distress or to parents’ positive experiences. The present study found that mothers with a post graduate degree ($N=3$) reported less parenting distress than did mothers with a high school diploma or some college/university. While it is possible that mothers with a post graduate degree have a larger income, there was no relationship between family income and distress. It is possible that mothers with higher levels of education have learned more effective ways to cope with their distress throughout their education. It should be noted that the small number of mothers with a post graduate degree in the present sample limits the generalizability of this finding to the larger autism population.

The present study found that greater levels of mothers’ parental distress were related to greater levels of child challenging behaviours and lower levels of child adaptive behaviours. This is consistent with previous research (e.g., Hastings, 2003; Hauser-Cram et al., 2001; Lecavalier et al., 2006; Sloper et al., 1991; Tomaik et al., 2004; Weiss et al., 2003). Thus, mothers’ parental distress appears to be negatively influenced or affected by the presence of child challenging behaviours and low levels of adaptive behaviours. These relationships may in part be explained by the possibility that children’s behavioural difficulties might be perceived by mothers as a failure on their part to socialize their children or to effectively deal with their children’s behavioural challenges (Milgrim & Atzil, 1988). These results differ, however, from those found by Lecavalier
et al. (2006). They found no relationship between adaptive behaviours and parenting stress. Lecavallier et al, however, used a total stress score, including aspects of parent- and child-related stress whereas the present study only examined aspects of parent-related stress (i.e., parental distress). This difference suggests that children’s adaptive behaviours may have more of an impact on mothers’ distress (e.g., sense of competence and role restriction) than on total stress.

Similar to mothers, the present study also found that greater levels of child challenging behaviours, as reported by fathers, were related to greater levels of fathers’ parenting distress. Child adaptive behaviours, however, were not related to fathers’ parenting distress. The results for challenging behaviours were generally consistent with previous research with a developmental disabilities population (Hauser-Cram et al., 2001; Weiss et al., 2003). While Hastings (2003) also found similar results for fathers of children with autism, this correlation no longer existed when maternal mental health was controlled for. Unlike results from the developmental disability population (Weiss et al., 2003) and results concerning mothers, the present study found no significant direct relationship between fathers’ reports of their children’s adaptive behaviours and parental distress. While children’s adaptive behaviours may not be directly related to fathers’ parenting distress, such behaviours appear to be indirectly related.

Higher levels of child challenging behaviours and lower levels of adaptive behaviours, as reported by mothers, were significantly related to higher levels of parental distress in fathers. In addition, mothers’ reports of parenting distress and child challenging and adaptive behaviours were positively related to fathers’ reports of these same variables. These findings are consistent with General Systems Theory (Hecker et
al., 2003) and appear to be one of the few family-based evaluations involving these variables in the autism literature. Systems theory highlights the transactional nature of families. Evaluating stress in mothers and fathers separately (Dumas et al., 1991; Sharpley et al., 1997; Sloper et al., Rodrigue et al., 1990, 1992; Tomanik et al., 2004) does not take into account the holistic family experience. Given that mothers’ and fathers’ parental distress is positively related to each other, any factor influencing one parent’s distress is likely to indirectly influence the other parent’s distress. Thus, even though child adaptive behaviours were not directly related to fathers’ parental distress, they may still influence fathers’ level of distress because child adaptive behaviours are related to mothers’ parental distress. Thus, the results of the present study suggest that mothers’ parenting distress may be an intervening variable when examining the relationship between fathers’ reports of their children’s challenging and adaptive behaviours and fathers’ levels of parenting distress.

The present study also examined the role of parental involvement in childcare in terms of its relationship to child behaviours and parenting distress. Consistent with previous research on parents of typically developing children and children with disabilities, mothers reported higher levels of involvement in childcare than did fathers (Heller et al., 1997; Lamb, 1997; Roach et al., 1999; Rodrigue et al., 1990; Young & Roopnarine, 1994). None of the fathers in the present study reported more involvement in childcare than their spouses. The present study also found that mothers and fathers agreed that mothers were more involved in childcare. These findings may be a reflection of societal values. As Hawkins et al (1993) explain, women are typically socialized to care give from a very young age, and may also have more biological preparation than males.
because of the time the baby spends in the mother’s womb. They also stated that fathers’ involvement in childcare may be limited by their level of employment, financial concerns, and societal attitudes about men’s roles. In the present study 90% of fathers and only 35% of mothers were employed full-time. Thus, there appears to be an agreement in these families, whether explicit or implicit, that fathers will spend more time in an employment role and mothers more time in a care giving role. For example, in an open-ended question on the Parental Involvement Scale, one mother reported:

> Because of his autism intervention for almost 3 years I have had to stay at home and not work. It may seem like I do a lot, but I am a full time mother. We do not have any family support in this city. We have only been here 6.5 years. My husband works 55-60 hours per week so we do what we have to do.

Other participants reported similar experiences as reasons for mothers’ greater involvement in childcare than fathers. For example, one mother responded “I am an at home mom so I of course would be a major contributor.” A father also responded, “I work full time, my wife works half time” when explaining parental roles in childcare.

