

7-11-2015

# Stress-Related Growth of Parents Raising Children with Autism

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STRESS-RELATED GROWTH OF PARENTS RAISING CHILDREN WITH  
AUTISM

by

Mitchell S. G. Loepp

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

2015

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**Stress-Related Growth of Parents Raising Children with Autism**

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May 8, 2015

**Declaration of Originality**

I hereby certify that I am the sole author of this thesis and that no part of this thesis has been published or submitted for publication.

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### **Abstract**

The present study used the Organismic Valuing Theory as a theoretical framework to investigate the relationship and predictive ability of internal coping strategies and external support with perceived stress related growth (SRG) for mothers and fathers raising children diagnosed with autism spectrum disorder (ASD). Positive reframing coping, active coping, perceived social support, and low levels of stress predicted perceived SRG. The construct of perceived SRG was also found to be different from internal coping strategies. A second objective of this study examined the similarities and differences in parenting stress, coping strategies, perceived social support and SRG of mother-father couples raising children diagnosed with ASD. Mothers reported more stress and perceived SRG and also used active, instrumental support, planning, and self-blame coping strategies more than fathers. Fathers reported higher perceived support from their significant others when compared to mothers. Overall, the majority of mothers and fathers in the present study indicated that they have achieved growth in parenting children with ASD and this process was organic and occurred over a period of time. Implications of SRG as a result of parenting children with ASD are discussed for parents and professionals.

### **Dedication**

I would like to dedicate this research to the Centre for Autism Services of Alberta. Thank you for providing me with an opportunity to provide applied behavioural analysis (ABA) therapy to children with autism spectrum disorder (ASD). This journey began from the services and support you provide to the families of children with an ASD diagnosis in the greater Edmonton area. I would also like to thank the families I have met in recruiting participants for the present research study, this is for you. Last, I dedicate this to my two nieces Aaliyah and Ava. Thank you for waiting patiently back in Edmonton while I finished this research project.

### **Acknowledgements**

Thank you to all of the mothers and fathers of children with autism spectrum disorder (ASD) who took the time to share their experiences with me and participate in this study. Especially the mothers and fathers who also volunteered to complete a phone interview with me; I wish I had the opportunity to talk with you all. For the mothers and fathers who completed the follow-up interview with me, I enjoyed talking with each of you and listening to your journey in raising your child(ren) with ASD. To my parent advisors Freddy Kibambe and Melissa Grass I could not have completed this study without you. Freddy—thank you for this research idea, and Melissa—thank you for providing me with guidance in communicating with and recruiting parents.

I would like to extend my gratitude to my supervisor, Dr. Marcia Gragg. Her support, guidance, patience and commitment to me and my thesis was essential to its completion. Thank you as well to my committee members, Dr. Julie Hakim-Larson and Dr. Hernandez-Josefowicz, for their support, encouragement and valuable feedback in improving my research study. I would also like to acknowledge the Social Sciences and Humanities Research Council (SSHRC), for supporting this research through a Master's Scholarship.

I am grateful for the Summit Centre Preschool for Treatment of Children with Autism and Autism Ontario. Thank you for allowing me to recruit mothers and fathers at your agency events. Another big thank you to the organizations across Canada and the United States of America who promoted my study and recruited many parents, data collection was successful because of you. I would also like to thank the members of my research group at the University of Windsor for your support, reassurance, and humour.

Last but not least, I would like to thank my family and girlfriend for their endless support. To my parents, thank you for listening to me when I needed to vent about life as a graduate student and making it seem as though you were completing this program with me despite being across the country. To my sister Jessica, thank you for the text messages and phone calls checking in to see how everything was going and for the videos and pictures of my nieces Aaliyah and Ava. To my girlfriend Kiera, I do not know how I would have functioned without your continued support throughout my Master's degree. Thank you also for being my Research Assistant and helping me transcribe the qualitative interviews. I am truly blessed to have you all in my life.



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**Table 1***Abbreviations Used in Thesis*

<b>Abbreviation</b>	<b>Meaning</b>
APA	American Psychiatric Association
ASD	Autism Spectrum Disorder
BFS-PCAS	Benefit Finding Scale for Parents of Children with Asperger Syndrome
CAR	Cortisol Awakening Response
CDC	Center for Disease Control and Prevention
DSM	Diagnostic and Statistical Manual of Mental Disorders
DW	Durbin-Watson
EM	Expectation Maximization
HRA	Hierarchical Regression Analysis
KIPP	Kansas Inventory of Parental Perceptions
KMO	Kaiser-Meyer-Olkin
MCAR	Missing Completely At Random
MCSDS	Marlowe-Crowne Social Desirability Scale
MRA	Multiple Regression Analysis
MSPSS	Multidimensional Scale of Perceived Social Support
OVT	Organismic Valuing Theory
PCA	Principle Component Analysis
PDD-NOS	Pervasive Developmental Disorder – Not Otherwise Specified
PSI	Parenting Stress Index
PSS	Parental Stress Scale
PTG	Posttraumatic Growth
PTGI	Posttraumatic Growth Inventory
PTSD	Posttraumatic Stress Disorder
PWB-PTCQ	Psychological Well-Being Posttraumatic Changes Questionnaire
REB	Research Ethics Board
SCQ	Social Communications Questionnaire
SD	Standard Deviation

**Table 1** (*continued*)

<b>Abbreviation</b>	<b>Meaning</b>
SPSS-22	Statistical Package for the Social Sciences-22
SRG	Stress-Related Growth
SRGS	Stress-Related Growth Scale
VIF	Variance Inflation Factor
WPS	Western Psychological Services

## Introduction

### Overview

Autism spectrum disorder (ASD) is a neurological disorder characterized by impairments in communication and interactions with others as well as notable stereotyped repetitive behaviours and restricted interests (American Psychiatric Association [APA], 2013). The prevalence of ASD has increased in the past several decades from 10 in 10,000 between 1966 and 2001 (Fombonne, 2003) to one in 68 in 2014 (Centers for Disease Control and Prevention [CDC], 2015).

Parents raising children diagnosed with any type of developmental disability have much greater demands on them as caregivers when compared to parents of typically developing children. Studies indicate that parents raising children with developmental disabilities experience heightened stress levels (Pisula, 2011; Hudock, 2012). For example, Webster, Majnemer, Platt, and Shevell (2008) found almost half of parents raising children with language impairments or global delays were experiencing clinically significant stress levels. Although stress levels for parents are generally higher when raising children diagnosed with developmental disabilities, both mothers and fathers of children diagnosed with ASD have been found to have much higher stress levels than parents raising children with other developmental and intellectual disabilities (Abbeduto et al., 2004; Herring et al., 2006). Some studies of parents of children with ASD have also found mothers reported higher levels of stress in comparison to fathers (Baker-Ericzen, Brookman-Frazer, & Stahmer, 2005). Reports of negative impacts and increased stress levels by mothers and fathers has led to research studies on identifying factors that result in higher levels of well-being and quality of life experienced by parents raising children diagnosed with ASD (Tobing & Glenwick, 2006; Chiang & Wineman, 2014; Dardas & Ahmad, 2014). Researchers

have also investigated the positive experiences parents have as a result of raising children diagnosed with ASD (Kayfitz, Gragg & Orr, 2010).

The concept of growth is a relatively new area of research being conducted with parents of children with ASD. Researchers investigating individuals' trajectory of growth after experiencing a stressful or traumatic event have called it posttraumatic growth (PTG; Tedeschi & Calhoun, 2004), benefit finding (Samios, Pakenham & Sofronoff, 2009), or stress-related growth (SRG; Joseph & Linley, 2005). The term stress-related growth (SRG) was used in the present study to identify the amount of growth parents have experienced. The present study used the concept of SRG to examine the perceived growth mothers and fathers experience when raising children diagnosed with ASD. The main research goal was to identify the specific factors (e.g., coping, social support, and contextual factors) associated with increased perception of SRG in parenting children with ASD and the differences or similarities between mothers and fathers in these factors.

For the present study, the Organismic Valuing Theory (OVT; Joseph & Linley, 2005) was the theoretical framework used to understand the relationship between coping, social support, and contextual factors with the perceived SRG of parents raising children diagnosed with ASD. The OVT speculates that individuals are driven by intrinsic motivation to grow as a result of overcoming a traumatic event (Joseph & Linley, 2012). The process of achieving SRG results from the appraisal of the situation, internal resources and external support extant to the individual. The majority of studies on SRG have used participants who have experienced serious personal health issues, survived a natural disaster or are veterans of war, but few have looked at the impact of raising children with developmental disabilities (Vishnevsky, Cann, Calhoun,



Tedeschi, & Demakis, 2010). The present study aimed to expand the knowledge available about the SRG that mothers and fathers perceive as a result of raising children with ASD.

### **What is Autism?**

Autism spectrum disorder (ASD) is a developmental disorder defined by impairments in social communication and social interaction, restricted interests or activities, and repetitive patterns of play (APA, 2013). Children diagnosed with ASD may also display behaviour which is more impulsive (Richman, Belmont, Kim, Slavin, & Hayner, 2009), disruptive (Poon, 2012), self-injurious (Fodstad, Rojahn, & Matson, 2012), and less adaptive (Liss et al., 2001) when compared to typically developing children. Since the publication of the *Diagnostic and Statistical Manual of Mental Disorders (5<sup>th</sup> Edition; DSM-5)*, Asperger's disorder and Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS) are no longer included as disorders. However, children who previously received these diagnoses may now be diagnosed as ASD if they meet the specified criteria in the DSM-5.

Within the last decade, researchers noted an increase in the prevalence of ASD (Chakrabarti & Fombonne, 2005; CDC, 2015). Over the past several years, the CDC has estimated the prevalence of ASD in the United States of America, based on parent reports, to be one in 110 in 2006, one in 88 in 2008 and one in 68 in 2014. Reasons for this increase may be heightened awareness of the disorder, different criteria for the diagnosis of ASD, an actual increase in individuals being diagnosed with ASD, or a combination of these factors (APA, 2013).

### **Types of Stress**

There are many challenges that can arise in raising children with ASD which can result in varying levels of stress experienced by parents. Stress refers to “both the adjustive demands

placed on an individual and to the individual's internal biological and physiological responses to such demands" (Butcher, Mineka, Hooley, Taylor & Anthony, 2010, p. 150). Individuals' perception of their stress is based on their appraisal of whether an event exceeds their ability to adaptively manage their situation (Lazarus & Folkman, 1984). The type of stress an individual is experiencing can also play a role in how a person is impacted by stressful experiences (Foody, James, & Leader, 2015).

The American Psychological Association (2015) identifies three different types of stress: acute, episodic acute and chronic. Acute stress is the most common form of stress, is often short term and can be very sudden and intense (Hoff, 2001). It is the result of various pressures and demands of daily living which in small doses (e.g. riding a roller coaster) can be exciting but in larger doses (e.g. meeting an important, rushed deadline at work) can be exhausting and lead to further physiological symptoms. Episodic acute stress is a type of stress which affects individuals who experience acute stress on a very frequent basis. Individuals who are affected by this type of stress are always in a rush and appear as though their lives are in a constant state of chaos. Sufferers can be highly resistant to any types of change and very prone to worrying (American Psychological Association, 2015).

Chronic stress involves "one or more forms of stress ongoing for at least several months" (Butcher et al., 2010, p. 245) and is much longer in duration than the other two forms of stress. When people experience chronic stress they often feel they cannot see a way out of their situation which can also lead to the sufferers experiencing issues such as burnout and disease (Hoff, 2001). A major difference from acute stress is that chronic stress is less obvious and individuals are often less aware they are experiencing it. Therefore many people tend to ignore their chronic stress and become used to it over time. An example of chronic stress is in caregiver

situations such as parenting children with ASD. In these situations, parents are surrounded by the challenges which accompany ASD and can eventually become used to this lifestyle as being their new normal (American Psychological Association, 2015).

Butcher et al. (2010) note that individuals who have very sudden, unexpected traumatic, stressful experiences, sometimes develop posttraumatic stress disorder (PTSD) after their crisis. This involves the individual “re-experiencing the event, avoiding reminders of their trauma and exhibiting persistent increased arousal” (p. G-17). Posttraumatic stress disorder (PTSD) is something which is more commonly experienced by individuals who have dealt with more extreme traumas such as abuse, rape, or war. Casey et al. (2012) analyzed the severity of stress experienced by parents of ASD children and found that 20% of these parents reported “moderate to high levels of posttraumatic stress symptoms related to the ASD diagnosis” (p. 1190).

### **Stresses Involved in Raising Children with Developmental Disabilities and ASD**

Children with developmental disabilities face many challenges throughout their lifetimes, but these challenges also have major impacts on their families (Hudock, 2012). Raising children diagnosed with developmental disabilities increases the demands on parents when compared to raising typically developing children (Beckman, 1991). These increased demands may result in higher levels of stress for the caregivers. Webster et al. (2008) studied stress levels of parents of school-age children with either language impairment or global developmental delay. They found that over 40% of the parents had clinically significant parenting stress as measured by the Parenting Stress Index (PSI; Abidin, 1995). One of the main sources of stress for parents of children diagnosed with developmental disabilities is the specific characteristics of the children (Abbeduto et al., 2004). Research has shown that children diagnosed with developmental disabilities are more likely to display the following characteristics: lower social skills (Fenning,

Baker, & Juvonen, 2011), weaker adaptive behaviour (Liss et al., 2001), and more noncompliance, stubbornness, disobedience and impulsiveness (Jahromi, Gulrud, & Kasari, 2010) when compared to typically developing children. These characteristics may have a negative impact on their caregivers (Webster et al., 2008). Giallo et al. (2014) conducted a study on the factors associated with poorer mental health of fathers raising children diagnosed with intellectual disabilities. The researchers found that behaviour problems, daily stress in balancing personal needs and caregiving needs, and low parenting satisfaction were related to higher reported stress and depression for their sample of parents.

Children with ASD may engage in more externalizing behaviour and less adaptive behaviour when compared to children with other developmental disabilities (Abbeduto et al., 2004). Griffith, Hastings, Nash and Hill (2010) studied the adaptive and problem behaviours of children with ASD, Down syndrome and mixed etiology intellectual disabilities. These three groups were matched based on the child's age, gender, and communication skills. They found that parents of the children with ASD rated their children as having more self-injurious behaviour, lower social competency, and higher anxiety when compared to children with Down syndrome, or mixed etiology intellectual disabilities. Parents who reported higher levels of self-injurious behaviour, anxiety, and other externalizing behaviours, lower levels of social competency and adaptive behaviours in their children with ASD have also reported higher levels of personal stress and distress than parents raising children with other disabilities (Richman et al., 2009).

The parental stresses associated with raising children with ASD can start impacting them “as early as the moment they realize something is different about their child and potentially persist throughout a lifetime of caring for their child” (Hudock, 2012, p. 1). Parents of children

diagnosed with ASD have reported higher levels of stress and lower levels of overall well-being when compared to parents of children with other developmental disabilities (e.g., Fragile X syndrome, intellectual impairment, and Down syndrome) (White & Hastings, 2004). Abbeduto et al. (2004) compared the well-being of mothers raising an adolescent or young adult with Down syndrome ( $n = 39$ ), ASD ( $n = 174$ ), or Fragile X ( $n = 22$ ). They found that mothers of children with ASD displayed higher levels of pessimism and depressive symptoms, and a weaker mother-child bond. Mothers of children with ASD have also been shown to have higher levels of burnout when compared to mothers of children with intellectual impairments (Weiss, 2002).

The stress experienced by parents raising children diagnosed with ASD can result in higher levels of distress, such as anxiety and depression, and other physical and mental health concerns (Foody et al., 2015; Vogan et al., 2014). Gatzoyia et al. (2014) investigated the relationship between illness perceptions, depressive symptoms, and distress of mothers raising children diagnosed with ASD. The researchers defined illness perception as the parents' idea of the consequences, the number and the degree of severity of the symptoms, the cause, and the timeline of the disorder. The researchers found that 34.2% of mothers reported clinically significant depressive symptoms and 55% reported clinically significant levels of general distress.

Pisula (2011) outlined three major sources of stress in parents of children diagnosed with ASD: child characteristics, such as the presence of external maladaptive behaviours and absence of adaptive behaviours; unsatisfactory professional support; and the social attitudes and stigma towards children with ASD and the family, which includes, but is not limited to, the lack of understanding of the ASD diagnosis by the general population. Plant and Sanders (2007) explored which of these factors were the most stressful for mothers and fathers raising children

with ASD. Although not in the same order for mothers and fathers, both rated helping and supervising at mealtimes, cleaning up after and settling the children at bedtime, and helping and supervising at toileting to be the most stressful caregiving tasks. There is currently no consensus within research studies as to which behavioural factor(s) have resulted in the most stress for parents raising children with ASD. However, some researchers have indicated that the severity of the behavioural symptoms is the strongest predictor of parental stress (Abbeduto et al., 2004; Pozo, Sarria, & Brioso, 2014). Another study found impairments in social interaction and social communication to be the strongest significant predictors of parental stress (Konstantareas & Papageorgiou, 2006; Allen, Bowles, & Weber, 2013). Plant and Sanders (2007) concluded that the most significant contributor to parental stress is completing a caregiving task when the child is displaying behaviour problems, such as self-injury, or aggressive and destructive behaviours.