Based upon the theorizing of several researchers (Hastings, 2003; Rodrigue et al., 1992; Sloper et al., 1991; Tomanik et al., 2004), it was predicted that greater levels of child challenging behaviours and lower levels of adaptive behaviours would be related to greater levels of maternal involvement in childcare because such behaviours may pull for more attention from mothers. This hypothesis was not supported. It is possible that there was too little variability in mothers’ childcare involvement scores (SD = 1.39) in the present sample to find such associations. The small amount of variability in childcare involvement scores might be partly attributed to children’s low adaptive behaviour levels.
On average, mothers' reports of their children's adaptive behaviours placed their children's adaptive behaviours scores in the Extremely Low range of functioning ($M = 58.55$), indicating that, on average, the children in the present study had extreme difficulties behaving independently. Such difficulties might have required most mothers to be highly involved in childcare activities such as dressing, feeding, bathing etc.

This lack of relationship between children's challenging and adaptive behaviours and mothers' parental involvement may also be an artifact of the social context. Mothers might have to spend a particular amount of involvement in childcare regardless of their children's behaviours because fathers are typically working. In addition, according to Hawkins et al (1993) it is possible that some women are ambivalent about “making room” for fathers' participation in childcare. In such cases, some fathers might be encouraged to defer parenting to mothers. If fathers try to take more childcare responsibilities, they may not be positively reinforced for these attempts. Thus, some mothers might choose or prefer to be involved in many aspects of childcare. While mothers' level of parenting distress is influenced by the severity of their children's challenging and adaptive behaviours, their level of involvement appears to remain relatively constant, at least in the autism population. This is true across different severity levels of child behaviours perhaps because mothers choose, or feel obligated, to be more involved than fathers. In support of this assumption one mother described:

I made the choice to discontinue working outside the home in order to provide the support our daughter requires even though I had the higher income – because I was certain my husband had neither the skills nor the patience to do it. He has since
confirmed on several occasions that he couldn’t have. Since I am at home and he is the breadwinner he expects me to assume most of the responsibility.

The present study found no significant relationship between maternal involvement in childcare and mothers’ parenting distress. This finding is inconsistent with Roach et al (1999) in a developmental disability population. Roach et al. found that mothers experienced greater levels of stress when they were more involved in childcare. The finding of the present study suggests that child challenging and adaptive behaviours may be more directly related to maternal distress than mothers’ childcare involvement levels. Also, mothers of children with autism may be heavily involved regardless of their children’s behaviours, as opposed to mothers’ of children with developmental disabilities who may have less challenges with their children.

While there was no relationship between maternal childcare involvement and mothers’ parenting distress, the present study found evidence to suggest that the relationship between childcare involvement and parenting distress for fathers is possibly mediated by fathers’ satisfaction with social support. Consistent with Roach et al (1999), there was a non-significant trend that fathers’ involvement in childcare was negatively related to their levels of parenting distress. Fathers’ satisfaction with social support was positively related to levels of childcare involvement and negatively related to parenting distress. Thus, fathers were more involved in childcare and reported less distress when they were more satisfied with their level of social supports. The present findings indicate the importance of fathers’ satisfaction with their levels of social support. Fathers who feel supported may feel more competent with parenting, or at least more supported in their attempts to increase their levels of childcare involvement. This increased involvement in
childcare may subsequently be related to lower levels of fathers' parenting distress because they feel more supported, competent, and less restricted in their roles as fathers.

The present study also examined the role of fathers' childcare involvement in mothers' childcare involvement and parenting distress. Given the interactive nature of the family environment (Hecker et al., 2003), and the interdependence in the levels of stress between parents (Hastings, 2003; Roach et al., 1999), it was predicted that greater paternal childcare involvement would be negatively related to both mothers' childcare involvement and to maternal parenting distress. Neither of these hypotheses were confirmed. These results suggest that mothers' and fathers' level of childcare involvement may be relatively independent of each other.

To summarize the findings related to parental involvement in childcare, it is clear that mothers in this study were more involved than fathers. Mothers' level of childcare involvement was not found to be directly related to the severity of their children's challenging or adaptive behaviours, to their levels of parenting distress, or to the level of their husband's involvement. Therefore, child behaviours may be more related to mothers' parenting distress than their level of childcare involvement. Fathers, on the other hand, may have lower levels of parenting distress when they are more involved in childcare (conclusion based on trend approaching significance) and report greater levels of social support. Although fathers' level of childcare involvement is not related to mothers' level of childcare involvement or directly to mothers' parenting distress, lower levels of fathers' distress are related to lower levels of mothers' level of distress. Thus, mothers' might indirectly experience less parenting distress when their husbands are
more involved because their husbands experience less parenting distress in these circumstances.

The impact of social support on parenting stress was also examined. Results indicated that mothers reported a significantly greater social support network than did fathers. The reported level of satisfaction with social supports, however, did not differ between mothers and fathers. These results are consistent with previous research on gender differences in number of, and satisfaction with, social supports (Colarossi, 2001). Most of the participants were recruited from social support groups, and most of those in the social support groups were mothers. Thus, it is likely, at least with the present sample, that mothers had more access to social supports than fathers. However, greater access or a greater number of supports does not appear to be related to greater satisfaction. Although fathers reported significantly fewer individuals they relied on for support \((M = 1.31)\), fathers were just as satisfied as mothers.

Although mothers and fathers differed in their number of supports, both mothers and fathers reported greater numbers of social support when their partners reported lower levels of child challenging behaviours. It is possible that less severe child challenging behaviours make it easier for social supports such as friends and family to be available to parents because less severe child behaviours may interfere less with parents’ ability to socialize and receive support. Less severe child challenging behaviours may also provide more opportunity for others to be available to offer support to parents because others may not feel as threatened by the children’s challenging behaviours.

It was predicted in the present study that social support would be related to lower levels of parenting distress, as has been previously reported (Hauser-Cram et al., 2001;
Sharpley et al., 1997; Sloper et al., 1991; Walker, 2002; White & Hastings, 2004). As previously discussed, there was a negative association between fathers’ satisfaction with social supports and parenting distress. There was no correlation, however, between mothers’ number of, or satisfaction with, social supports and parenting distress. Given the consistent positive influence of social support on parenting stress outlined in the literature, it is difficult to ascertain why this finding was not replicated in the present study. Although most of the parents recruited for this study were mothers attending social support groups, it does not appear that there were ceiling effects for social support. Both mothers and fathers reported, on average, that they were between a little bit satisfied and fairly satisfied with their social supports. Perhaps the measure of social support (SSQ-6) did not yield measures of social support that were specific enough. On the Social Support Questionnaire, the people who parents list as social supports are not categorized according to types of social support, such as informal (spouse, friends) or formal (social agencies). White and Hastings (2004) found that informal, but not formal, social support was related to decreased stress for parents of children with intellectual disabilities. Therefore, it is possible that asking parents about different types of social supports and their satisfaction with these might yield different results than those found in the present study. However, the present study found a negative association between fathers’ satisfaction with social supports and parenting stress. Therefore, there might be gender differences between mothers and fathers with regards to the impact that informal or formal types of social support have on stress. It is also possible that there was not enough statistical power to find such a relationship between social support and parenting distress due to the small sample size.
The present study also examined the similarities and differences in the positive experiences of mothers and fathers of children with autism. Consistent with earlier research in school-aged developmental disability (Hastings et al., 2005) and pre-school-aged autism populations (Hastings et al., 2005), mothers reported significantly more positive experiences than did fathers on the total Positive Contributions Survey composite. In addition, mothers reported that their children were more of a source of strength and family closeness than did fathers. Mothers also reported that their children were more of a source of awareness about future issues and that their children were more of a source of expanded social networks than did fathers. Parental involvement in childcare did not account for these gender differences as suggested in earlier research by Hastings et al. (2005). Hastings et al theorized that mothers might report more positive experiences than fathers would because they have the opportunity to experience more positive aspects of their children while involved in greater levels of childcare. While mothers were involved in more childcare responsibilities than fathers were, their level of childcare involvement seemed to be unrelated to their children's behavioural levels, parenting distress, or positive experiences.

Perhaps different coping strategies can explain the gender differences in the positive experiences that parents report. Coping is an important aspect to examine when studying parents' positive experiences because parents who raise children with autism also have simultaneous stressful experiences; including low levels of child adaptive behaviours and high levels of child challenging behaviours. Thus, parents' adaptation to their stressful experiences might be related to the levels of positive experiences they report. Previous research has shown that mothers of children with developmental
disabilities report more positive experiences when they positively reframe events to make them more manageable (Hastings et al., 2002). Research on fathers' coping strategies in relation to their positive experiences has not been examined. However, it is known that mothers and fathers cope differently with life situations. For example, in a study on parents of adults with mental retardation, Essex, Setlzer, and Krauss (1999) found that mothers used problem focused coping strategies more than their spouses. Gavidia-Payne and Stoneman (1997) found that mothers of children with developmental disabilities coped with their life situations by turning to religion, expressing their emotions, and seeking instrumental and emotional social support more than their spouses. Thus, it is possible that mothers and fathers cope differently with their life situations. The present study, however, did not examine parents' coping strategies.

Although parental involvement in childcare was not related to parents' reports of their positive experiences, mothers' positive experiences were negatively related to their parenting distress. This result is inconsistent with research on mothers of preschool-aged children with autism (Hastings et al., 2005), but consistent with mothers of school-aged children with intellectual disabilities, some of who had autism (Hastings et al., 2005). There was also a trend approaching significance that fathers' positive experiences were negatively related to fathers' parenting distress. Given such correlations, it is unlikely that parenting stress and positive experiences are independent constructs, as suggested by Hastings and Taunt (2002). The results of the present study suggest that both mothers and fathers tended to experience more positive aspects of their children when they reported less parenting distress. This finding may in part be explained by the Family Adjustment and Adaptation Model (FAAM; Patterson, 1988, 1989, 1993). According to the model, it
might be easier for parents to pay less attention to the limitations of their children, more attention to the positive aspects of their children, and more attention to the positive ways their children have influenced their lives when parents experience less parental distress.

Fathers’ positive experiences were also negatively related to mothers’ parental distress and to mothers’ reports of child challenging behaviours. Mothers’ positive experiences were not related, however, to fathers’ parental distress or to fathers’ reports of child challenging behaviours. This finding is consistent with Hastings et al. (2005) who also found that father variables were not related to mothers’ positive experiences. The results of the present study suggest that fathers had more positive experiences when their wives experienced less parental distress and when their children had less challenging behaviours, as reported by their wives. Thus, in a similar manner to parenting distress, it appears that child challenging behaviours indirectly influence fathers’ positive experiences. These results also imply that fathers’ positive experiences raising their children are directly associated with their spouses’ level of distress, but that mothers’ positive experiences are not associated with fathers’ level of distress. The present results are consistent with General Systems Theory (Hecker et al., 2003) and suggest that parents’ level of distress and positive experiences need to be understood through the transactions between husbands and wives.
CHAPTER V

CONCLUSION

The present study examined the similarities and differences between child challenging and child adaptive behaviours, parental distress, involvement in childcare, social support, and positive experiences for parents of children with autism. Mothers reported significantly greater child challenging behaviours, greater involvement in childcare, and more positive experiences raising their children than did fathers. These results highlight the different experiences that mothers and fathers have when raising the same children.