Parents may seek formal (i.e. doctors and psychologists) means of obtaining social support to assist them in raising their children diagnosed with ASD. Despite the potential for positive gain, the act of seeking out and obtaining formal social support can also result in increased stress levels for parents (Pisula, 2011). This can be due to the multitude of formal treatment options available, length of treatment waiting lists and time since the children's ASD diagnosis (O'Brien & Dagget, 2006). Van Tongerloo, van Wijngaarden, van der Gaag, and Lagro-Janssen (2015) conducted a qualitative study on caregivers' experience with formal support during the process of their children being diagnosed of ASD and supports received after the diagnosis. The researchers found that the dissatisfaction experienced by the caregivers was associated with professionals not "properly listening" to the caregivers. The sub-themes within this theme included professionals making decisions about the children diagnosed with ASD without the caregivers' input, the process of the diagnosis (i.e. took too long), and the children

being wrongly diagnosed. Along with the stress experienced in obtaining formal treatment, parents may also experience stress from financial difficulties. Families who do not have adequate support services in place often have to spend more time caregiving for their children, which may impact the employment decisions both the mother and father need to make (Montes & Halterman, 2008).

These difficulties may result in fewer opportunities for informal (i.e. family and friends) social support for parents of children diagnosed with ASD (Pozo et al., 2014). For example, greater time spent caregiving may result in increased isolation for the parents who have no spare time for friends or pleasure (Stein, Foran, & Cermak, 2011). Parents of children with ASD may also experience stress due to the negative opinions and judgments from friends, family, and the general population (Pisula, 2011). Unlike disorders such as Down syndrome, Gray (1993) notes that ASD has no characteristic atypical physical features to easily identify the children, and ASD may involve “extremely disruptive social behaviours” (p. 103). This can result in a greater lack of understanding from the general population who may react insensitively and at times with hostility toward children with ASD leaving parents feeling helpless to manage the situation. Farrugia (2009) studied parents’ perception of the stigmatization they experienced while raising children with ASD. All parents in the study reported they had experienced loss of friendships. One father with two children diagnosed with ASD noted that his friends had stopped spending time with him due to his children’s behaviours. Another mother reported loss of friendships due to the unsupportive nature of her friends regarding her ability to raise her child with ASD.

### **Comparison of Stress between Mothers and Fathers Raising Children with ASD**

Raising children with ASD has been associated with a perception of higher levels of stress and negative well-being for both mothers and fathers (Herring et al., 2006). Historically,

many studies measuring stress in caregivers of children with ASD have focused primarily on the parental responsibilities of mothers (Lamb, 2010; Tehee, Honan, & Hervey, 2009). That being said, fathers have developed more of a caregiving role within the past 20 years and more research is now being conducted on fathers (Lamb, 2010). Mothers and fathers raising children with ASD engaged in a comparable amount of sensitivity and warm discipline in parent-child interactions during an observational study (Hirschler-Guttenberg, Golan, Ostfeld-Etzion, & Feldman, 2014).

Baker-Ericzen et al. (2005) compared the stress levels of mothers and fathers of children diagnosed with ASD, and found that mothers reported higher levels of stress in comparison to fathers. This observation was hypothesized to be a result of mothers often being the primary caregivers while fathers were more often the providers, spending less time in caregiving activities with their children. However, fatherhood has seen a transition from primarily a provider role to both the role of provider and caregiver (Lamb, 2010). This transition has sparked interest in more studies investigating the influence children with ASD have on their fathers and vice versa (Fayerberg, 2011). One study to date, conducted by Rivard, Terroux, Parent-Boursier, and Mercier (2014) found fathers reported higher stress levels than mothers in raising children diagnosed with ASD. Rivard and colleagues found that fathers reported higher stress levels than mothers, and were more likely to report higher levels of stress than mothers on the severity of ASD symptoms and the gender of the children. Stress levels between mothers and fathers were the same for their children's age, intelligence quotient (IQ), and adaptive behaviours. The researchers also found that parents reported higher stress in regards to their parenting roles rather than to the children's ASD characteristics, or parent-child relationship. A possible reason for this finding could be fathers in their study having more of a caregiving role than mothers. The



mothers and fathers were raising the same child with ASD; therefore, the only differences between the severity of ASD symptoms was the individual perceptions of mothers and fathers.

Davis and Carter (2008) investigated the stress of mothers and fathers raising young children recently diagnosed with ASD. They found no statistically significant group differences between the levels of stress reported by mothers and fathers when they compared the total Parenting Stress Index (PSI) scores of each parent. Ozturk, Riccadonna, and Venuti (2014) found that mothers and fathers raising children diagnosed with ASD did not report different levels of stress; however, mothers reported significantly higher levels of depression when compared to fathers.

Despite the finding from Rivard et al. (2014), when considering the potential sources of parental stress in raising children diagnosed with ASD, more studies have found that mothers report higher levels of stress when compared to fathers (Baker-Ericzen, et al., 2005; Davis, 2008; Herring et al., 2006). Foody et al. (2015) conducted a study on mothers and fathers raising children diagnosed with ASD and compared levels of stress, salivary biomarkers, and ambulatory blood pressure. The researchers found that mothers reported higher levels of parenting responsibility, distress, anxiety, and depression when compared to fathers. Fathers had higher blood pressure and more heart rate variability. This may indicate that the stress experienced in parenting children with ASD may physically and mentally impact mothers and fathers differently.

There are different theories why mothers and fathers report different levels of stress while raising children diagnosed with ASD. Gray (2003) indicated that elevated stress levels could be associated with mothers spending more time caregiving for the children, or being more susceptible to becoming stressed and being negatively impacted from a very stressful event in

comparison to fathers. He concluded that the stress mothers experienced in raising children diagnosed with ASD was a direct result of the defining characteristics of their children's ASD such as their various maladaptive external behaviours. The fathers' stress on the other hand, resulted from the stress experienced by mothers and was not directly associated with their children's behaviour. One of the fathers in Gray's study stated, "I suppose the most detrimental effect I believe really is [my son's] effect on [my wife] and her effect on me, you know" (p. 634). Other studies that found no differences in stress between mothers and fathers may have resulted from having a more evenly distributed caregiving role between the two parents or fathers participating in treatment programs (Hudock, 2012). These conflicting findings regarding parental stress may be associated with the severity of the defining characteristics of the child with ASD. Fathers were more likely to report higher stress levels when their children engaged in more maladaptive behaviour (Brobst, Clopton, & Hendrick, 2009; Rivard et al., 2014) and less adaptive behaviour (Honey, Hastings, & McConachie, 2005); while mothers reported more stress when their children displayed more profound limitations in their social interaction skills (Baker-Ericzen et al., 2005) and more repetitive behaviours (Davis & Carter, 2008).

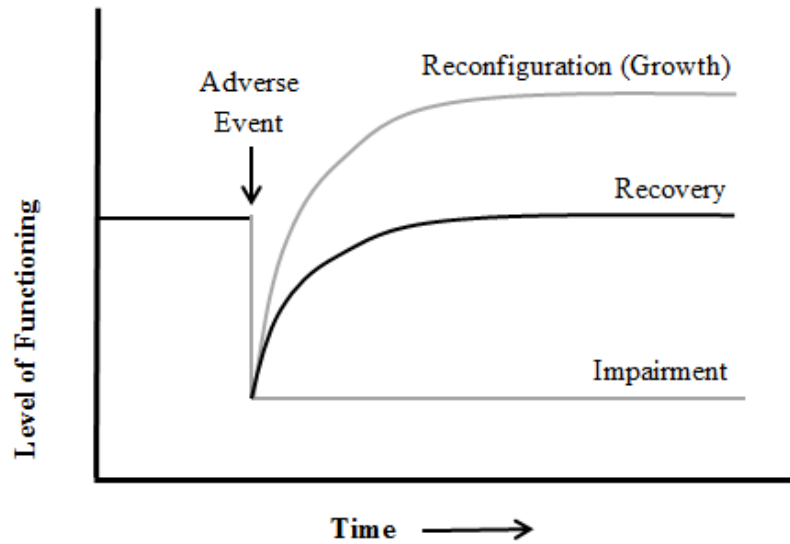
### **Concept of Stress-Related Growth**

A large majority of previous research studies to date have highlighted the challenging aspects of raising children with ASD. At present, the efforts of researchers have begun to focus more on the positive aspects and growth experienced by parents as a result of raising children diagnosed with ASD (Kayfitz et al., 2010; Altieri & von Kluge, 2009; Zhang, Yan, Barriball, While, & Liu, 2015). As previously mentioned, research on growth experienced by individuals following a stressful event has been called different names with PTG (Tedeschi & Calhoun, 2004) and SRG (Park & Fenster, 2004) being the most common two. Stress-related growth

(SRG) has been defined as “positive life changes that people make as a result of their struggles to cope with their negative life events and adverse situations” (Finzi-Dottan, Triwitz & Golubchik, 201, p. 511). Posttraumatic growth (PTG), a term coined by Tedeschi and Calhoun (2004), is described as the “experience of positive change as a result of the struggle with highly challenging life circumstances” (p. 1). In other research studies, the concepts of SRG and PTG have also been called “benefit finding” (Samios et al., 2009) or “perceived benefits” (Tedeschi & Calhoun, 2004). These terms have been used interchangeably within the majority of research studies (Bjorck & Byron, 2014; Joseph & Butler, 2010). That being said, there are theorized differences between these three terms. Posttraumatic growth (PTG) should be used with stressors defined as traumatic, whereas benefit finding should be used with stressful life events. Stress-related growth (SRG), however, could be used for both individuals who experience a traumatic event or very stressful life events (Bjorck & Byron, 2014). Another theorized difference between the three terms of growth is the cognitive processes necessary for individuals to achieve growth. For PTG and SRG individuals must engage in deliberate reflection of the stressful event in order for growth to be achieved (Joseph & Linley, 2005; Tedeschi & Calhoun, 2004). However, individuals may still be able to identify benefits and positive experiences from their stressful event without the use of reflection (Tedeschi & Calhoun, 2004).

For the present study, the research focused on parents’ SRG as a result of raising children diagnosed with ASD. Researchers have used the concept of SRG in studies of bereavement (Currier, Mallot, Martinez, Sandy, & Neimeyer, 2013; Currier, Holland, & Neimeyer, 2012), cancer survivors (Connerty, & Knott, 2013; Slezackova, Loucka, & Bartosova, 2012), war survivors (Gallaway, Millikan, & Bell, 2011; Tedeschi, 2011), and survivors of natural disaster (Wang, Wang, Zhang, Liu, & Wu, 2012; Saccinto, Prati, Pietrantonio, & Perez-Testor, 2013).

Despite the majority of studies on SRG focusing on individuals who experienced a traumatic negative life event, some non-trauma events may also result in growth. For example, Taubman-Ben-Ari, Ben Shlomo, and Findler (2012) investigated mothers and grandmothers who had experienced SRG as a result of the birth of their first child or grandchild. In the present study, SRG was used to define parent's perception of growth experienced while raising children diagnosed with ASD. To further explain the concept of SRG, Joseph (2011) used a metaphor of a tree during a storm to explain the process of recovery and SRG. When the wind is strong enough to bend the tree during the storm but the tree returns back to its normal position after the storm, this is recovery. Similarly, some individuals experience a stressful event and eventually return to their baseline functioning and thus do not report SRG. In other situations, the tree bends from the wind but does not return to its normal position. At first, the tree may seem twisted and broken but eventually there is growth and "new leaves and branches sprout from the trunk where old growths were severed" (p. 68). Individuals who go through this process may experience a sense of growth resulting from their stressful experience (see Figure 1).

**Figure 1.** Three Trajectories of Adjustment Following Adversity

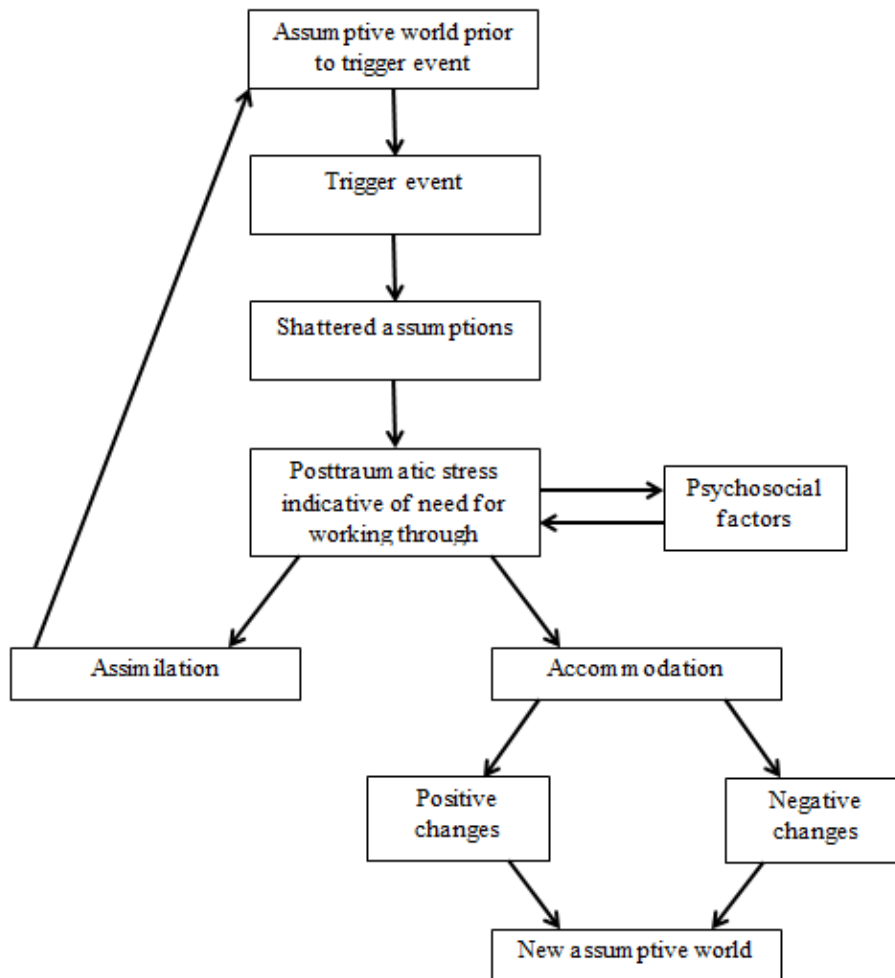
*Figure 1.* Following an adverse event, individuals can experience reconfiguration through positive individual development and growth, recover to a baseline level of functioning, or experience prolonged negative impairments. Reprinted with permission from *What Doesn't Kill Us: The New Psychology of Posttraumatic Growth* (p. 69), by S. Joseph, 2011, New York, NY: Basic Books. Copyright 1995 by V. E. O'Leary and J. R. Ickovics.

### **Theories on Stress-Related Growth**

Stress-related growth (SRG) has been conceptualized by three primary models: Shattered Assumptions Theory (Janoff-Bulman, 1992), Transformational Model (Tedeschi & Calhoun, 2004), and the Organismic Valuing Theory (OVT; Joseph & Linley, 2005). All three theories are based on the premise that after experiencing a life altering event, the cognitive beliefs of the individual are threatened. The process of achieving SRG out of this event is one in which an individual makes an intentional attempt to benefit from and find meaning in their stressful experience (Sears, Stanton, & Danoff-Burg, 2003). The outcome of this stressor on the well-being of the individual results from their utilization of both internal and external factors.

The present study used the OVT model as defined by Joseph and Linley (2005). This theory states that individuals intrinsically strive to become more fulfilled and actualized, and that SRG is an individual process based on the type of stressor experienced and the available internal and external resources the individual possesses. According to Park and Fenster (2004), SRG has been shown to develop for individuals in three different ways. First, an individual can use the knowledge they have accumulated from their stressful experiences to re-establish their own personal worldview. Second, through coping strategies such as meaning making or cognitive processing, individuals can experience SRG in their lives. Finally, they state that SRG is a more conscious process which people can engage in through “religious participation (Tedeschi & Calhoun, 1996), personal resources and cognitive appraisals” (Cain Spannagel, 2011, p. 30). Joseph and Linley (2005) claim that after individuals experience a stressful event and have the potential for SRG, they either assimilate or accommodate the information about this event. They state that individuals who positively accommodate this information report higher levels of well-being when compared to individuals who assimilate or negatively accommodate the information.

Assimilation and accommodation are terms developed by Jean Piaget (1980) to describe how individuals respond to novel information. Individuals who assimilate information explain the situation in terms of existing schemas resulting in an individual's coping strategies and outlook on life to remain the same. On the other hand, individuals who accommodate information explain the situation by changing their existing schemas resulting in an individual looking at the world in a new way. According to Piaget's model, the processes of assimilation and accommodation work together in harmony to achieve equilibration (integration of information to maintain a balance). The OVT also posits equilibration for an individual to return to baseline following an adverse event; however, to experience reconfiguration accommodation is required. As a person moves through the stages of growth outlined by the OVT they are forced to deal with adversity and follow through with assimilation and/or accommodation (Joseph & Linley, 2005) (see Figure 2).