The present study also examined factors that might be related to parenting distress and to positive experiences for both mothers and fathers. Mothers reported significantly lower levels of parental distress when they reported lower levels of child challenging behaviours and higher levels of child adaptive behaviours. While generally not directly related to fathers’ parental distress, child challenging behaviours and child adaptive behaviours were indirectly associated (through mothers’ reports of these variables) with fathers’ parental distress. The results also suggest that mothers of children with autism appeared to be highly involved in childcare regardless of the levels of their children’s challenging or adaptive behaviours. They also suggest that children’s behaviours may better account for mothers’ parenting distress than levels of childcare involvement. Fathers, however, tended to experience less parental distress when they were more involved in childcare and when they are more satisfied with their level of social supports. The present study also found that both mothers and fathers experienced more positive experiences when they reported lower levels of parenting distress. In addition, fathers
reported more positive experiences when mothers reported less severe child challenging behaviours.

This systems analysis has broadened the scope of factors that influence mothers' and fathers' parenting distress and positive experiences. Mothers' and fathers' experiences within their families do not occur independently of each other. Greater levels of mothers' parenting distress was associated with greater levels of fathers' parenting distress. Results from the present study suggest that both direct and indirect factors related to parenting distress and positive experiences need to be examined within a family context.

Limitations and Directions for Future Research

The present study had two main limitations. The first was a small sample size. The second was the lack of generalizability of the sample. The small sample size ($N = 20$) likely reduced the statistical power of the $t$ tests and Pearson correlations, and might be one reason why certain relationships were not found, such as the relationship between child behaviours (i.e., challenging and adaptive) and mothers' childcare involvement, and the relationships between mothers' parenting distress and both childcare involvement and social support. In addition, some of the trends approaching statistical significance for fathers (i.e., fathers' parenting distress and childcare involvement, and fathers' parenting distress and positive experiences) might have reached statistical significance had the sample size been larger. The small sample size also limited the opportunity to perform multiple regression analysis. Multiple regression analysis is used to predict an outcome variable (e.g., parenting distress or positive experiences) from a set of predictor variables (e.g., child challenging behaviours, childcare involvement etc.) and can provide some
evidence for causality in statistical relationships. Using Pearson correlations in the present study limited the ability to causally interpret statistically significant relationships found.

A contributing factor to the small sample size was the difficulty recruiting mothers and fathers who were married, who raised a child with autism between the ages of 5 to 12, and who both agreed to participate. While many mothers at social support groups and mothers who contacted the researcher via the flyer posted on the Internet were willing to participate, many of their husbands chose not to participate, thus excluding these families in the present study. Mothers cited their husbands busy work schedules as one of the main reasons for their husbands' choice to not participate. In some cases, however, both parents who initially expressed interest in participating reported that they had too many commitments in their lives (e.g., working and taking care of their children) to participate. It is possible that parents who chose to participate were different (e.g., had different life circumstances and different personalities) than those who chose not to participate.

Thus, the second limitation of the present study was a lack of generalizability to the general population of parents of children with autism. It is likely that parents who participated in the present study were different from parents of children with autism who did not. Parents who participated generally identified themselves as Caucasian or Canadian, were married, well educated, of relatively high Social Economic Status (SES), and were connected to the autism community. The stresses and positive experiences of parents from multicultural backgrounds and of single mothers or fathers of children with autism may be different from primarily Caucasian or Canadian married parents. The parenting stresses and positive experiences of parents who are not connected to the
autism community are also unknown. Parents who were not aware of various autism agencies that conduct social support groups and social skills groups, or parents without access to the Internet to find such resources were not able to be reached for the present study. It is possible that such parents may have even more parenting stress than parents who participated in the present study because these parents may have even less access to helpful resources.

The limitations of the present study, as well as the results from the present study suggest future research directions or advancements when exploring mothers' and fathers' parenting stress and positive experiences. Replicating the present research with a larger sample size would further clarify the nature of the relationships explored in the present study. A larger sample size would also allow for further specificity of these relationships. Similar to Tomanik et al (2004), parenting stress could be predicted from specific child challenging (e.g., externalized, internalized, and asocial) behaviours and specific aspects of child adaptive behaviours (e.g., motor skills, social and communication skills, personal living skills, and community living skills) than from more global aspects of child challenging and adaptive behaviours (e.g., GMI and BABI). Greater specificity in these areas may help researchers and clinicians understand the specific aspects of children's behaviours that are most stressful to parents.

Given that married and single parents of children with autism likely have different experiences, future research should explore these differences. More specifically, future research could address the different stressful and positive experiences between single and married mothers, and single and married fathers. Such information could be useful for autism agencies and mental health professionals who may benefit from understanding the
different experiences, and factors related to these experiences, for married and single parents.

Continued work on the positive experiences of parents of children with autism is needed. An important direction in the continued use of the Positive Contribution Survey (Behr et al., 1992) when examining parents' positive experiences is to provide norms for specific disability populations. While parents of children with autism reported positive experiences in the present study, it is unknown how the levels of these positive experiences compare to parents of children with other developmental disabilities (e.g., Down syndrome or Mental Retardation) or to parents of typically developing children. Future research could also clarify if the positive experiences reported by parents of children with autism on the Positive Contributions Survey (e.g., expanded social network, personal growth/maturity, source of happiness etc.) are unique to parents of children with disabilities or if these experiences are more general aspects of raising children.

Including siblings of children with autism in future research would further advance the family-wide perspective taken in the present study. According to General Systems Theory, siblings’ positive and negative experiences likely impact their parents’ experiences and vice versa. Thus, a more complete picture of the impact of children with autism on families can be achieved by including siblings and parents in the same research study.

The experiences of the primary researcher while attending social support groups suggested that parents' satisfaction with their children’s education, and the financial and supportive resources available (or lack of resources available) to parents and their children, also contributed to parents' stress levels in addition to the many child
challenging behaviours that parents reported in the social support groups. During social support group meetings many parents described their displeasure with the education system, the difficulties obtaining useful Individual Education Plans that are followed by teachers, and the low number of teachers and Educational Assistants trained to work with their children as some factors contributing to their stress levels. Further examining aspects of the education system that are most stressful for parents seems particularly important for parents of school-aged children, because the academic and social development of these children and parents' stress levels can be greatly affected by childrens' school situations.

Practical Implications and Recommendations

The present study may have practical implications for researchers who plan to study parents of children with autism, clinicians who work with families of children with autism, and for parents of children with autism themselves. There are many important participant recruitment factors that may be helpful for researchers interested in studying parents of children with autism. While recruiting parents of children with autism in general is a difficult task, recruiting fathers of children with autism is even more difficult than recruiting mothers. The experiences of the primary examiner revealed that mothers, more so than fathers, typically attended community events or looked for research opportunities on the Internet. Many of the fathers who participated in the present study had wives who felt that the primary researcher cared about their experiences and felt that the present research was useful to them. Thus, one of the best ways to motivate fathers to participate in research (when fathers do not attend community events) is to build a working relationship with mothers based on openness, respect, and trust so that mothers...
can help motivate fathers to participate in research they believe in. It is important for researches to attend community events (e.g. discussion forums, parties, social support groups) on a regular basis to build relationships with potential participants. Providing parents with useful information (e.g. parent training opportunities, conferences, research information in understandable terms, etc.) is another way to build trusting relationships with parents. Parents are also more likely to participate in research if they find the research helpful to their lives. Many mothers in the present study were interested in participating because they described that they were unaware of their husband’s feelings and experiences when parenting their children. Thus, many mothers may have felt that this research project would provide some insight into their husband’s experiences.

While building positive relationships with parents and conducting research on useful topics for parents is important, there are some more practical considerations when recruiting participants. Parents of children with autism have many commitments and stresses in their lives. They are more likely to participate in research if they are given time to complete the study. The primary researcher was patient with participants and conveyed an understanding of the busy schedules parents have. Sending participants friendly reminders (i.e., e-mails) approximately every two weeks concerning their progress with the questionnaires, as well as asking participants if they had any questions regarding the study seemed to be appreciated by parents. Another important practical consideration has to do with the time of year researchers ask parents to participate in studies. The primary researcher found that parents had the most time to complete questionnaires near the end of September and near the end of January. These times appear to be when parents seem to reacquaint themselves with daily routines of school.
and extra curricular activities for their children following the summer and winter holidays. Trying to recruit participants during holiday seasons is difficult because families are typically either on holidays, or are even busier than during the school year because there are less activities (e.g., school) to keep their children occupied.

Results of the present study outline the importance of positive social support. Given that fathers experienced less parenting distress when they were more satisfied with their level of social supports, it might be important to provide fathers with opportunities for social support that they find satisfying. Research indicates that the types of social support that men and women seek are different. House (1981) described four types of social supports: emotional (empathy, caring, love), informational (offering information, giving advice to deal with problems), appraisal (seeking feedback on performance), and instrumental (providing time, resources, and skills). Men tend to use informational and instrumental types of support more than women do, whereas women tend to use more emotional types of support than men do (Monnier, Stone, Hobfoll, & Johnson, 1998; Porter & Stone, 1995). Few fathers attended the social support groups in which most parents were recruited in this study. Thus, fathers may find talking about their feelings and experiences with their children less helpful than do mothers. Fathers may feel more satisfied with social supports that provide information or that provide useful skills to help deal with their stresses. Therefore providing information forums about the causes and characteristics of autism, as well as teaching practical strategies for dealing with children’s behaviours may be useful for fathers. Fathers may also be more likely to seek social supports if they are provided with opportunities to attend groups that cater to fathers’ interests such as barbeques, or sporting leagues. Attempts at increasing fathers’
satisfaction with social support might also create an atmosphere where fathers feel more comfortable engaging in more childcare responsibilities because they feel supported.