**Figure 2.** Organismic Valuing Theory of Growth through Adversity Schematically Represented

*Figure 2.* The process of experiencing growth involves a cognitive process in which an individual moves through a cycle of various stages in response to a traumatic event. These stages involve appraisal of an event, various emotional states and the use of coping strategies. Reprinted with permission from *Trauma, Recovery and Growth: Positive Psychological Perspectives on Posttraumatic Stress* (p. 13), by S. Joseph & A. P. Linley, 2012, Hoboken, NJ: John Wiley & Sons. Copyright 2008 John Wiley & Sons.



The OVT posits four hypotheses associated with SRG: degree of disparity, prior personality, concordance with the organismic valuing process, and post trauma social environment. Joseph and Linley (2005) believe SRG more often results when individuals experience moderate levels of stress as a result of a trauma and their core beliefs become shattered. Research has found stress and SRG, in these scenarios, to have a curvilinear relationship (Joseph, 2011). Individuals who report moderate levels of stress are most likely to report SRG; while individuals who report low and high levels of stress report less growth from a stressful experience. This may be explained by individuals either not reporting shattered beliefs (low levels of stress) or being too overwhelmed to find meaning in the suffering (high levels of stress) (Lechner et al., 2003). Per the prior personality hypothesis, intrinsic factors or personalities of the individuals, plays an important role in achieving SRG (Joseph & Linley, 2005). Within the organismic valuing process hypothesis “autonomy, competence, and relatedness” are associated with positive accommodation in being hopeful and finding meaning in the suffering (p. 274). The post trauma social environment hypothesis is associated with the current social support individuals receive. The OVT states that individuals whose social environment facilitates their underlying need for autonomy, competence, relatedness, and effortful reframing of the situation after trauma, will experience more SRG.

### **Factors Predicting SRG as Theorized by OVT Model: Literature Review of Parents of Children with ASD**

Organismic Valuing Theory (OVT) notes that there are components of an individual's social environment which can impact the amount of SRG they experience. As a result of the higher levels of stress surrounding parents raising children with ASD, research has been conducted on which factors are associated with promoting greater well-being (Chiang &

Wineman, 2014), quality of life (Dardas & Ahmad, 2014), and lower reported levels of stress (Dardas & Ahmad, 2015). These factors are impacted by the type of internal resources used by parents and whether they have the necessary external resources and supports available to assist them in raising their children with ASD. The OVT posits that these resources, both internal and external, will also result in individuals experiencing growth as a result of the stressors involved in parenting a child with ASD.

Internal resources, or more specifically coping, are defined as “constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person” (Lazarus & Folkman, 1984, p. 141). Joseph (2011) discussed two categories of coping strategies: approach-oriented and avoidance-oriented coping. In approach-oriented coping, an individual purposefully attempts to effectively manage their emotions or change their situation. However, in avoidance-oriented coping, the individual denies or ignores the life altering event they are dealing with. In general, research has found avoidance-oriented coping to be the coping strategy most associated with negative life outcomes (Littleton, Horsley, John, & Nelson, 2007). Researchers have also studied emotion-oriented (e.g., reflection and ruminative brooding) and task-oriented coping styles (Dabrowska & Pisula, 2010). Individuals who engage in reflection involving a conscious processing of information will often use more adaptive forms of coping. Whereas individuals who engage in ruminative brooding will often use more maladaptive forms of coping (i.e. feeling emotionally overwhelmed and worried) (Joseph, 2011). Individuals who use task oriented coping strive to implement strategies to solve the problem. This coping strategy is problem focused as an individual will seek to directly act in a way so as to alter their situation and reduce their stress.

Task-oriented coping strategies have been said to result in the most adaptive forms of coping (Dabrowska & Pisula, 2010).

The influence of different coping strategies on the facilitation of perceived SRG has been studied by numerous researchers. These studies have investigated the predictive ability of emotion-focused (Maercker & Langner, 2001), negative religious (Koenig, Pargament, & Nielsen, 1998), positive religious (Pargament, Smith, Koenig, & Perez, 1998), and problem focused (Evers et al., 2001) coping strategies with perceived SRG. Urcuyo, Boyers, Carver, and Antoni (2005) investigated which coping strategies predicted SRG in a sample of women diagnosed with breast cancer. The researchers found positive reframing to be the strongest predictors of SRG, followed by religious coping, active coping and acceptance.

Parents of children with ASD may utilize different types of coping strategies and styles in response to the stresses associated with raising children with ASD (Littleton et al., 2007). Some coping styles may result in poorer well-being (Lai, Goh, Oei, & Sung, 2015); whereas other coping strategies result in less stress and greater well-being (Ruiz-Robledillo, De Andrés-García, Pérez-Blasco, González-Bono, & Moya-Albiol, 2014). Piazza, Floyd, Mailick, and Greenberg (2014) found that mothers were more likely to use more maladaptive forms of coping, such as active avoidance coping in parenting children with ASD when compared to mothers raising typically developing children. Mothers of children with developmental disabilities, especially ASD, may also report higher levels of self-blame compared to mothers of typically developing children (van Kraayenoord, 2002). Despite research indicating that the causes of ASD are not the mother's fault, some mothers still blame themselves for their children's diagnosis of ASD (Pisula, 2011). Mothers raising children with ASD who report higher levels of self-blame are also more likely to report higher levels of depression and anger (Benson, 2010).

Studies have examined the extent to which approach, avoidance, emotion, religious/denial, and task-oriented coping impacted the management of stress and well-being for parents raising children diagnosed with ASD (Pisula & Kossakowska, 2010; Little, 2003). Hastings et al. (2005) conducted a study on the effects of four coping strategies on positive well-being for mothers and fathers of children diagnosed with ASD. The coping strategies were active-avoidance, problem-focused, positive and religious/denial coping. Of these, active-avoidance coping was the only one found to be related to more mental health problems and stress for both mothers and fathers. Hastings and colleagues also concluded that positive reframing was the most effective coping strategy parents can utilize to reduce psychological distress in very stressful circumstances, when compared to the other three coping strategies. Obeid and Daou (2015) also found cognitive reframing to be associated with higher levels of well-being; whereas, disengagement and distraction coping were associated with lower levels of well-being.

Mothers and fathers who adopt an active coping style, by actively seeking support from professionals and family members, and information about ASD, was found to be more effective for families of children with ASD and result in better adjustment with the ASD diagnosis (Lee, 2009). Jones, Hastings, Totsika, Keane, and Rhule (2014) investigated the relationship between acceptance coping, mindfulness, child negative behaviours and parental distress of parents raising children diagnosed with ASD. The researchers found that acceptance mediated the relationship between children's negative behaviour and parental distress. Parents who reported that they have accepted their children's diagnoses reported lower levels of parental distress regardless of the behaviours of their children. The researchers concluded that parents who reported higher levels of acceptance of their children's diagnoses were more likely to embrace their circumstances and frame the difficulties in a more positive way.

There have been few studies investigating the role of coping strategies in promoting growth and benefit finding for parents raising children with developmental disabilities (Zhang, Yan, Du, & Liu, 2013; Zhang et al., 2015). Barak-Levy and Atzaba-Poria (2013) recently conducted a study on whether parents accepted the diagnoses of their child and its relationship to their personal growth. They compared the experiences of mothers and fathers raising children with developmental delays by analyzing the parents' usual coping strategies. They also used interrater agreement to analyze the qualitative data and investigate the degree to which parents were resolved or unresolved about their children's diagnosis. Parents who were resolved about the diagnosis reported they felt a sense of change and personal growth; while parents who were unresolved about the diagnosis discussed more feelings of guilt, negative well-being, and negative thinking. The researchers measured three types of coping styles: emotional, cognitive, and action. The emotional coping style was characterized by adaptive emotional coping for the parents who were resolved regarding their children's diagnosis and emotional brooding for the parents who were unresolved. The cognitive coping style was characterized by positive thinking and more hope for parents who were resolved and negative thinking and blaming for the parents who were not resolved. Finally, the action coping style was characterized by approach-oriented coping for parents who were resolved and avoidance-oriented coping for parents who were unresolved.

A qualitative study conducted by Kuhaneck, Burroughs, Wright, Lemanczyk, and Darragh (2010) investigated coping strategies of mothers raising children with ASD. They found six common themes: me time, planning, knowledge is power, sharing the load, lifting the restraints of labels, and recognizing the joys. Due to the amount of time dedicated to raising children with ASD, mothers indicated the importance of taking time for themselves to avoid

burnout and to plan ahead to keep routines in order. Mothers also mentioned the importance of both parents sharing the responsibilities in raising their children with ASD and to educate themselves on the services available in their area. The final two themes that emerged were associated with treating children with ASD like typical children without the label “autism” and focusing on the positives of raising children diagnosed with ASD.

Along with effective coping strategies, social support has also been found to be an important factor that promotes well-being (Bromley, Hare, Davison, & Emerson, 2004) and higher levels of quality of life (Chiang & Wineman, 2014; Dardas & Ahmad, 2014) for parents raising children with ASD. Social support includes informal support which parents receive from significant others, family or friends, (Glidden, & Natcher, 2009), and formal support from professionals (Renty, & Roeyers, 2006). Social support may also be distinguished by the amount of emotional or instrumental support a person receives (Pottie, Cohen, & Ingram, 2009). Keefe et al. (2001) defined emotional support as having an individual who cares for and shows concern for the person, while instrumental support is more concrete and direct ways an individual helps someone, such as providing child care or financial assistance.

Research has found that mothers of children raising children with ASD report lower levels of perceived social support as compared to mothers of neurotypical children (Obeid & Daou, 2015). This finding is more likely a result of time constraints with receiving available support in conjunction with daily life stresses associated with raising children with ASD, rather than mothers of children with ASD not seeking social support. Despite this finding, regardless of the type of social support received by parents of children with ASD, the amount of support available can have substantial impacts on the parents’ overall well-being. Parents who feel satisfied by the amount of social support available to them are observed to have lower levels of

psychological distress than those individuals who are unsatisfied with their available social support (Tobing & Glenwick, 2006). Pottie et al. (2009) found that emotional and instrumental support were the two best predictors of daily positive mood for mothers raising children with ASD, although they failed to buffer against the impact of the stress reported by parents. Ruiz-Robledillo et al. (2014) conducted a study on the relationship between resilience, reported health outcomes and cortisol awakening response (CAR) for parents raising children with ASD. The researchers found that social support was positively related with resilience and mediated the relationship between resilience and health outcomes. There is also evidence that the accessibility of resources and supports of parents raising children with ASD may be more important than intrinsic, individual, or family factors in predicting resilience (McConnell, Savage, & Breitkreuz, 2014).

Due to fathers developing more of a caregiving role in raising their neurotypical children and children diagnosed with ASD, more research has been conducted on support received from “significant others” (Lamb, 2010). Mothers who reported that their husbands were more involved in the caregiving of their children with ASD were more likely to report lower levels of depressive symptoms (Laxman et al., 2014). As mentioned, Kuhaneck et al. (2010) conducted a qualitative study on mothers of children with ASD and noted the importance of both mothers and their husbands sharing the load of caregiving for their children.

Studies have also compared the perceived and received social support for individuals, as well as the influence each type of support had on the participants’ well-being (McDowell & Serovich, 2007). Received social support is the actual support an individual obtains from others whereas perceived social support is the individual’s perception of and satisfaction with their social support (Wills & Shinar, 2000). Pottie et al. (2009) notes that perceived social support

may be more important for well-being than the actual amount of social support received for parents of children diagnosed with ASD.

Many studies have been conducted on a parent's perception of the social support they have received and the impact this has had in helping them raise their children with ASD (Bromley et al., 2004; Elci, 2004; Pottie et al., 2009). These studies have investigated both the informal (Renty & Roeyers, 2006) and formal (Pisula, 2011) avenues to which parents have received social support, as well as the impact of different types of emotional or instrumental support (Pottie et al., 2009). From the literature reviewed, it appears as though regardless of the avenue to which parents obtain their social support or the type of social support they receive, "perceived social support can be considered a major coping resource for both mothers and fathers" (Fayerberg, 2011, p. 5).

### **Differences between Mothers and Fathers in Coping Strategies and Social Support**

When dealing with stressful situations, men are more likely to turn to individual coping resources whereas women often reach out to external means of social support as a way of coping with their stress (Littleton et al., 2007; Fayerberg, 2011). Despite these general differences there are also differences with the use of coping strategies and social support between mothers and fathers raising children with ASD. Research has focused on investigating differences between mothers and fathers which exist in the use of particular coping strategies by mothers and fathers who are raising children with ASD (Hall & Graff, 2012; Barak-Levy & Atzaba-Poria, 2013; Kaniel & Siman-Tov, 2011). Little (2003) found that mothers were more likely to use active coping than fathers when raising children diagnosed with ASD. That being said, in the study conducted by Barak-Levy and Atzaba-Poria (2013) on whether acceptance and other coping strategies predict growth in parents raising children with developmental disabilities, the



researchers found no differences between mothers and fathers in their use of the action coping style. However, they did find that mothers were more likely to use an emotional coping style while fathers were more likely use a cognitive coping style. Overall, it appears as though mothers and fathers can display both similarities and differences in their use of certain coping strategies in response to the stresses experienced in raising children with ASD (Hall & Graff, 2012; Kaniel & Siman-Tov, 2011).

Altiere and von Kluge (2009) found that having a means of “social support is especially important for mothers raising children with ASD” (p. 84). They studied parents of children diagnosed with ASD and analyzed both the family dynamics and coping behaviours. Mothers and fathers were found to be equal in their use of all of the variables examined (received social support, cohesion, and adaptability) except for their perceived level of social support. The mothers in their study were found to perceive higher levels of social support from their family and friends than the fathers. Konstantareas and Homatidis (1989) also studied the effect of levels of perceived social support on the stress levels of mothers with children diagnosed with ASD. They determined that mothers who perceived that they had higher levels of social support experienced fewer stress-related depressive symptoms and physical problems than mothers who perceived they had lower levels of social support.

Research up to this point has primarily focused on the impact of perceived social support on mothers stress levels, as opposed to fathers, as a means of improving their coping techniques and overall well-being (Bromley et al., 2004). Although Altieri and von Kluge (2009) highlighted the importance of social support to mothers, they also investigated fathers and found that some fathers felt their levels of social support decreased as a result of raising children with ASD due to a lack of understanding of the general public. However, support groups for fathers

have also been demonstrated to have positive impacts on their coping techniques and overall well-being (Lamb, 2010). Krauss (1993) found no significant difference between mothers and fathers of children with various disorders in their perception of available social support. However, it is important to note that these findings are from 20 years ago and could have been due to the inclusion of a more generalized sample of children with various disorders, as opposed to specifically investigating children diagnosed with ASD.

### **Contextual Factors Found to Influence SRG**

In order to achieve SRG it is necessary that an individual experiences a certain level of stress before achieving growth (Joseph, 2011). According to the OVT, it is essential that individuals have factors in place to help them manage their stress and experience greater SRG (Joseph & Linley, 2005). Researchers have studied factors which result in growth across different stressful and potentially traumatic events as well as the differences between mothers and fathers in this growth (Bellizzi, 2004). Vishnevsky et al. (2010) conducted a meta-analysis of the differences between mothers and fathers in PTG across different samples and traumas. Across different measures of growth, the researchers consistently found that women were more likely to report more growth after experiencing a stressor when compared to men. They also found higher levels of reported growth for individuals older than 35 compared to individuals between the ages of 18 and 34. Carpenter, Brockopp and Andrykowski (1999) studied self-esteem and well-being of breast cancer patients. They found that women with an average age of 48.3 reported more growth when compared to the cancer patients with an average age of 50.2 and 59.2.

Conflicting evidence has been found regarding the relationship between SRG and the time since individuals received a diagnosis of serious medical issues (Cordova, Cunningham,

Carlson, & Andrykowski, 2001; Weiss, 2004). Cordova et al. (2001) conducted a study on breast cancer survivors and found women reported more SRG when a longer period of time had passed which allowed them to process and accept their diagnosis. In contrast, Weiss (2004) found women reported more SRG shortly after receiving their diagnoses in comparison to women who lived with their diagnoses for a longer period of time. The conflicting findings in these studies indicate that an individual's levels of SRG after receiving a diagnosis of serious medical issues is an individual process and may be influenced by internal coping strategies, perception of stress, reflection or rumination, and social support received.

Thus far, there have been few studies comparing the factors of social support, coping strategies, and stress, with the contextual factors in the prediction of SRG in parents raising children diagnosed with disabilities, more specifically ASD (Elci, 2004; Samios et al., 2009). These studies will be reviewed in further detail in the following sections.

### **Stress-Related Growth in Raising Children with Disabilities**

Due to the limited studies on growth experienced by parents raising children with ASD, the following section will be examining studies using all of the growth terms mentioned previously: PTG, SRG, perceived benefit, benefit finding, and positive experiences. There is also an overlap between the use of the terms growth and positive experiences (Joseph & Butler, 2010).

Joseph (2011) noted how individuals who experience growth as a result of a stressful experience may report growth in some, but not all, aspects of their lives. Some of the more common areas individuals can experience growth, include recognizing a greater meaning in one's life, heightened spirituality or religious awareness (Joseph, 2011), better relationships with others (Tedeschi & Calhoun, 1996), identifying new possibilities, growth in personal character,

and positive effects of one's children (Samios et al., 2009). However, depending on the individual, some people may not experience growth in any of these areas.

Researchers have found that specific coping strategies may predict these positive impacts in the form of SRG in parents who are raising children diagnosed with disabilities (Graungaard, Andersen, & Skov, 2011). Minnes, Perry, and Weiss (2014) investigated predictors of distress and positive gain in mothers caregiving for children diagnosed with ASD, intellectual/developmental disabilities or Down syndrome. The researchers found that positive reframing and parent empowerment predicted positive gain. Based on the similarities between competence and parent empowerment in parenting children with disabilities, this finding can be explained by OVT (Joseph & Linley, 2005) as a hypothesis of finding meaning in suffering. Boström and Broberg (2014) conducted a qualitative longitudinal study on the experience of seven fathers' who were raising children diagnosed with intellectual disabilities. These children were diagnosed with ASD, Down syndrome, or a learning disability. The fathers were followed for five years, from 2005 to 2010, and completed three semi-structured interviews during that period. The researchers found three themes that emerged from the interviews: an interrupted path—no longer taking things for granted, being a good father, and dealing with the unexpected. The first theme was associated with a change in the perspective on life of the fathers. Although the goal of their study was not to identify growth or positive aspects, some of the fathers for the second theme claimed that raising children with a disability influenced their parenthood positively and made them a better parent. The third theme was associated with how fathers dealt with the unexpected.

There have been both qualitative (Thompson & McFerran, 2015) and quantitative studies (Phelps, McCammon, Wuensch, & Golden, 2009; Pakenham, Sofronoff, & Samios, 2004) that

have investigated the growth and positive impacts on parents of raising children diagnosed with ASD. DePape and Lindsay (2014) conducted a meta-analysis of qualitative information on the experience of mothers and fathers in caregiving children diagnosed with ASD. The researchers identified six themes: pre-diagnosis, diagnosis, family life adjustment, navigating the system, parental empowerment, and moving forward. For parental empowerment, parents reported educating themselves with “everything” ASD and experimenting with different coping strategies to test their effectiveness in parenting children with ASD. For moving forward, parents reported benefits of raising children diagnosed with ASD and concerns for the future. The majority of benefits mentioned by parents were stronger parent-child and marital relationships, and personal growth, such as more patience and tolerance.

Myers, Mackintosh, and Goin-Kochel (2009) conducted a qualitative study on both the positive and negative experiences of raising children diagnosed with ASD from a family perspective. The researchers categorized their findings into clusters of negative and positive themes. The positive themes parents reported were stronger marriage, spiritual growth, appreciation of the little things, use of more positive emotions, and seeing it as a blessing to the family. One father in their study stated that “ASD does one of two things: it drives families apart, or makes them stronger” (p. 82).

Zhang et al. (2015) used Tedeschi and Calhoun’s (2004) model of PTG to investigate the growth experienced by 11 mothers raising preschool children diagnosed with ASD. From the qualitative data the researchers found five themes of PTG: a new philosophy of life, appreciation of life, relating to others, personal strength, and spiritual change. A new philosophy of life was most similar to new possibilities (one of the five sub-factors of the PTGI); however, the researchers found that this theme was also related to a change of priorities. Spiritual change was

less evident in the responses when compared to the other themes. The researchers found that perceived social support, peer example (i.e., following the examples of “successful” parents raising children with ASD) effective coping strategies (i.e. planning and anticipating the difficulties of the day), and self-efficacy enhancement were more likely to result in growth.

Similar to the qualitative studies, quantitative studies that investigated growth experienced by parents raising children with ASD found that parents reported personal growth (e.g., becoming more patient and tolerant), strengthening of relationships, and appreciation of life (Xue, Ooh, & Magiati, 2014; Zhang et al., 2013). Samios et al. (2009) developed a benefit-finding measure for parents raising children diagnosed with Asperger’s syndrome. The researchers found that parents raising children with Asperger’s syndrome experienced growth in six domains: new possibilities, personal growth, appreciation, spiritual growth, positive effects of the child, and development of a greater awareness. However, in some cases, the sixth factor appreciation was predicted to lead to development of assumptions of vulnerability and a questioning of self-worth. They also found that women reported more growth than men in all factors except for positive effects of the child. Samios and colleagues note that despite the usefulness of these findings in understanding the impact of stress on parents of children with Asperger’s syndrome, finding benefits when faced with adversity doesn’t always diminish a person’s stress.

### **Comparison of Positive Experiences of Mothers and Fathers**

To date there have been few studies investigating how mothers and fathers raising children diagnosed with ASD differ in their experience of SRG (Samios et al., 2009). However, differences have been found between mothers and fathers using the Kansas Inventory of Parental Perceptions (KIPP) which measures positive experiences in raising children with ASD (Hastings,

Beck & Hill, 2005). Kayfetz et al. (2010) found that mothers reported more positive experiences in parenting children with ASD when compared to fathers. These positive experiences were associated with four distinct yet related categories: learning through the experience of special problems, strength and family closeness, understanding life's purpose, and expanding social networks. Tobing and Glenwick (2006) stated that the differences in positive experiences may be associated with the parents' level of competence in raising children with ASD. They found that mothers who reported higher levels of competence in raising children with ASD also reported higher levels of well-being. Sawyer et al. (2010) stipulate that mothers may report higher levels of competency than fathers due to the time they spend caring for their children with ASD which was found to be an average of six hours a day. Another reason could be mothers' greater reliance on social support from other people and agencies as a means of dealing with the stresses of raising children with ASD (Altiere & von Kluge, 2009).

### **Measuring Stress-Related Growth**

Several measures have been developed to assess the SRG individuals experience as a result of a traumatic event including: Benefit Finding Scale for Parents of Children with Asperger Syndrome (BFS-PCAS; Samios et al., 2009), Posttraumatic Growth Inventory (PTGI; Tedeschi & Calhoun, 1996), Stress Related Growth Scale (SRGS; Park, Cohen, & Murch, 1996), and The Psychological Well-Being Post-Traumatic Changes Questionnaire (PWB-PTCQ; Joseph et al., 2012). The major difference between these measures is the validity of the factors in their ability to predict the presence of SRG. The PWB-PTCQ and SRGS found one general factor, whereas the PTGI found five specific factors: Relating to Others, New Possibilities, Personal Strength, Spiritual Change, and Appreciation of Life. The BFS-PCAS, which was used in the

present study, found six specific factors: New Possibilities, Personal Growth, Appreciation, Spiritual Growth, Positive Effects of the Child, and Greater Awareness.

Although most studies on the PTGI have found five factors (Brunet, McDonough, Hadd, Crocker, & Sabiston, 2010; Kaler, Erbes, Tedeschi, Arbisi, & Polusny, 2011), some studies have found the PTGI to have fewer than five factors (Powell, Rosner, Butollo, Tedeschi, & Calhoun, 2003; Kagan, Gulec, Boysan, & Cavus, 2012). Taku, Cann, Calhoun, and Tedeschi (2008) used confirmatory factory analysis to analyze whether the PTGI comprised of one, three or five general factors. They found the best fit for the items was associated with the five-factor structure and that the five factors appeared to tap an underlying construct, (a general factor) of PTG. Less research has been conducted on BFS-PCAS due to its recent development in 2009, but Sears et al. (2003) concluded that measures with a high internal consistency indicate a general loading on one factor. The overall internal consistency of the BFS-PCAS was found to be  $\alpha = .92$ , which is higher than the overall internal consistency of the PTGI ( $\alpha = .90$ ). The BFS-PCAS allows researchers to investigate more specific information regarding the overall growth that caregivers raising children diagnosed with ASD experience rather than general questionnaires for more inclusive traumatic or stressful experiences.

### **Limitations with Measuring Stress-Related Growth**

Despite the popularity of the PTGI and other SRG measures, researchers have frequently questioned the validity and accuracy of their results in investigating perceived SRG (Joseph, 2011). Bitsch, Elklit, and Christiansen (2009) discussed the most common concerns about measures of SRG. The first issue, as discussed previously, is the lack of agreement on the number of factors within measures. Secondly, there is an issue with the inconsistent definition of what constitutes trauma or growth associated with the outcome of SRG. Researchers have



conducted studies on different populations of individuals who encountered a stressful life event that may or may not be defined as traumatic. Some researchers have speculated that reported growth may be an illusion or a coping strategy (i.e. positive reframing coping is the same as perceived growth) (Bjorck & Byron, 2014). Tedeschi and Calhoun (2004) point out that one of the difficulties in defining SRG is whether it is a process or an outcome. Some researchers believe that SRG is both a process and an outcome and that coping is a crucial part of the growth process although not conceptually the same as SRG. Bitsch et al. (2009) further clarifies the distinction between SRG and coping by explaining that individuals who achieve SRG reach a higher level of functioning; whereas, utilizing coping strategies may lead to growth but will more likely lead to recovery back to pre-trauma functioning.

Another difficulty with distinguishing SRG from coping is research methodology. Studies that utilize a cross-sectional design assess perceived-SRG while studies that utilize a longitudinal design assess actual SRG. Frazier et al. (2009) conducted a study which assessed the relationship between perceived growth and actual growth of university students who experienced a negative life event. The researchers gathered data before and after the traumatic event to assess actual growth experienced after the event to obtain information on perceived growth. Frazier and colleagues used different questions which assessed the same construct to obtain reliable results and found that the correlation between perceived and actual growth was small. In addition to this, they also found that perceived growth was strongly related to reinterpretation coping while actual growth was not. Joseph (2011) claimed that growth truly does happen in individuals who experience a traumatic or stressful event, but emphasized the importance of scientists utilizing a methodology that results in a more accurate measure of growth. This could be achieved by administering the self-report SRG inventory before and after an individual experiences a

traumatic event. The final issue Bitsch et al. (2009) discussed in regards to SRG measures is associated with the participant sample used in the development of the PTGI and SRGS which was composed of college students. With this very narrow population, results from using these measures may not be generalizable to more specific populations dealing with stress, (i.e. parents of children diagnosed with ASD).

Bitsch et al. (2009) included four recommendations to improve the accuracy of the reported growth on SRG measures. The first recommendation was to develop a consistent definition of trauma and growth to be utilized in measures. Secondly, they suggested that researchers include questions on the self-report instruments which assess if growth is maximized more in any particular domains of a person's life. The third recommendation was the inclusion of measures which assess negative well-being in addition to positive growth to confirm that the existence of personal growth is real and not illusory. Due to the curvilinear relationship between SRG and stress, researchers should include measures of both stress and SRG to investigate whether individuals who experience SRG have moderate levels of stress associated with their experiences as hypothesized. The last recommendation was to ask individuals open-ended questions about their stressful experiences in order to gain more in-depth information about the growth they have experienced. The present study implemented three of these recommendations: include questions on the self-report instrument regarding specific areas of life where a person experienced SRG, include a measure of negative well-being, and ask open-ended questions about the stressful experiences. In the present study, the first recommendation was not addressed as researchers have not yet developed a consistent definition of SRG and the distinction between perceived SRG and coping have also resulted in inconsistent findings (Frazier et al. 2009; Bitsch et al. 2009).

### **Purpose of Study**

The present study investigated factors that correlated and predicted SRG in mothers and fathers of children with ASD. It also examined any differences between the mother's and father's perceptions of SRG, stress, coping strategies, and social support in raising children with ASD. There have been numerous studies on the impact that coping strategies, social support, and stress have on the well-being and quality of life of parents raising children with ASD (Tobing & Glenwick, 2006; Bromley et al., 2004; Pottie et al., 2009) as well as, several on predicting positive experiences of parents (Kayfitz et al., 2010; Elci, 2004). However, until recently there have been few studies conducted on the factors that predict the SRG parents experience in raising children diagnosed with ASD (Thompson & McFerran, 2015; Zhang et al., 2015), and fewer studies have investigated the differences between mothers and fathers in SRG when caregiving for children with ASD (Samios et al., 2009). Stress-related growth (SRG) is an active process in which individuals partake in an effortful (active) perusal of positive outcomes in response to a stressful situation (Joseph, 2011). Research studies have found that 40-70% of individuals who have experienced a stressful event reported some sort of SRG following the event (Frazier, Tashiro, Berman, Steger, & Long, 2004; Woodward & Joseph, 2010).

The present study used the Organismic Valuing Theory (OVT; Joseph & Linley, 2005) as a framework to investigate which factors were related to and predicted SRG. For example, individuals who report moderate levels of stress from raising children with ASD will report higher levels of SRG than parents who report either low or high levels of stress (Joseph & Linley, 2005). Another factor predicting SRG are the intrinsic factors an individual possesses, specifically feelings of competence as a parent. Sears et al. (2003) found that other intrinsic attributes including "both hope and positive reappraisal coping, [which includes effortful

reframing], reflect more active, intentional attempts to pursue positive outcomes” (p. 494) and will more likely result in SRG. A final factor in predicting SRG is the individual’s level of perceived social support. A higher level of perceived social support, which promotes a sense of competence and effortful reframing coping strategies, has been hypothesized to predict SRG (Joseph & Linley, 2005). In addition to stress, coping strategies, and social support predicting SRG, researchers have found contextual variables (e.g., time since diagnosis and age) to also significantly predict SRG (Cordova et al., 2001; Weiss, 2004). Therefore, the present study, examined the relationship between different contextual variables and SRG.

The present study also investigated the differences between the growth experienced and the internal and external resources used by mothers and fathers raising children with ASD. The OVT does not hypothesize any differences between mothers’ and fathers’ stress levels, but researchers have found that mothers report higher levels of SRG than fathers after experiencing a stressful event (Vishnevsky et al., 2010). These findings have also been demonstrated in parents raising children with Asperger’s syndrome (Samios et al., 2009) and ASD (Elci, 2004).

This study also investigated the degree of shared common variance between perceived SRG and coping strategies, specifically reappraisal coping. Previous research has found that the perception of growth may be an illusion of growth or a coping strategy, and is more likely a process rather than an outcome (Bjorck & Byron, 2014). The concept of SRG is still a relatively new phenomenon for parents raising children diagnosed with a developmental disability (Samios et al., 2009). This study used both quantitative methods (i.e. online questionnaire) and qualitative methods (i.e. phone interviews) to gain information about the stress and growth experienced by parents raising children diagnosed with ASD. The qualitative section provided parents an opportunity to expand on their responses provided in the online questionnaire about the

challenges and growth experienced in raising children diagnosed with ASD. The qualitative interview also investigated the cognitive processes parents underwent to achieve growth, parenting strategies used for children diagnosed with ASD, and advice for parents whose children have just been diagnosed with ASD. Recent research on parents of children diagnosed with ASD has focused on factors that relate to and predict well-being and better quality of life (Chiang & Wineman, 2014; Dardas & Ahmad, 2015). Research has found that individuals who report higher levels of growth also report better general well-being (Cordova et al., 2001) and better quality of life (Ruini, Vescovelli, & Albieri, 2013). Teodorescu et al. (2012) conducted a study on the PTG, PTSD, depressive symptoms, quality of life, and post-migration stressors with psychiatric patients with a refugee background. The researchers found that the individuals who reported more growth also reported better quality of life.

The more professionals know about which factors promote SRG for mothers and fathers raising children with ASD, the more a professional will be able to provide parents with important information about managing and possibly improving their overall well-being and quality of life. The present study also provided information about the different experiences of mothers and fathers in raising children with ASD, and gave insight into possible interventions which could be designed specifically for mothers and/or fathers. The experience of raising children with ASD can invoke feelings of great stress and fear (Hudock, 2012). Having a greater awareness of the potential sources of stress and an understanding of the importance of available resources may help improve the overall wellbeing and reduce stress levels parents experience in raising children with ASD.

In the development of the present study, a father of a son diagnosed with ASD was used as a collaborator (i.e. Parent Advisor) in the research process. He is also an active member of a

number of parent support groups and a client of various professional support services. In conversations with the Parent Advisor, he discussed how raising a child diagnosed with ASD had impacted his marriage, parenting style, coping strategies, and outlook on life in different ways. The researcher used this information about the Parent Advisor's experiences to select the main topic of investigation. Two Parent Advisors were used throughout the research process for guidance, support and assistance with recruitment of parent participants. Bigby, Frawley and Ramcharan (2013) investigated the use of a collaborative approach to research studies which includes both academic researchers as well as community advocates. They note that this approach has the potential to result in better research and a greater understanding of the issue being investigated. The use of Parent Advisors helped to ensure the main concerns and interests of parents of children diagnosed with ASD were addressed in the present study.