Results of the present study may also be useful for mental health practitioners who work with families of children with autism, as well as for parent advocacy groups. One of the goals of such groups is pressuring the government to provide more useful services, increase funding for services, and increase the availability of these services to parents and their children with autism. The results of the present study may suggest that a useful service would be treatments aimed at improving children's challenging and adaptive behaviours. Given the nature of the relationships between mothers' reports of their children's challenging and adaptive behaviour and their own and their partner's level of parenting distress, it is possible that behavioural interventions (e.g. Applied Behaviour Analysis) aimed at reducing child challenging behaviours and increasing adaptive behaviours might help lower mothers' and fathers' level of parenting distress. Such reductions in distress may in turn further help with children's developmental progress. Robbins et al (1991) found an inverse relationship between levels of mothers' parenting stress and improvements in various child developmental domains.

Reductions in parenting distress may also help parents experience more positive aspects of their children, as the present study found a negative relationship between parenting distress and positive experiences. Parents may also find that writing about two to three positive experiences they have with their children on a daily basis useful. This recommendation may have several benefits. First, it may motivate parents to focus on the positive aspects of their children as opposed to only the negative aspects. Second, over time, a log of all of the positive aspects of their children (e.g., goal attainments,
developmental and social progress etc.), and the positive experiences parents have with their children (e.g., having fun on a family outing), may provide a sense of joy and a sense that parents helped to play a role in the positive development of their children. Such feelings may also help increase parents’ sense of competence in the parenting role.
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APPENDIX A

Demographic Questionnaire

1) What is your gender, Male or Female? (Please Circle)

2) What is your current age? __________

3) What culture group do you identify with? __________

4) What is your highest level of education: (Please Circle)
   a) Some High School
   b) High-School diploma
   c) Technical school
   d) Some college/some university
   e) University degree or college degree
   f) Post graduate degree (e.g., Master’s or PhD)
   g) Other ________________ (Please write in)

5) What is your employment status? (Please Circle)
   a) Unemployed
   b) Part time employed
   c) Full time employed
   d) Leave of absence from work

6) What is your child’s diagnosis? (Please Circle)
   a) Autistic Disorder
   b) Asperger’s Disorder
   c) Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS)

7) Who diagnosed your child with the disorder circled you in question 6? (Please Circle)
   a) psychologist
   b) psychiatrist
   c) pediatrician
   d) developmental pediatrician
   e) neurologist
   f) Other ________________(Please write in)

8) What is the gender of your diagnosed child, Male or Female? (Please Circle)

9) What is your diagnosed child’s age in years? __________
10) What is the number of children you raise in your family (please include your child with Autism in this number)? ______________

12) Please state the ages of all your children and their genders (Please include your child with autism):

Child 1: Age_________________ Gender_________________
Child 2: Age_________________ Gender_________________
Child 3: Age_________________ Gender_________________
Child 4: Age_________________ Gender_________________
Child 5: Age_________________ Gender_________________
Child 6: Age_________________ Gender_________________

13) What is your family income? (Please Circle)

   a) Under $15 000
   b) $15 000-$25 000
   c) $25 000-$35 000
   d) $35 000-$50 000
   e) $50 000-$70 000
   f) $70 000-$100 000
   g) Over $100 000
APPENDIX B

Parental Involvement Scale-Revised

The following questions are designed to help us know more about how fathers'/mothers' are involved in the lives of their children and how much responsibility they have for various activities with their children. Families differ and roles within families differ. So your involvement may or may not be in these areas, and may be greater or lesser than another parent's involvement. There is no 'right' answer. What we are looking for is a picture of what fathers'/mothers' roles are like within the family.

A) In the blank space, please indicate the number of days per week (0 days – 7 days) that you are involved in each of the following activities with your child:

1) Dressing your child (e.g., in morning,) ..................................................

2) Feeding your child (e.g., breakfast, lunch, dinner, snacks) .................

3) Bathing your child (either helping them take a bath or shower) ........

4) Putting your child to bed (e.g., tucking them into bed, helping them brush teeth) .................................................................

5) Reading to your child (e.g., books, magazines, newspaper) ..............

B) Who is responsible for the following tasks? Please circle the option that is most accurate with your situation.

1) Transporting your child (e.g., to school, to friends houses, to daycare)

<table>
<thead>
<tr>
<th>Number</th>
<th>Father always</th>
<th>Father usually</th>
<th>Mother/father equally</th>
<th>Mother usually</th>
<th>Mother Always</th>
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<tr>
<td></td>
<td>Responsible</td>
<td>Responsible</td>
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</table>

2) Arranging childcare for your child (e.g., calling daycare centers, calling family to take care of child)

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<tr>
<th>Number</th>
<th>Father always</th>
<th>Father usually</th>
<th>Mother/father equally</th>
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3) Shopping for clothes for your child

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<th>Mother/father equally</th>
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1 scale revised from Parent Involvement Scale (Roach, Orsmond, & Barratt, 1999)
4) **Shopping for toys for your child**

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<tr>
<td>Father always</td>
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<td>Father usually</td>
<td>Responsible</td>
<td>Mother/father equally</td>
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5) **Scheduling appointments for your child (e.g., doctor, dentist, therapist etc.)**

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<td>Father usually</td>
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<td>Mother/father equally</td>
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6) **Taking your child to the scheduled appointment**

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7) **Paperwork**

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<td>Mother/father equally</td>
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8) **Taking care of your child when he/she is sick (e.g., taking a day off work)**