### **Research, Exploratory Questions and Hypotheses**

The following are the research goals of the present study and the associated hypotheses based upon findings of previous research studies. It is the expectation that the parents of children diagnosed with ASD who participated in the present study from locations in Canada and the United States of America, will show similar results as other parents with children diagnosed with ASD in the following ways. For more information on the variables and measures used in the research and exploratory questions please see Table 2.

**Table 2***Variables and Measures Used in Research Questions*

<b>Main Variables</b>	<b>Measures for Variables</b>	<b>Subscale of Measures</b>	<b>Range of Scores</b>	<b>Range of Subscale Score</b>	<b>Scale</b>
Participant Information	Demographic Questionnaire	Gender	n/a	n/a	Nominal
		Parental age		>18	Interval
		Time since child's diagnosis of autism		n/a	Interval
		Child's age		2-18	Interval
Stress	Parental Stress Scale (PSS)	Positive themes of parenthood	18 - 90	8-40	Ordinal
		Negative components of parenthood		10-50	
Coping Strategies	Brief COPE	Self-distraction	28 - 112	2-8	Ordinal
		Active coping		2-8	
		Denial		2-8	
		Substance use		2-8	
		Use of emotional social support		2-8	
		Use of instrumental support		2-8	
		Behavioural disengagement		2-8	
		Venting		2-8	
		Positive reframing		2-8	
		Planning		2-8	
		Humor		2-8	
		Acceptance		2-8	
Religion	2-8				
Self-blame	2-8				
Perceived Social Support	Multidimensional Scale of Perceived Social Support (MSPSS)	Perceived support from family	12 - 94	4-28	Ordinal
		Perceived support from friends		4-28	
		Perceived support from significant other		4-28	

**Table 2** (continued)

<b>Main Variables</b>	<b>Measures for Variables</b>	<b>Subscale of Measures</b>	<b>Range of Scores</b>	<b>Range of Subscale Score</b>	<b>Scale</b>
Stress-Related Growth (SRG)	Benefit Finding Scale for Parents of Children with Asperger's Syndrome (BFS-PCAS)	New Possibilities	40 - 200	10-50	Ordinal
		Personal Growth		10-50	
		Appreciation		8-40	
		Spiritual Growth		4-20	
		Positive Effects of the Child		5-25	
Greater Awareness	3-15				

*\*Note: High scores in all variables indicate more positive themes except in the Positive themes of parenthood in the Parental Stress Scale. The eight questions which create this subscale are reverse coded thus low scores indicate more positive themes.*



**Independent Group** (Mothers and fathers who participated in the study who were single or their partner did not participate.)

**Research Question 1:** To what extent does social support, different coping strategies, and stress predict perceived SRG?

*Hypothesis 1a:* High scores of perceived social support will predict perceived SRG.

*Hypothesis 1b:* High scores of reappraisal coping will predict perceived SRG.

**Couples Group** (Both mother and father raising the same child with ASD participated.)

**Research Question 2:** Do mothers and fathers of children with ASD differ in perceived social support from significant others, family, and friends?

*Hypothesis 2:* Mothers will report higher levels of perceived social support when compared to fathers.

**Research Question 3:** Do mothers and fathers of children with ASD differ in their levels of caregiving stress?

*Hypothesis 3:* Mothers will report higher levels of parenting stress when compared to fathers (Pisula, 2011).

**Research Question 4:** Do mothers and fathers of children with ASD differ in perceived SRG?

*Hypothesis 4:* Mothers will report higher levels of perceived SRG (general factor) when compared to fathers.

**Research Question 5:** Do mothers and fathers of children with ASD differ in their use of coping strategies: Active coping, Instrumental support, Emotional support, Positive reframing, Planning, Acceptance, and Self-blame?

**Research Question 6:** Do mothers and fathers of children with ASD differ in the sub-themes of the BFS-PCAS: New Possibilities, Personal Growth, Appreciation, Spiritual Growth, Positive Effects of the Child, and Development of a Greater Awareness.

## Method

### Participants

Participants were 169 mothers ( $n = 130$ ) and fathers ( $n = 39$ ) of children with ASD. All of the participants recruited for the present study were from Canada and the United States of America. Twenty of these participants, 10 mothers and 10 fathers, also completed a 20 minute phone interview. Inclusion criteria for the present study included being a biological, step or adoptive mother or father of a child with ASD, raising a child with ASD between the ages of three years, zero months and 17 years, 11 months, and obtaining a score of 15 or greater on the Social Communication Questionnaire (SCQ). Due to the inclusive and easy access of on-line questionnaires and the possibility of non-target participants completing the study, participants were required to complete the SCQ for their children. Completion of the SCQ was used as an ASD screening measure.

There were a total of 239 participants who accessed the online questionnaire. Data from 66 of these participants were excluded from the analysis. Thirty-nine of these participants failed to meet the eligibility criteria (19 participants scored 14 or lower on the SCQ—cut-off of 15, 11 participants had children outside inclusion criteria for age, and nine were not a mother or father. The remaining 27 participants failed to complete significant portions of the study including at least one of the measures. Participants who completed at least 80% of the questionnaire were given the opportunity to receive a \$5 Starbucks eGift card as a token of appreciation.

The total number of participants was separated into two groups due to the possible violation of the statistical assumption independence of observations. When analyzing statistical techniques, the assumption of independence of observations must be met in order to ensure accurate results. For example, when both the mother and father raising the same child with ASD

complete the online questionnaire, these observations may be dependent (significantly related to one another) and could possibly skew the results. The first group of participants included 27 mother-father couples and no restrictions were placed on the relationship the participant had with the child and their partner as long as they were both raising the child with ASD. For example, a biological mother and a step-father raising the same child with ASD were considered a couple. The second group consisted of 115 respondents who did not have a partner complete the study. These two samples will be referred to as the Couples Group and the Independent Group respectively. The demographic information for both groups is provided below.

For simplicity when referring to mothers and fathers in this section it will refer to biological, step- and adoptive unless otherwise specified. For the mother-father Couples Group the majority of mothers (96.3%) and fathers (92.6%) were biological parents and identified themselves as Caucasian, mothers (85.2%); fathers (81.5%). Over half of mothers (59.3%) and fathers (63%) had at least a university or college degree and were in the 35 to 44 year age range. Fathers (77.8%) were more likely to list full-time work as their employment status when compared to mothers (40.7%). Three fathers and nine mothers were unemployed. All mothers reported they have experienced growth as a result of parenting a child with ASD and will experience more growth in the future. However, 92% of fathers reported experiencing growth and 96.3% believed they would continue to experience growth. There were 30 participants who were raising multiple children with ASD; 15 couples (55%) were raising two children and four couples were raising at least two children with ASD (19%; parent report). The average number of children the couples were raising was 2.11. For more information about the demographic characteristics of the respondents in the Couples Group, please see Table 3.

**Table 3***Participant Demographic Information for the Couples Group (Parents)*

Variable	Mothers ( <i>n</i> = 27)		Fathers ( <i>n</i> = 27)	
	Frequency	(%)	Frequency	(%)
<b>Relationship to Child</b>				
Biological Parent	26	96.3	25	92.6
Step Parent	0	-	1	3.7
Adoptive Parent	1	3.7	1	3.7
<b>Age of Parent</b>				
25-34	3	11.1	1	3.7
35-44	18	66.7	14	51.9
45-54	6	22.2	11	40.7
55-64	0	-	1	3.7
<b>Country</b>				
Canada	21	77.8	21	77.8
United States	6	22.2	6	22.2
<b>Marital Status</b>				
Married, Living with Partner	24	88.9	24	88.9
Living with Partner	3	11.1	3	11.1
<b>Annual Household Income</b>				
\$20 000 - \$30 000	1	3.7	1	3.7
\$30 000 - \$40 000	4	14.8	2	7.4
\$40 000 - \$50 000	5	18.5	7	25.9
\$50 000 - \$75 000	4	14.8	3	11.1
\$75 000 - \$100 000	3	11.1	2	7.4
\$100 000 - \$150 000	6	22.2	7	25.9
\$150 000 or more	4	14.8	5	18.5
<b>Employment Status</b>				
Full-Time	11	40.7	21	77.8
Part-Time	5	18.5	3	11.1
Unemployed	9	33.3	3	11.1
Leave of Absence	2	7.4	0	-

**Table 3** (*continued*)

Variable	Mothers ( <i>n</i> = 27)		Fathers ( <i>n</i> = 27)	
	Frequency	(%)	Frequency	(%)
Education				
High School Graduate or Equivalency	1	3.7	2	7.4
Technical School	4	14.8	3	11.1
Some College/University (no Degree/Diploma)	6	22.2	5	18.5
University or College Degree	9	33.3	13	48.1
Graduate or Professional Degree	7	25.9	4	14.8
Race/Ethnicity				
Aboriginal	-	0	1	3.7
African American	1	3.7	0	-
Arab	1	3.7	2	7.4
Latin American	1	3.7	1	3.7
White/Caucasian	23	85.2	21	77.8
Other	1	3.7	2	7.4

**Children.** For the Couples Group, the majority of the parent's children with ASD were male (87%) and Caucasian (83.3%). The mean age of the children at the time of the study was 9.57 years ( $SD = 3.29$ ), while the mean age of the ASD diagnosis was 4.37 years ( $SD = 2.38$ ). The range of the ASD diagnosis was between 22 months and 12 years, two months of age. For more information about the demographic characteristics of the children in the Couples Group, please see Table 4.

**Table 4***Demographic Information for the Couples Group (Children)*

<b>Variable</b>	<b>Frequency</b>	<b>(%)</b>
Gender ( <i>n</i> = 53)		
Male	47	81.7
Female	6	16.6
Race/Ethnicity ( <i>n</i> = 54)		
Aboriginal	2	3.7
African American	1	1.9
Arab	4	7.4
Latin American	1	1.9
White/Caucasian	45	83.3
Other	1	1.9



For the Independent Group, the majority of participants were biological mothers (84.3%); Caucasian (80.9%), and married (68.7%). Approximately half of the participants reported working full-time (46.1%), having a university or college degree (56.5%) being in the 35 to 44 year age range (57.4%) and being from Ontario, Canada (46.1%). The entire sample was either from Canada (80.9%) or from the United States of America (19.1%). The majority of participants reported an annual family income between \$50,000 and \$150,000. Sixty-four percent of respondents were raising at least two children in total and 12% were raising at least two children with ASD. The average number of total children raised by the respondents was 1.90. Similar to the Couples Group, a large majority of the respondents indicated they have experienced growth as a result of parenting a child with ASD (93.9%) and will continue to experience more growth (94.8%). For more information about the demographic characteristics of the respondents in the Independent Group, please see Table 5.

**Table 5***Participant Demographic Information for the Independent Group (Parents)*

<b>Variable</b>	<b>Frequency</b>	<b>(%)</b>
Relationship to Child ( <i>n</i> = 115)		
Biological Mother	97	84.3
Biological Father	9	7.8
Step-Mother	4	3.5
Step-Father	2	1.7
Adoptive Mother	2	1.7
Adoptive Father	1	0.9
Age of Parent ( <i>n</i> = 115)		
18-24	1	0.9
25-34	18	15.7
35-44	66	57.4
45-54	27	23.5
55-64	3	2.6
Country ( <i>n</i> = 115)		
Canada	93	80.9
United States	22	19.1
Marital Status ( <i>n</i> = 114)		
Single	8	7.0
Married, Living with Partner	79	68.7
Living with Partner	11	9.6
Separated	4	3.5
Divorced	12	10.4
Annual Household Income ( <i>n</i> = 114)		
Under \$20 000	6	5.2
\$20 000 - \$30 000	6	5.2
\$30 000 - \$40 000	6	5.2
\$40 000 - \$50 000	8	7.0
\$50 000 - \$75 000	18	15.7
\$75 000 - \$100 000	29	25.2
\$100 000 - \$150 000	20	17.4
\$150 000 or more	21	18.3

**Table 5** (*continued*)

<b>Variable</b>	<b>Frequency</b>	<b>(%)</b>
Employment Status ( <i>n</i> = 114)		
Full-Time	53	46.1
Part-Time	23	20
Unemployed	30	26.1
Retired	2	1.7
Leave of Absence	6	5.2
Education ( <i>n</i> = 115)		
Less than High School	2	1.7
High School Graduate or Equivalency	5	4.3
Technical School	5	4.3
Some College/University (no Degree/Diploma)	14	12.2
University or College Degree	65	56.5
Graduate or Professional Degree	24	20.9
Race/Ethnicity ( <i>n</i> = 115)		
Aboriginal	2	1.7
African American	2	1.7
Chinese	2	1.7
Filipino	1	0.9
Japanese	1	0.9
Korean	1	0.9
Latin American	3	2.6
South Asian (Bangladeshi, East Indian, Pakistani, Sri Lankan, etc.)	2	1.7
Southeast Asian (Cambodian, Indonesian, Laotian, Vietnamese, etc.)	2	1.7
West Asian (Afghan, Iranian, etc.)	3	2.6
White/Caucasian	93	80.9
Other	3	2.6

\**Note.* Some participants did not respond to some questions.

**Children.** For the Independent Group, the majority of the parent's children with ASD were male (79.1%) and Caucasian (83.5%). The mean age of the children at the time of the study was 9.25 years ( $SD = 4.2$ ), while the mean age of the ASD diagnosis was 4.65 years ( $SD = 2.93$ ). The range for the ASD diagnosis was between 18 months and 16 years of age. For more information about the demographic characteristics of the children in the Independent Group, please see Table 6.

**Table 6***Demographic Information for the Independent Group (Children)*

<b>Variable</b>	<b>Frequency</b>	<b>(%)</b>
Gender ( <i>n</i> = 115)		
Male	92	80.0
Female	23	20.0
Race/Ethnicity ( <i>n</i> = 115)		
Aboriginal	2	1.7
African American	3	2.6
Chinese	1	0.9
Latin American	4	3.5
South Asian (Bangladeshi, East Indian, Pakistani, Sri Lankan, etc.)	1	0.9
Southeast Asian (Cambodian, Indonesian, Laotian, Vietnamese, etc.)	1	0.9
West Asian (Afghan, Iranian, etc.)	1	0.9
White/Caucasian	96	83.5
Other	6	5.2

*\*Note.* Two respondents indicated the gender of their child with ASD as “other”. These two respondents both had two children diagnosed with ASD, one male and one female. The additional children have been added to their respective frequency for male and female children.

The 10 mothers and 10 fathers who completed the in-depth phone interviews, were chosen based on select criteria from the 105 parents (86 mothers and 19 fathers) who indicated their interest in participating in the phone interview on the online questionnaire. Respondents were selected with the intention of including diverse characteristics in the interview participant sample. For example, participants were chosen based on their relationship to their child (biological, step-, and adoptive parents), age of parent, whether they reported experiencing growth as a result of parenting a child with ASD, and having more than one child with ASD. The majority of mothers and fathers who completed the phone interview were biological parents and Caucasian. One hundred percent of fathers and 73% of mothers in the phone interviews reported having at least a college or university degree. Approximately half of the mothers were in the 25-35 age range and unemployed. Half of the fathers were in the 45-54 age range and the majority reported full-time employment status. One father was raising two children diagnosed with ASD and one mother was raising three children with ASD. For more information about the demographic characteristics of the respondents who completed an in-depth interview please see Table 7.

**Table 7***Participant Demographic Information for the In-Depth Phone Interview*

Variable	Mothers ( <i>n</i> = 10)		Fathers ( <i>n</i> = 10)	
	Frequency	(%)	Frequency	(%)
<b>Relationship to Child</b>				
Biological Parent	8	80	8	80
Step Parent	1	10	1	10
Adoptive Parent	1	10	1	10
<b>Age of Parent</b>				
25-34	4	40	2	20
35-44	3	30	3	30
45-54	2	20	5	50
55-64	1	10	0	-
<b>Country</b>				
Canada	7	70	9	90
United States	3	30	1	10
<b>Marital Status</b>				
Married, Living with Partner	5	50	10	100
Living with Partner	3	30	0	-
Divorced	2	20	0	-
<b>Annual Household Income</b>				
Under \$20 000	1	10	0	-
\$20 000 - \$30 000	1	10	0	-
\$30 000 - \$40 000	1	10	1	10
\$40 000 - \$50 000	0	-	0	-
\$50 000 - \$75 000	2	20	1	10
\$75 000 - \$100 000	3	30	1	10
\$100 000 - \$150 000	1	10	2	20
\$150 000 or more	1	10	4	40
<b>Employment Status</b>				
Full-Time	3	30	7	70
Part-Time	1	10	2	20
Unemployed	6	60	0	-
Leave of Absence	0	-	1	10

**Table 7** (continued)

Variable	Mothers ( <i>n</i> = 10)		Fathers ( <i>n</i> = 10)	
	Frequency	(%)	Frequency	(%)
Education				
High School Graduate or Equivalency	1	10	0	0
Technical School	0	-	0	0
Some College/University (no Degree/Diploma)	2	20	0	0
University or College Degree	4	40	7	70
Graduate or Professional Degree	3	30	3	30
Race/Ethnicity				
African American	1	10	0	-
White/Caucasian	9	90	9	90
Other	0	-	1	10



**Children.** The mean age of the children at the time of the study was very similar for mothers (9.32;  $SD = 4.49$ ) and fathers (9.75;  $SD = 4.71$ ) who completed the phone interview. This was also true for the mean age of ASD diagnosis (mothers = 3.58; fathers = 3.84). The majority of mothers (70%) and fathers (80%) were raising a male child with ASD. Two of the mothers reported their children's ethnicities differed from their own. One child was African American and one child did not have their ethnicity listed as an option. Three of the fathers reported their children's ethnicities differed from their own. One child was Aboriginal, one child was Arab and one child was Latin American.

### Measures

The online questionnaire consisted of seven measures. The participants in the Couples Group and Independent Group completed the same measures in the online questionnaire. A subset of these groups completed the six question in-depth phone interview. The internal consistencies of both groups was provided for each measure, please see Table 8. The names of the measures were removed when put onto the online format of FluidSurveys in order to reduce potential expectation effects. Permission was given to the principal investigator by the authors of the Benefit Finding Scale for Parents of Children with Asperger's Syndrome (BFS-PCAS; Samios et al., 2009) to alter the Likert rating system and the terminology in the questions to suit parents of children with ASD not Asperger's syndrome. The seven measures and the six questions included in the phone interview are described below.

**Table 8***Internal Consistency for the Couples Group and the Independent Group*

<b>Measures for Variables</b>	<b>Subscale of Measures</b>	<b>Internal Consistency (Couples Group <i>n</i> = 54)</b>	<b>Internal Consistency (Independent Group <i>n</i> = 115)</b>
Brief COPE	General Factor	n/a	n/a
	Active coping	.504	.622
	Emotional support	.798	.726
	Instrumental support	.756	.826
	Positive reframing	.695	.738
	Planning	.448	.775
	Acceptance	.663	.708
	Self-blame	.743	.805
	MSPSS	General Factor	.929
Significant Other		.957	.956
Family		.965	.954
Friends		.951	.953
BFS-PCAS	General Factor	.932	.948
	New Possibilities	.852	.857
	Personal Growth	.858	.897
	Appreciation	.806	.818
	Spiritual Growth	.958	.957
	Positive Effects	.499	.674
	Greater Awareness	.389	.769
PSS	General Factor	.863	.886
MCSDS Revised (Form C)	General Factor	.753	.712

*\*Note.* MSPSS = Multidimensional Scale of Perceived Social Support; BFS-PCAS = Benefit Finding Scale for Parents of Children with Asperger's Syndrome; PSS= Parental Stress Scale; MCSDS= Marlowe-Crowne Social Desirability Scale

### **Demographic Questionnaire**

A 15-item questionnaire was designed for this study to acquire information on parent and child demographics (see Appendix F). In addition to completing standard demographic questions such as age, gender, race/ethnicity, household income, education, age at diagnosis, etc., parents were also asked two dichotomous questions on whether they have experienced personal growth and whether they will continue to experience growth in the future. Parents were also asked about the number of children they were raising, their children's ages, and the diagnosis/diagnoses of these children, including the "target" child with ASD for which the respondents were completing the online survey. The final two questions that appeared at the end of the online questionnaire asked respondents if they would agree to complete a 20-minute phone interview and if they would like to receive a \$5 Starbucks eGift card.

### **Social Communication Questionnaire**

For the purposes of this study the Social Communication Questionnaire (SCQ) was used as a screening measure to ensure that the respondents were raising a child diagnosed with ASD (see Appendix G). Use of the SCQ prevented the need to obtain release forms from parents to obtain official clinician diagnostic reports (Rutter, Bailey & Lord, 2003). The SCQ consists of 40 items associated with the defining features of ASD and has been validated for individuals between the ages of four years, zero months to 39 years, 11 months. This parent-report measure consists of questions about social interaction, communication, abnormal language, and stereotyped behaviour. To assess the effectiveness of the SCQ in identifying individuals with ASD, the concept of sensitivity and specificity are utilized. Sensitivity is assessed by the inventory's ability to correctly identify individuals with ASD, while specificity is assessed by the inventory's ability to correctly identify individuals without ASD. The researcher used the cutoff

score of 15 on the SCQ, found by Berument, Rutter, Lord, Pickles, and Bailey (1999) to be associated with the highest sensitivity (.85) and specificity (.75). Permission required for use of this measure was obtained through Western Psychological Services (WPS; see Appendix N). Each use of the SCQ was purchased and a license was obtained for use of the SCQ in an online format. This license was displayed on FluidSurveys before the SCQ measure as per the request of WPS. In terms of psychometric properties for the current study, the internal reliability of the SCQ was found to be adequate  $\alpha = .76$ . Two steps were taken to ensure that the parents who completed the online questionnaire had children diagnosed with ASD: completion of the SCQ and recruitment at ASD organizations.

### **Brief COPE**

The Brief COPE questionnaire, which was obtained from the public domain, (Carver, 1997; see Appendix H) is a self-report measure designed to assess the degree to which respondents employ strategies in response to life events. The Brief COPE was chosen as it has the benefit of fewer items and less redundancy than the full COPE measure while serving the same purpose (Carver, 1997). The Brief COPE questionnaire consists of 28 items and provides information on 14 different types of coping strategies. These strategies include Self-distraction, Active coping, Denial, Substance use, Use of emotional social support, Use of instrumental support, Behavioural disengagement, Venting, Positive reframing, Planning, Humor, Acceptance, Religion and Self-blame. For the present study, only a subset of these strategies was statistically analyzed: Active coping, Use of emotional support, Use of instrumental support, Positive reframing, Planning, Acceptance, and Self-blame. The COPE and Brief COPE are two of the most commonly utilized questionnaires when measuring individual coping strategies in research across situations (Taylor, 1998), which includes parents of children diagnosed with

ASD (Benson, 2010). The Brief COPE has been determined to have good internal consistency (Tuncay, Musabak, Gok, & Kutlu, 2008). Carver (1997) reported that for the 14 subscales of coping strategies, the internal reliabilities ranged from .57 to .90. Al-Dubai, Al-Naggar, Alshagga, and Rampal (2011) found similar results with internal reliabilities ranging from .50 to .90.

Participants were asked to rate each item on a 4-point Likert scale from one “I haven’t been doing this at all” to four “I’ve been doing this a lot” based on how they respond when confronted by difficult or stressful events in their daily life. Scores were summed for each of the subtypes of coping strategies with higher scores indicating a greater use of that specific type of coping. The internal consistencies of the seven subscales ranged from .44 to .80 in the Couples Group and from .62 to .83 in the Independent Group. Two of the internal consistencies in the Couples Group were weak; however, these values will not greatly impact the statistical analyses for this group. Planning had the lowest Cronbach’s alpha in the Couples Group but third highest in the Independent Group. For more information on the internal consistencies for the Brief COPE please see Table 8 above.

### **Multidimensional Scale of Perceived Social Support**

The Multidimensional Scale of Perceived Social Support, which was obtained from the public domain, (MSPSS; Zimet, Dahlem, Zimet, & Farley, 1988; see Appendix I) was used to assess the degree of perceived social support the respondents reported from their significant other, family, and friends. The MSPSS is a self-report measure consisting of 12-items (four items for each of the three subscales). Researchers have used this scale to measure the perceptions of social support reported by parents of children with cognitive delays (Shin & Nhan, 2009; Shin & McDonough, 2008), as well as parents of children with ASD (Stuart & McGrew, 2009). The

MSPSS has been shown across studies to have high internal consistency for Family ( $\alpha = .88$ ) and Friends ( $\alpha = .90$ ) subscales but low internal consistency for the Significant Other subscale ( $\alpha = .61$ ) (Zimet, et al., 1988; Stuart & McGrew, 2009).

Participants were asked to rate each item on a 7-point Likert scale ranging from one “very strongly disagree” to seven “very strongly agree” based on how much support they have been receiving from their significant other, family and friends. The total social support score ranges from 12 to 84, while each individual subscale score ranges from four to 28, with higher scores indicating a higher perception of received social support. In terms of the psychometric properties for the MSPSS for the present study, the internal reliability of the general factor and individual subscales for both the Couples Group and Independent Group was very high;  $\alpha > .92$ . A general factor internal consistency which is very high can be problematic when conducting some statistical analyses (Streiner, 2003). In response to the general factor having very high internal consistency, analyses, which excludes mean comparisons, conducted on this scale will only include the total MSPSS score and not individual subscales. For more information on the internal consistencies for MSPSS please see Table 8 above.

### **Benefit Finding Scale for Parents of Children with Asperger’s Syndrome**

The Benefit Finding Scale for Parents of Children with Asperger’s Syndrome, which was obtained from the public domain, (BFS-PCAS; Samios et al., 2009; see Appendix J) was used to assess the degree of perceived SRG experienced by parents raising children diagnosed with ASD. Permission was obtained from the authors to adapt the Likert rating system, as well as the terminology in the questions for this to suit parents of children with ASD not Asperger’s syndrome (see Appendix N).

The BFS-PCAS originally used a 3-point Likert scale ranging from “not at all” to “a great deal”. However, the primary investigator modified the Likert-scale to a 5-point scale from one “I have not at all experienced this” to five “I have experienced this to a very great degree”. This was done to provide more variability and increase the sensitivity on the respondents’ perception of growth in raising children with ASD. The BFS-PCAS is comprised of 41 items (1 dichotomous question and 40 scaled questions) representing six scales of growth (New Possibilities, Personal Growth, Appreciation, Spiritual Growth, Positive Effects of the Child, and Greater Awareness). Scores on the BFS-PCAS range from 40 to 200 with higher scores indicating a greater level of benefit finding and personal growth. The number of items which comprise each sub-scale was based on a factor analysis conducted by Samios et al. (2009). The subscales New Possibilities and Personal Growth consist of 10 items, Appreciation consists of eight items, Positive Effect consists of five items, Spiritual Growth consists of four items, and Greater Awareness consists of three items.

Few studies have used this self-report measure to investigate benefit finding and growth in parents of children with Asperger’s or ASD (Samios et al., 2009). Samios, Pakenham and Soffronoff (2012) used the BFS-PCAS and found it to have adequate internal reliabilities. The general factor reliability for the BFS-PCAS was found to be  $\alpha = .95$  while the six sub-factors showed a range of reliabilities from  $\alpha = .72$  to  $\alpha = .94$ . The highest sub-factor reliability was spiritual growth, while the lowest sub-factor reliability was found to be positive effects of the child.

In terms of the psychometric properties for the BFS-PCAS for the present study, the internal reliability of the general factor was found to be very high for both groups (Couples Group  $\alpha = .93$ ; Independent Group  $\alpha = .95$ ). The BFS-PCAS subscales ranged from unacceptable

(.39) to excellent (.96) for the Couples Group and from acceptable (.67) to excellent (.96) for the Independent Group (see Table 8 above). As previously mentioned, strong internal consistency coefficients are more important when conducting regression analyses as compared to mean comparisons. Similar to the general factor for the MSPSS, the BFS-PCAS had a very high internal consistency. Therefore, analyses on the BFS-PCAS, excluding mean comparisons, only included the BFS-PCAS general factor and not individual subscales.

### **The Parental Stress Scale**

The Parental Stress Scale, which was obtained from the public domain, (PSS; Berry & Jones, 1995; see Appendix K) was used to measure the level of stress mothers and fathers experience in raising children with ASD. The PSS is a self-report measure consisting of 18-items describing both negative and positive themes of parenthood. The questionnaire asks parents to indicate the level to which they agree with certain parenthood themes in their parent-child relationships. Of these 18 items, 10 are negative and eight are positive. Both positive and negative items were included to assess the parents' stress by comparing the negative impacts to the benefits of parenting (Lessenberry & Rehfeldt, 2004, p. 235). To determine the total amount of stress the respondents are experiencing the eight positive items are reverse scored and combined with the remaining 10 items. Scores range from 18 to 90 with higher scores indicating parents are reporting higher levels of stress in their relationships with their children (Berry & Jones, 1995).

This inventory uses a 5-point Likert scale ranging from one "strongly disagree" to five "strongly agree" (Lessenberry & Rehfeldt, 2004). The PSS has been determined to have adequate internal reliability ( $\alpha = .83$ ) as well as test-retest reliability ( $\alpha = .81$ ). In terms of the



psychometric properties for the PSS for the present study, the internal reliability was found to be good for both the Couples Group ( $\alpha = .86$ ) and the Independent Group ( $\alpha = .89$ ).

This self-report questionnaire has been used with parents of children diagnosed with neurodevelopmental disorders and behavioural disorders, as well as children without a clinical diagnosis (Berry & Jones, 1995). No significant differences in parenting stress levels have been found between mothers and fathers (Berry & Jones, 1995; Lessenberry & Rehfeldt, 2004).

### **Marlowe-Crowne Social Desirability Scale Revised-Form C**

The Marlowe-Crowne Social Desirability Scale Revised-Form C, which was obtained from the public domain, (MCSDS Revised-Form C; Reynolds, 1982; see Appendix L) was used to assess socially desirable responding. Self-report measures of SRG or benefit finding require individuals to accurately reflect on their past experiences, which respondents may frame in a more positive light (Bitsch et al., 2009). A measure of social desirability is required when measuring such experiences to ensure the participants of the study are not misrepresenting themselves and reporting more growth than actually experienced.

The original MCSDS (Crowne & Marlowe, 1960) consisted of 33 dichotomous items; however, shorter forms have been developed with a subset of the original 33-items. The MCSDS short form which has been found to demonstrate the most reliable results is the Form C consisting of 13 items taken from the original 33-item MCSDS (Zook & Sipps, 1985). True or false responses are coded as one or zero depending on the question and summed to create a total score. There are no cut-off scores with the MCSDS Revised-Form C. The higher the score the more the participant is responding in a socially desirable way.

This measure has shown acceptable levels of reliability ( $\alpha = .76$ ) and compares favorably to the reliability found from the original MCSDS ( $\alpha = .82$ ). In terms of the psychometric

properties for the MCSDS Revised-Form C for the present study, the internal reliability was found to be good for both the Couples Group ( $\alpha = .75$ ) and Independent Group ( $\alpha = .71$ ).

### **Phone Interviews**

A sample of the participants (10 mothers and 10 fathers) completed a semi-structured interview, to provide a greater understanding of the SRG mothers and fathers experience as a result of raising a child diagnosed with ASD. The interview consisted of six questions designed to provide additional information to the online survey on the challenges and growth experienced by the respondents (Loepp & Gragg, 2013; see Appendix C). Mothers and fathers were asked about 1) the most challenging aspects in raising their child(ren) with ASD, 2) how growth has been a part of their journey, 3) how their perspective on life/perception of themselves has shifted or changed, 4) how their parenting style has changed, 5) what advice they have for parents whose children have just been diagnosed with ASD, and 6) how much growth they feel they have experienced on a scale from one to 10.

### **Procedure**

The study was conducted online due to the efficiency of this method when compared to the traditional pencil-paper methods (Evans & Mathur, 2005). Online surveys are more likely to result in increased global reach, speed and timeliness, convenience, ease of data entry and analysis, and sample size. After receiving clearance from the Research Ethics Board (REB) from the University of Windsor, parents were recruited via face-to-face and online methods. The primary investigator and research assistants recruited participants face-to-face by attending ASD related events such as parent support groups, peer support groups, and fundraisers in Windsor, Ontario and Edmonton, Alberta. Online recruitment was done by the primary investigator who joined Facebook groups and Listservs whose members were mothers and fathers raising children

with ASD. Other online methods used to recruit was emails sent to ASD related organizations across Canada and the United States of America (see Appendix O) which asked them to post recruitment flyers on their Facebook pages and/or websites and if possible to email their client families about the study. The primary researcher also attempted to recruit with agencies in the United Kingdom and Australia; however, no participants from these locations completed the present study.

In order for participants to complete the study they required the link and password for the online questionnaire. The password was required by WPS publishers to protect the copyright of the SCQ. Therefore, the recruitment flyers provided a description of the study, the primary investigator's contact information (email and phone number), and an opportunity to receive a token of appreciation (\$5 gourmet coffee eGift card) (see Appendix A). If parents were interested in participating they were required to contact either the primary investigator or a staff member from an organization that was promoting the study. Organizations that agreed to assist in recruiting by sending emails to their families receiving services were given the link and password by the primary investigator. By organizations sending these emails, respondents were able to complete the on-line survey with more convenience.

Once respondents received the link and password they were able to navigate to the online questionnaire. The Letter of Information and Consent to Participate form (see Appendix B) was the first page of the questionnaire. Participants selected a checkbox to indicate they consented to participating in the study and were then able to continue with the survey. This form provided more details about what participation in the study involved, as well as the potential benefits and risks of participation. Respondents also had the opportunity to print a copy of this form for their personal records. Once participants provided consent, they completed the screening questions to

determine their inclusion/exclusion in the study. These included questions about their relationship to their child with ASD, the age of their child with ASD, and then completion of the SCQ ASD screening measure. Participants who were biological, step, or adoptive mothers or fathers, raising a child with ASD between the ages of three years, zero months and 17 years, 11 months, and scored 15 or above on the SCQ met inclusion criteria and were able to continue to the next measure. If respondents did not meet these criteria they were sent to a Termination Page (Appendix M) and not able to complete the rest of the questionnaire. Those who met the inclusion criteria completed the rest of the online questionnaire in the following order: Demographic questionnaire, Brief COPE, MSPSS, BFS-PCAS, PSS, and MCSDS Revised-Form C. The on-line questionnaire, which includes the inclusion criteria and the six questionnaires, took the respondents an average of 30.46 minutes to complete (two responses were excluded as they were outliers).