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<td>Father usually</td>
<td>Responsible</td>
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9) **Play partner for quiet activities (e.g., puzzles)**

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<td>Fathers usually</td>
<td>Responsible</td>
<td>Mother/father equally</td>
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10) **Active play partner (e.g., sports, horsing around)**

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<td>Father usually</td>
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11) **Partner on social outings (e.g., to the zoo, to the park)**

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<td>Father usually</td>
<td>Responsible</td>
<td>Mother/father equally</td>
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</table>
12) Nurturer (e.g., caring for child when upset)

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13) Teacher (e.g., teaching child social skills, daily living skills)

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14) Disciplinarian (e.g., enforcing punishments)

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***Roles differ and your involvement may be different from what we have asked. Is there anything that you would like to add about your involvement with your child?***
APPENDIX C

Social Support Questionnaire-6

The following questions ask about people in your environment who provide you with help or support. Each question has two parts. For the first part, list all the people you know, excluding yourself, whom you can count on for help or support in the manner described. Give the person's initials and their relationship to you (see example). For the second part, circle how satisfied you are with the overall support you have. If you have no support for a question, circle "No one," but still rate your level of satisfaction. Do not list more than nine people per question. All your responses will be kept confidential.

EXAMPLE

Who do you know whom you can trust with information that could get you in trouble?

No one  1) T.N. (brother)  4) T.N. (father)  7)
2) L.M. (friend)  5) L.N. (employer)  8)
3) R.S. (friend)  6)

How satisfied?

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<tbody>
<tr>
<td>Very Dissatisfied</td>
<td>Fairly Dissatisfied</td>
<td>A Little Dissatisfied</td>
<td>A Little Satisfied</td>
<td>Fairly Satisfied</td>
<td>Very Satisfied</td>
<td></td>
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1. Whom can you really count on to distract you from your worries when you feel under stress?

No one  1)
2)
3)

How satisfied?

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<tbody>
<tr>
<td>Very Dissatisfied</td>
<td>Fairly Dissatisfied</td>
<td>A Little Dissatisfied</td>
<td>A Little Satisfied</td>
<td>Fairly Satisfied</td>
<td>Very Satisfied</td>
<td></td>
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</tbody>
</table>

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2 Sarason, Sarason, Shearin, & Pierce (1987)
2. Whom can you really count on to help you feel more relaxed when you are under pressure or tense?

No one 1) 4) 7)  
       2) 5) 8)  
       3) 6) 9)  

How satisfied?

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<tbody>
<tr>
<td>Very Dissatisfied</td>
<td>Fairly Dissatisfied</td>
<td>A Little Dissatisfied</td>
<td>A Little Satisfied</td>
<td>Fairly Satisfied</td>
<td>Very Satisfied</td>
<td></td>
</tr>
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3. Who accepts you totally, including both your worst and best points?

No one 1) 4) 7)  
       2) 5) 8)  
       3) 6) 9)  

How satisfied?

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<tbody>
<tr>
<td>Very Dissatisfied</td>
<td>Fairly Dissatisfied</td>
<td>A Little Dissatisfied</td>
<td>A Little Satisfied</td>
<td>Fairly Satisfied</td>
<td>Very Satisfied</td>
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</tbody>
</table>

4. Whom can you really count on to care about you, regardless of what is happening to you?

No one 1) 4) 7)  
       2) 5) 8)  
       3) 6) 9)  

How satisfied?

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<td>Very Dissatisfied</td>
<td>Fairly Dissatisfied</td>
<td>A Little Dissatisfied</td>
<td>A Little Satisfied</td>
<td>Fairly Satisfied</td>
<td>Very Satisfied</td>
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</tbody>
</table>
5. Whom can you really count on to help you feel better when you are feeling generally down-in-the-dumps?

No one 1) 4) 7) 2) 5) 8) 3) 6) 9)

How satisfied?

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<tr>
<td>Very</td>
<td>Dissatisfied</td>
<td>Fairly</td>
<td>Dissatisfied</td>
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<td>Dissatisfied</td>
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<td>Dissatisfied</td>
<td>Satisfied</td>
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<td>Satisfied</td>
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6. Whom can you count on to console you when you are very upset?

No one 1) 4) 7) 2) 5) 8) 3) 6) 9)

How satisfied?

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</table>
CONSENT TO PARTICIPATE IN RESEARCH

Title of Study: Stress and Positive Experiences of Mothers and Fathers of Children with Autism

You are asked to participate in a research study conducted by Adam Kayfitz, Dr. Robert Orr, and Dr. Marcia Gragg, from the Psychology Department at the University of Windsor. The results will contribute to Adam Kayfitz’s Master’s thesis.

If you have any questions or concerns about the research, please feel to contact Dr. Robert Orr: Faculty Supervisor. Dr. Orr’s daytime phone number is (519)253-3000 ext. 2222 or 2026 His email is rrorr@uwindsor.ca. You can also contact Adam Kayfitz: kavfitz@uwindsor.ca

PURPOSE OF THE STUDY

The purpose of the present study is to look at a range of positive and negative experiences for mothers and fathers of children with autism. We are interested in knowing about four things. 1) the types of child behaviours parents deal with, 2) the amount of parental involvement in child care, 3) the levels of parenting stress for both mothers and fathers of children with autism, and 4) the range of positive experiences mothers and fathers have as a result of raising their child with autism.