Once all measures were completed the participants were asked if they would agree to a 20-minute phone interview and if they would like to receive a \$5 Starbucks eGift card. Respondents who agreed to the phone interview provided both their phone number and email; while those who were interested solely in the \$5 Starbucks eGift card provided just their email. One hundred and thirty one online questionnaire respondents out of 169 accepted the offer of a \$5 Starbucks eGift card. The respondents who did not want to complete a phone interview or receive a gift-card had complete anonymity. Respondents who provided contact information were assured their responses, both online and over the phone, were confidential. Upon completion of the study the participants were sent to a Completion Page which provided them with the rationale and purpose of the study, the website the results would be posted, and the contact information of the primary investigator and his supervisor (Appendix M).

From the 105 respondents (86 mothers and 19 fathers) who agreed to be contacted for the phone interview, 10 mothers and 10 fathers were selected. These respondents were selected based on diverse characteristics as described previously in the Participants section. The chosen respondents were sent an email and asked four questions: to confirm their agreement to a phone interview, their name, confirmation of their phone number, and convenient times to call. Once participants responded and confirmed their interest, as well as provided the responses to the other three questions, the interviews were scheduled. At this time, they were emailed another copy of the Letter of Information and Consent to Participate (see Appendix B) and a Consent to Electronically Record the Phone Interview form (see Appendix D). The primary investigator followed an interview script designed specifically for this study to allow for consistency of interview procedures (Loepp & Gragg, 2013) see Appendix C). To ensure the participants understood and consented to the phone interview being recorded, the primary investigator reviewed the informed consent and permission to record interviews at the beginning of the interview. The interviews were completed over the telephone and were an average of 27.6 minutes. Those interviews that took longer were due to time spent reviewing the Letter of Information and Consent to Participate as well as the Consent to Electronically Record the Phone Interview forms with the participant. At the completion of the interview the respondents were asked if the primary investigator had their permission to use their interview responses for his Master's Thesis research study. They were then provided with an opportunity to receive an additional \$5 Starbucks eGift card. Ten out of 20 participants in the phone interview accepted the offer of an additional \$5 Starbucks eGift card. The interviews were transcribed and checked by the primary investigator and a trained research assistant.

### **Statistical Analysis**

Several statistical analyses were conducted to answer the quantitative research questions. The Independent Group answered Research Question 1; however, three preliminary analyses were conducted to determine which variables would be included in Research Question 1. The statistical analysis used for Preliminary Analysis 1 was a principal component analysis (PCA; Caserta, Utz, & de Vries, 2009). The statistical analysis used for Preliminary Analysis 2 was a curvilinear hierarchical regression analysis (HRA; Joseph, 2011). The statistical analysis used for Preliminary Analysis 3 was a bivariate correlation. Last, the statistical analysis used for Research Question 1 was a hierarchical multiple regression analysis (MRA). This regression analysis was chosen because of this technique's ability to control for contextual variables that are not part of the planned analysis.

The Couples Group answered Research Questions 2 to 6. The statistical analysis used to assess the differences between mother-father pairs raising children with ASD across perceived growth, coping, and stress was a dependent t-test. Descriptive statistics of the scores (mean, standard deviation, and range) and the statistical methods mentioned above were calculated using the Statistical Package for the Social Sciences-22 (SPSS-22). The only statistical analyses that were calculated without using SPSS-22 was the Pitman-Morgan test, which analyzed the homogeneity of correlated variance for the paired t-tests, and Cohen's D (effect size).

Finally, the qualitative responses to the phone interviews were analyzed with thematic analysis (Braun & Clarke, 2006). For the qualitative data, the researcher and a trained research assistant transcribed the electronically recorded interviews. Each individual question was then analyzed for all interviews to determine three to five common primary themes which appeared in

the participant's responses. Less frequent sub-themes were placed under the corresponding primary themes.

## Results

### Quantitative Analysis

#### Preliminary Analyses for the Independent Group

The quantitative data were first examined for accuracy and completeness before analysis of the three Preliminary Analyses and Research Question 1. This included analyzing the amount and consistency of responses missing. In total, less than 1% of the data were missing from the 115 respondents. Little's Missing Completely At Random (MCAR) test of missing data indicated the responses were missing at random  $\chi^2(3176) = 3129.29, p = .719$ . According to Tabachnick and Fidell (2007), when less than 5% of the data are missing and these responses are missing at random, missing data may be estimated using the expectation maximization (EM) method. To ensure more accurate estimates were achieved, missing data analyses were conducted on each individual subscale.

A total of 16 responses across all of the measures for the 115 participants were identified as outliers (greater or less than 2.5 standard deviations from the mean) within the data-set. Fifteen out of the 16 of these outliers had a negative Z-score which indicated the participants' reported a significantly lower score than the average. These cases were individually analyzed for consistent and meaningful responses. Given the relatively high mean ( $M = 153.20$ ; see Table 9) of total perceived SRG reported from the participants in the Independent Group, the participants who reported a total growth score of less than 90 were considered outliers. Some of the participants who reported lower levels of growth also reported in the dichotomous question that they have not experienced growth as a result of parenting children with ASD. For this reason, no responses were excluded from the group.



**Table 9**

*Descriptive Statistics of Coping Strategies, Social Support, and Stress Related Growth for the Independent Group*

Measure	Variables	<i>n</i>	<i>M</i>	<i>SD</i>	Range	
					Potential	Actual
<b>Brief COPE</b>	Active coping	115	6.57	1.33	2-8	2-8
	Emotional support	115	5.53	1.67	2-8	2-8
	Instrumental support	115	5.86	1.79	2-8	2-8
	Positive reframing	115	5.89	1.64	2-8	2-8
	Planning	115	6.78	1.40	2-8	2-8
	Acceptance	115	6.99	1.24	2-8	3-8
	Self-blame	115	4.21	1.86	2-8	2-8
<b>BFS-PCAS</b>	<b>Stress-Related Growth</b>	<b>115</b>	<b>153.20</b>	<b>25.62</b>	<b>40-200</b>	<b>92-200</b>
	New Possibilities	115	36.52	8.14	10-50	18-50
	Personal Growth	115	41.31	7.03	10-50	16-50
	Appreciation	115	33.11	5.30	8-40	20-40
	Spiritual Growth	115	9.38	5.62	4-20	4-20
	Positive Effects	115	19.54	3.75	5-25	9-25
	Greater Awareness	115	13.34	1.91	3-15	7-15
<b>PSS</b>	<b>Stress</b>	<b>115</b>	<b>47.28</b>	<b>11.49</b>	<b>18-90</b>	<b>20-75</b>
<b>MSPSS</b>	<b>Social Support</b>	<b>115</b>	<b>57.76</b>	<b>16.93</b>	<b>12-84</b>	<b>12-84</b>

*\*Note.* Bolded terms are general factor scores. BFS-PCAS = Benefit Finding Scale for Parents of Children with Asperger's Syndrome; PSS = Parental Stress Scale; MSPSS = Multidimensional Scale of Perceived Social Support

The main goal of the Independent Group was to identify the relationship and predictive ability of different internal coping strategies, stress, and external support with perceived SRG. Previous research has claimed perceived SRG to be similar to internal coping strategies (Bjorck & Byron, 2012) and that stress has a curvilinear relationship with SRG (Joseph, 2011). Therefore, the exact number of predictor variables was not fixed in predicting SRG before the analyses were conducted (Research Question 1). Therefore, three preliminary analyses were conducted to determine the number of predictors to be used for the multiple regression analysis (MRA) in predicting SRG (Research Question 1).

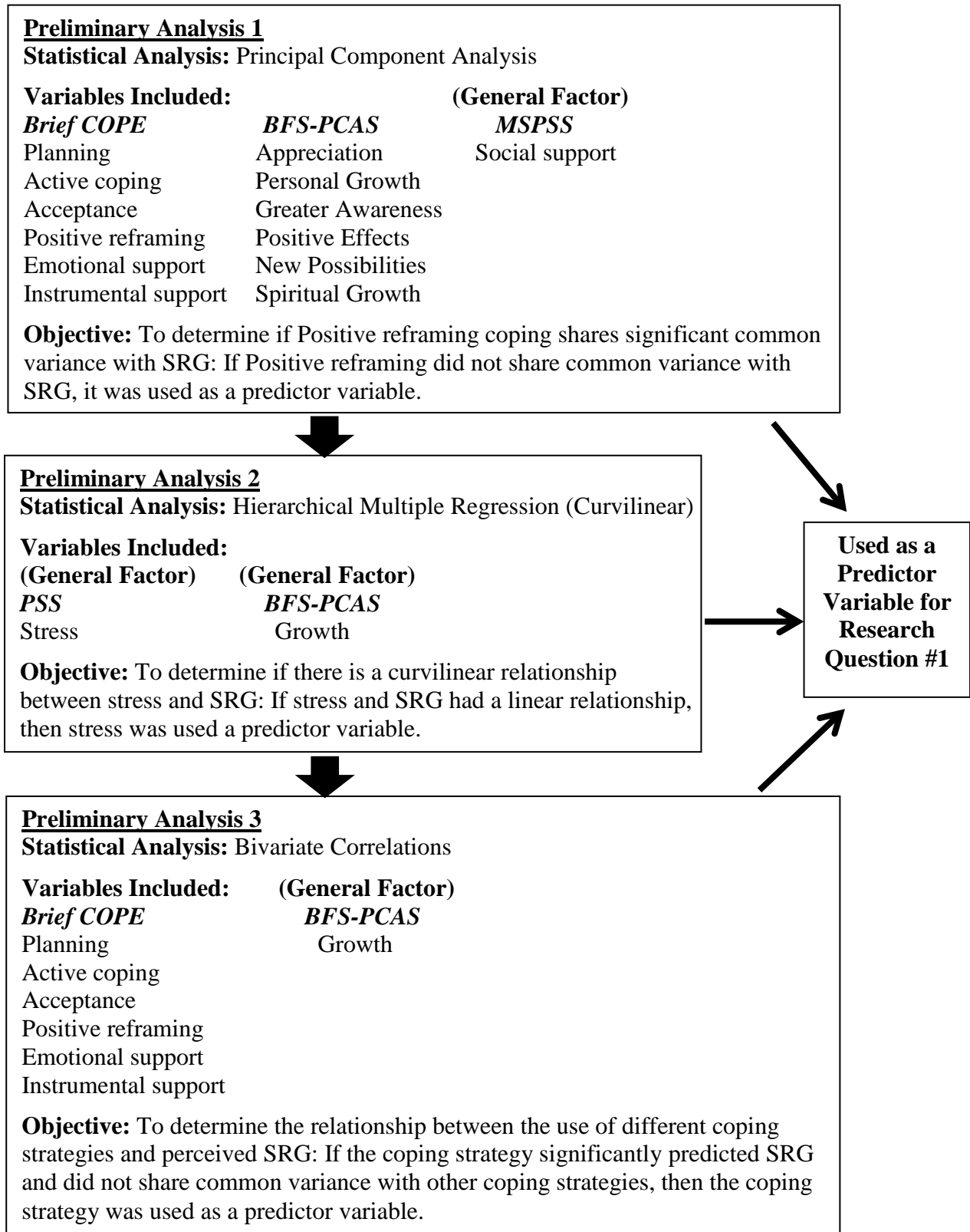
**Preliminary Analysis 1:** Does perceived SRG, share significant common variance with Active, Positive reframing, Planning, and Acceptance coping, as well as Emotional support, Instrumental support, and support received from family and friends (Bjorck & Byron, 2014)? A PCA was conducted for the first preliminary analysis to investigate if Positive reframing coping shared common variance with perceived SRG. If Positive reframing did not share common variance with the sub-factors of perceived SRG, then Positive reframing was used as a predictor variable in predicting SRG.

**Preliminary Analysis 2:** How does stress relate to the general factor of perceived SRG (Joseph, 2011)? A curvilinear regression was conducted for the secondary preliminary analysis to investigate if there was a curvilinear relationship between stress and SRG. If stress and SRG had a linear relationship, then stress was used a predictor variable in predicting SRG.

**Preliminary Analysis 3:** How do different coping strategies relate to the general factor and subscales of perceived SRG? Bivariate correlations were conducted for the third preliminary analysis to investigate the relationship between different coping strategies, and external support with perceived SRG. This research question also identified the strength of relationships between

different coping strategies and external support. If a coping strategy significantly predicted SRG and did not share common variance with other coping strategies, then that particular coping strategy was used as a predictor variable in predicting SRG. For a visual depiction of the preliminary analyses please see Figure 3.

**Figure 3.** Flow Chart of the Preliminary Analyses Conducted with the Independent Group



**Similarities and Differences between Coping Strategies, Social Support and Perceived SRG**

**Preliminary Analysis 1:** Does perceived SRG, share significant common variance with Active, Positive reframing, Planning, and Acceptance coping, as well as Emotional support, Instrumental support, and support received from family and friends (Bjorck & Byron, 2014)?

The exploratory PCA was conducted with the Independent Group to address previous findings that perceived SRG may be conceptually the same as coping strategies such as Positive reframing (Caserta et al., 2009). In total, 13 variables were included in the PCA (see Table 10). Also included in this PCA were coping variables from the Brief COPE (i.e. Planning, Active, and, Acceptance Coping, Emotional support and Instrumental support), and the general factor score of social support (MSPSS). Self-blame was excluded based on having a negative correlation with the six factors of SRG, six coping scores, and the general factor social support score. A PCA having one variable that negatively correlates with the other variables will result in a factor structure with one extra factor based on the inverse relationship with the other variables. The 13 variables were centered for the analysis to control for scale variability.

**Table 10** *Results of the Principal Component Analysis for Stress-Related Growth, Coping, and Social Support*

Variable	Rotated Factor Loading		
	Stress-Related Growth	Internal Coping	External Coping
Appreciation	<b>.877</b>	.049	-.017
Personal Growth	<b>.871</b>	-.067	.020
Greater Awareness	<b>.845</b>	.125	-.281
Positive Effects	<b>.820</b>	.055	.033
New Possibilities	<b>.795</b>	.035	.082
Spiritual Growth	<b>.462</b>	.010	.275
Planning	-.016	<b>.919</b>	-.111
Active coping	.081	<b>.801</b>	-.061
Acceptance	.082	<b>.560</b>	.100
Positive reframing	.278	<b>.419</b>	.253
Emotional support	-.105	.107	<b>.876</b>
Social support	.281	-.216	<b>.694</b>
Instrumental support	-.136	<b>.489</b>	<b>.637</b>

\**Note.* Factor loadings > .40 are in boldface ( $n = 115$ ).

The R-matrix (correlation coefficients between all variables) indicated that the majority of individual correlations ranged between weak positive relationships (.2 to .299) to strong positive relationships (.4 to .699). Based on the extent and magnitude of these correlations, the rotation method used for the PCA was direct oblimin (oblique), which allows the components to be correlated. Although the recommended sample size for data reduction techniques is between 200-300 respondents (Tabachnick & Fidell, 2007), the current sample ( $n = 115$ ) size was acceptable ( $KMO = .783$ ) in conducting a PCA with 13 variables.

To determine the number of components to include in the PCA, a path analysis was conducted. The previous method of extracting the number of factors based solely on having an eigenvalue of one or greater has been criticized (Tabachnick & Fidell, 2007). Path analysis determines the number of factors to extract from the data based on a predetermined confidence interval. For this analysis, a confidence interval of 95% was selected. The first significant component accounted for 38.6% of the variance and had an eigenvalue of 5.02, with a critical value of 1.75. The second significant component accounted for 15.5% of the variance and had an eigenvalue of 2.00, with a critical value of 1.54. The third significant component accounted for 10.9% of the variance and had an eigenvalue of 1.42, with a critical value of 1.41. The three components combined for 64.96% of variance.

Table 10 above shows the rotated factors of the PCA. Variables pertaining to SRG appeared to cluster on component one, variables pertaining to internal coping strategies appeared to cluster on component two, and variables pertaining external coping strategies appeared to cluster on component three. Instrumental support loaded on both internal coping and external coping. Although Positive reframing coping did not necessarily have a large factor loading on internal coping (.419), this strategy appeared to load best on the internal coping factor and not

SRG (.278) or external support (.253). Contrary to what Bjorck and Byron (2014) theorized, perceived SRG is distinct from internal coping strategies, more specifically Positive reframing coping. The factor scores obtained from the PCA were solely used to determine if perceived SRG and Positive reframing were conceptually different. Further analyses will no longer use the factor scores. Positive reframing coping was used as a predictor variable for Research Question 1.