PROCEDURES

If you choose to participate in this study, we would ask you to do the following things:

You will be asked to fill out a questionnaire package. You will be asked about your child’s behaviours, your parenting stress, your level of involvement in childcare, the amount of help from other people (e.g., neighbours and family) that you get with your child, and your positive experiences of raising your child with autism.

The package should take between 45-60 minutes to finish. If you choose to participate, please do the questionnaire alone. Please do not talk about the answers with your spouse until both of you have finished the questionnaires. We are interested in your experiences. Although you likely have similar experiences to your spouse, you might also have different experiences.

If you choose to participate, you can fill out the questionnaire at this event, or you can take home the questionnaire to finish. If you finish the questionnaire at home, please mail it back to the researcher in the self-addressed, stamped envelope given to you. Both mother and father will be given separate envelopes to mail back the questionnaire.

If you do the questionnaire at home, you can do different parts of the questionnaire on different days. Therefore, you do not need to do the whole questionnaire in one time block. You can take as long as you like to finish the questionnaire. However, it is recommended that you finish all parts of the questionnaire within 1 to 2 weeks of this event. If you choose, you can give the researcher your phone number or email address. He will call or email you once a week to see how you are doing with the questionnaire.

POTENTIAL RISKS AND DISCOMFORTS

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.
You will not experience any unusual uneasiness by completing the questionnaire. However, you might feel some uncomfortable feelings when thinking about different experiences with your child. If so, please see the list attached to this consent form. This list has the contact information for many support groups and clinics that can help you with these feelings.

**POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY**

By participating in this research you will be given a chance to think of all of the positive ways you have been touched by your child. When parenting a child with autism it is easy to think of the negative, stressful experiences. However, it is also important and helpful to think of all the positives your child has brought to your life.

The results from this research will also be helpful to the scientific community. The results of this study will fill some of the information gaps in the literature, such as information about the positive experiences of parents. The results of the study may also help professionals who work with families of children with autism. The information for professionals will in turn be helpful for parents of children with autism.

**PAYMENT FOR PARTICIPATION**

You will not receive payment for participation in this study. Many parents I have spoken to have said that a small payment would not make them want to participate in research. Most parents want time to complete the research, which you will be given in this study. They also want research that is helpful to parents.

**CONFIDENTIALITY**

Any information we get in this study that can be identified with you will remain confidential. This information will be given out only with your permission. Your name will not appear on any part of the questionnaire. Instead, a numerical code will appear on each questionnaire. I will have a form that will match the specific code to your name, if you decide to give your contact information. The purpose of this contact form is so that I can call or email you to see how you are doing with the questionnaire. This form will be stored separately from the questionnaires. The questionnaires and the contact form will stay in a locked cabinet in a locked room of Dr. Orr’s office in the psychology department at the University of Windsor.

**PARTICIPATION AND WITHDRAWAL**

You can choose whether to be in this study or not. If you choose to be in this study, you may pull out at any time without penalty of any kind. You may also refuse to answer any questions you don’t want to answer and still stay in the study. The investigator may take your questionnaire out from this study if situations arise which warrant doing so. If mother and father do not both send back the questionnaire, then the participant who sent back the questionnaire will be taken out from the study. If you choose to give your name to the researcher and then decide to pull out from the study, you can call or email the researcher and he will shred your questionnaire.

**FEEDBACK OF THE RESULTS OF THIS STUDY TO THE SUBJECTS**

The results of this research will likely be available in December 2006. You can find the results of this study on www.uwindsor.ca/autism. If you click on the Adam Kayfitz link on the left side of the webpage you will find the results. If you choose to give your email address, the researcher can also email you the results of this study.

**SUBSEQUENT USE OF DATA**

This data may be used in other studies. Any reported data, however, will not identify any individuals.

**RIGHTS OF RESEARCH SUBJECTS**

You may withdraw your consent at any time and discontinue participation without penalty. If you have questions regarding your rights as a research participant, contact: Research Ethics Coordinator, University of Windsor, Windsor, Ontario, N9B 3P4; telephone: 519-253-3000, ext. 3916; e-mail: lbunn@uwindsor.ca.
SIGNATURE OF RESEARCH SUBJECT/LEGAL REPRESENTATIVE

I understand the information provided for the study "Stress and Positive Experiences of Mothers and Fathers of Children with Autism" as described above. My questions have been answered to my liking, and I agree to participate in this study. I have been given a copy of this form.

Name of Participant

Signature of Participant __________________________ Date __________

SIGNATURE OF INVESTIGATOR

These are the terms under which I will conduct research.

Signature of Investigator __________________________ Date __________
I have had the opportunity to work with many children with autism and their parents. I have greatly enjoyed my experiences working with these children. Through my work, I have encountered many of the stressful behaviours that parents of children with autism may deal with on a daily basis such as hitting, kicking, spitting, etc. However, I have also had many positive experiences working with these children and have enjoyed watching the children I worked with attain personal living goals no matter how small such goal attainments may have seemed (e.g., holding a spoon independently). Working with children with autism has also taught me to appreciate the finer details in life. Although my experiences working with children have not been as intense as raising children with autism on a daily basis, I appreciate some of the difficulties and the joys that parents likely experience. My goal is to research factors that can help reduce some of the stresses parents experience and increase the positive experiences have.