### **Relationship between Stress and Stress-Related Growth**

**Preliminary Analysis 2:** How does stress relate to the general factor of perceived SRG (Joseph, 2011)?

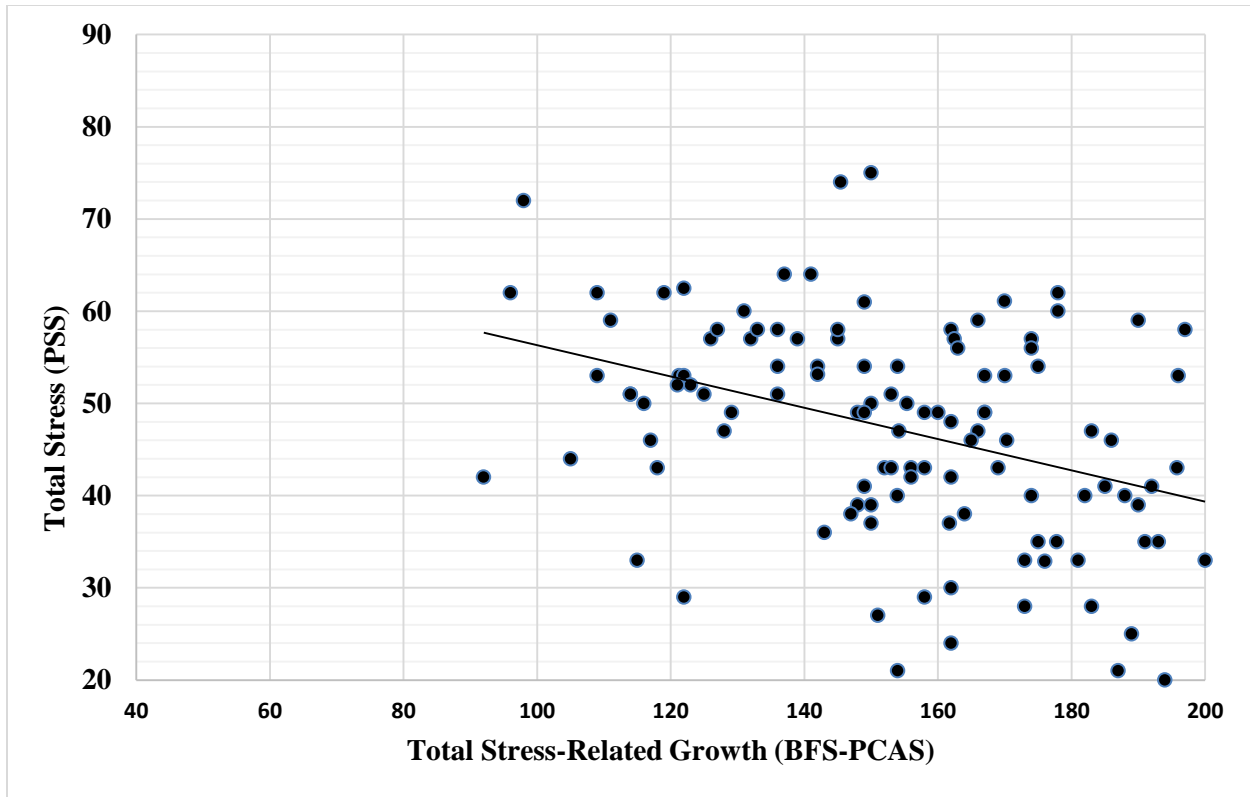
This analysis assessed the relationship between stress and the general factor score of perceived SRG. Joseph (2011) theorized a quadratic (curvilinear) relationship between stress and SRG. In order to analyze this relationship a curvilinear regression analysis was conducted with stress being the predictor and SRG being the criterion variable. Before the curvilinear regression analysis was conducted the assumptions of regression were tested. The analysis had a total of three outliers on the X, two outliers on the Y, and zero influential observation outliers. To ensure these outliers did not significantly influence the regression model, regression analyses were conducted with all the cases included and the five cases missing. The regression analyses yielded negligible differences between the adjusted  $R^2$ , b-weights, and beta weights, therefore all cases were included in the group. Following the examination of outliers, the assumptions of heteroscedasticity and normality were not violated based on the investigation of the predicted Y versus residual scatterplots. Last, the Durbin-Watson value (DW value = 1.85; less than one and greater than three may indicate problematic correlation) indicated that observations were independent. Multicollinearity/singularity did not apply for this analysis.



Despite all the assumptions being met for this particular analysis, the descriptive statistics indicated that stress scores measured by the PSS, and growth measured by the BFS-PCAS had a restricted range. The range of the PSS for the Independent Group was 20-75 with a possible range of 18-90 (range of the PSS for the Couples Group was 31-67 for mothers and 21-58 for fathers). A statistical method commonly used by researchers to investigate the presence of a restricted range is to use percentile ranks (Field, 2009). Previous research has used the descriptive statistics (mean and standard deviation) of the original PSS to assess the cut-off scores for low stress, moderate stress, and high stress. Despite the original PSS having descriptive statistics for both parents raising children with developmental disabilities and neurotypical children, the present study used the descriptive statistics from a sample of parents raising children with ASD (Firth & Dryer, 2013). This was due to previous research that indicated parents of children with ASD experience more stress than parents of children with other developmental disabilities. Therefore, the descriptive statistics from Firth and Dryer ( $M = 52.11$ ,  $SD = 11.09$ ) are more likely a better representation of the descriptive statistics of the present study.

The most common way to use percentile ranks is breaking the data into quarters, or quartiles (25<sup>th</sup> percentile, 50<sup>th</sup> percentile, and 75<sup>th</sup> percentile). Victory (2014) used quartile percentile ranks to categorize the amount of stress parents experience as a result of raising children with ASD. Parents who reported stress scores lower than the 25<sup>th</sup> percentile were considered low, between the 25<sup>th</sup> percentile and 75<sup>th</sup> percentile were considered moderate, and participants above the 75<sup>th</sup> percentile were considered high. For the present study these percentile ranks, using the descriptive statistics from Firth and Dryer ( $M = 52.11$   $SD = 11.09$ ), were broken down by scores of under 45 as low, between 46 and 59 as moderate and greater than 60 as high.

Forty participants (34.8%) had a score of less than the 25<sup>th</sup> percentile (low stress), 64 participants (55.6%) had a score between the 25<sup>th</sup> and 75<sup>th</sup> percentile (moderate stress), and 14 participants (12.2%) had a score of greater than the 75<sup>th</sup> percentile (high stress). As a consequence of the restricted range of values, the result of the curvilinear regression should be interpreted with caution. Due to the range of scores in the present study, a curvilinear regression was difficult to portray because the mothers and fathers who participated in the study were more likely to report low to medium levels of stress and moderate to high levels of growth. For a visual depiction of the restricted range for stress and SRG see Figure 4.



**Figure 4.** Scatterplot of the Relationship between Stress and Stress-Related Growth.

*\*Note.* The possible range of scores was included on both axes to visually depict the restricted range of scores on the Parental Stress Scale (PSS) and the Benefit Finding Scale for Parents of Children with Aspergers Syndrome (BFS-PCAS).

The responses for the 115 participants in the Independent Group were analyzed using a bivariate correlation and a hierarchical regression analysis (HRA). The linear relationship between stress and perceived SRG was found to be significant,  $r = -.38, p < .001$ . To determine if a quadratic (curvilinear) relationship was present between stress and SRG, stress was entered into block one of the HRA and stress squared was entered into block two of the HRA. If the  $R^2$  change is significantly different from model two to when compared to model one, then stress had a curvilinear relationship with SRG. Although the overall model significantly predicted perceived SRG,  $R = .38, F_{(2, 112)} = 9.40, p < .001$ , results of the HRA indicated that stress did not have curvilinear relationship with perceived SRG,  $\Delta R^2 < .001, \Delta F_{(1, 112)} = .063, p = .802$ . Stress had a linear relationship with, and significantly predicted perceived SRG,  $R = .378, R^2 = .144, F_{(1, 113)} = 18.88, p < .001$ . Results of the curvilinear (quadratic) regression may be seen in Table 11. Contrary to what Joseph (2011) theorized, parents who reported lower levels stress were more likely to report higher levels of growth. Based on these findings, stress was used as a predictor variable in predicting the general factor of perceived SRG.

**Table 11***Regression Coefficients for Stress Predicting Stress-Related Growth*

<b>Predictor</b>	<b><i>B</i></b>	<b><i>SE B</i></b>	<b><i>β</i></b>	<b><i>T</i></b>	<b><i>p</i></b>
Step 1					
Constant	193.06	9.44		20.455	<.001
Stress	-0.843	.194	-.378	-4.346	<.001
Step 2					
Constant	199.58	27.63		7.224	<.001
Stress	-1.15	1.22	-.514	-.938	.35
Stress Squared	.003	.013	.137	.251	.80

### **Relationship between Internal Coping Strategies, External Social Support and Perceived SRG**

**Preliminary Analysis 3:** How do different coping strategies relate to the general factor and subscales of perceived SRG?

The goal of the bivariate correlations conducted with the Independent Group was to identify the strength of relationships between internal coping strategies and external support with perceived SRG, and to investigate the strength of the relationship between the internal and external strategies. The internal coping strategies included were Active, Planning, Positive reframing, and Acceptance coping, while the external supports included were Emotional support, Instrumental support, and the general factor score for social support (includes Significant Other, Family, and Friends). Despite Self-blame being negatively correlated with SRG, the strength of the relationship was not significant,  $r = -.171$ ,  $p = .067$ . As a result, Self-blame was not included in the table. For more information on the correlations between the internal coping strategies and external supports please see Table 12.

**Table 12**

*Correlations between Internal Coping Strategies, External Social Support and Stress-Related Growth*

	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>
1. SRG	-							
2. Soc Sup	.36**	-						
3. Accept	.25**	.14	-					
4. Planning	.24*	.03	.40**	-				
5. Pos Ref	.46**	.21*	.44**	.32**	-			
6. Ins Sup	.23*	.29**	.38**	.42**	.36**	-		
7. Emo Sup	.21*	.47**	.17	.19*	.30**	<b>.62**</b>	-	
8. Active	.32**	.11	.21*	<b>.71**</b>	.36**	.38**	.19*	-

\**Note.* SRG = stress-related growth; Soc Sup = Social support; Accept = Acceptance coping; Pos Ref = Positive reframing; Ins Sup = Instrumental support; Emo Sup = Emotional support; Active = Active coping.

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

To reduce the possibility of multicollinearity between internal coping strategies and external support in predicting perceived SRG (Research Question 1), some variables were excluded. For example, the correlations between Active coping and Planning, and Emotional support and Instrumental support may result in multicollinearity when predicting SRG. As a result, the variables Planning and Instrumental support were excluded as predictors in the hierarchical MRA (Research Question 1). Active coping was chosen over Planning because of a stronger correlation with SRG. In addition, Planning may be seen as a sub-factor of Active coping (Woodman & Hauser-Cram, 2012). Planning was excluded from the analysis and not combined with Active coping because of the instructions for the Brief-Cope (Carver, 1997), and also the importance of planning for parents within the first year of receiving their children's diagnosis of ASD (DePape & Lindsay, 2014). Conceptually, Planning was not included based on the possibility of different Planning scores between mothers and fathers raising children recently diagnosed with ASD as compared to parents who have been raising children with ASD for a longer period of time.

Emotional support was chosen over Instrumental support based on the amount and degree of significant correlations with other predictor variables. In addition to this, the questions that assessed Instrumental support were narrower in scope for this coping strategy when compared to the questions that assessed Emotional support. As a result of the three aforementioned analyses, there were six predictor variables included in the hierarchical MRA for Research Question 1: Active coping, Emotional support, Positive reframing, Acceptance, social support (general factor) and stress.



### **Analyses of Assumptions and Identification of Possible Confounding Variables in Predicting SRG (Independent Group)**

**Research Question 1:** To what extent does social support, different coping strategies, and stress predict perceived SRG?

The present study hypothesized (*1a*) that positive reframing coping and (*1b*) social support would predict perceived SRG in the Independent Group. Based on three preliminary analyses, four other variables, in addition to Positive reframing and social support, were selected to predict perceived SRG: Active coping, Emotional support, Acceptance, and stress. After the predictor variables were selected, the Independent Group was examined to ensure the six statistical assumptions associated with regression were not violated. These six assumptions included (a) identification of outliers, (b) multicollinearity/singularity, (c) heteroscedasticity/homoscedasticity, (d) assumption of independent errors, (e) normality of residuals, and (f) linearity. Examination of standardized residuals, leverage values, mahalanobis and Cook's distance revealed six outliers on the *X* axis and two outliers on the *Y* axis. Despite these eight outliers exceeding the residual cut-off, only one had a Cook's distance (influential observation) that may be of concern. To ensure these outliers did not significantly influence the regression model, regression analyses were conducted with all the cases included, eight cases missing, and only one case missing (the possibly influential observation). There were differences between the three models as adjusted  $R^2$ , b-weights and beta weights changed, with some b-weights becoming significant. That being said, the differences were negligible between the model with eight cases missing and the model with only one case missing. To maximize statistical power, the regression analyses were conducted with the single influential observation case excluded. There were no issues with multicollinearity or singularity based on tolerance

values ranging from .64 to .84 (less than .2 is problematic) and variance inflation factor (VIF) values being between one and two (greater than 10 is problematic). Investigation of the predicted *Y* versus residual scatterplots indicated the assumption of heteroscedasticity was not violated, and variance of residual terms remained fairly constant. The independence of observations assumption was met according to the Durbin-Watson value (DW value = 1.81; less than one and greater than three may indicate a problematic correlation). The assumption of normality was assessed by observing probability plots (P-P plots) and examining the skewness and kurtosis of each variable. Kurtosis scores between -2 to 2 and skewness scores between -3 to 3 indicate a normal distribution. Normality tests, such as the Kolmogorov-Smirnov, were not utilized to test normality because of the large sample size (Field, 2009). The skewness and kurtosis of all variables were within normal limits and the P-P plots appeared relatively normal for SRG, social support and stress. Due to the potential violation of normality for Active coping, Positive reframing, Acceptance, and Emotional support, a bootstrapping method of resampling was used (number of samples = 600). Last, the predictor variables all had a linear relationship with SRG.

Previous research on SRG has found a variety of variables, in addition to coping strategies, social support and stress, that significantly correlated with and predicted growth (i.e. gender, age, and time since diagnosis) (Vishnevsky et al., 2010; Pakenham et al., 2004). This study was unable to account for all of the potential confounding variables that have been linked to SRG, but some of the extraneous variables that were previously found to correlate significantly with SRG were analyzed in the Independent Group. Correlations were conducted between seven possible confounding variables and SRG: gender, age, marital status, income, level of education, time since diagnosis, and social desirability (see Table 13). Only social desirability was significantly correlated with SRG and was therefore controlled in the

hierarchical MRA, although income and level of education approached significance. It should be noted that social desirability was treated as a continuous variable even though it was a categorical variable (i.e. participants responded either “T” or “F” for each question). The participants’ social desirability score was the total score reported, which ranged from 0-13, rather than each individual item. This was important in the bivariate correlation and regression analysis because all variables must be continuous. The variables gender, age, marital status, income, and level of education were also categorical variables. In the bivariate correlation these variables were dummy coded to allow for correlations of different categories.

**Table 13***Correlations between Stress-Related Growth and Possible Confounding Variables*

	1	2	3	4	5	6	7	8
1. SRG	-							
2. Gender	.09	-						
3. Age	-.054	-.061	-					
4. Marital status	.03	.027	.12	-				
5. Income	-.168	-.07	.129	-.211*	-			
6. Level of education	-.157	.013	.242**	-.087	.408**	-		
7. Time since diagnosis	.05	.113	.157	.159	.075	-.022	-	
8. Social desirability	.231*	.182	.108	.218*	.034	.004	.05	-

\*Note. \* $p < .05$ . \*\* $p < .01$ .

**Hierarchical MRA Analysis (Research Question 1)**

The hierarchical MRA using bootstrapped estimates was conducted to explore the predictive ability of Active coping, Emotional support, Positive reframing, Acceptance, social support, and stress on SRG, with social desirability being controlled. The general factor score for perceived SRG was the only outcome variable because of the very high internal consistency found for this measure. For the correlations between Positive reframing, Active coping, Acceptance, Emotional support, stress, social support, and social desirability with perceived SRG please see Table 14. The G\*power analysis of six tested predictors and seven total predictors with a medium effect size of .25 resulted in a minimum sample size of 91. Therefore, the current sample size of 114 (one participant was excluded for this analysis) has adequate power for this analysis.

**Table 14**

*Correlation between Coping Strategies, Social Support, Stress Social Desirability and Stress-Related Growth*

	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>
1. SRG	-							
2. Active coping	.319**	-						
3. Emotional support	.251**	.196*	-					
4. Positive reframing	.447**	.358**	.323**	-				
5. Acceptance	.241**	.209*	.186*	.438	-			
6. Stress	-.399**	-.052	-.006	-.276**	-.106	-		
7. Social support	.401**	.118	.456**	.225*	.149	-.384**	-	
8. Social desirability	.231*	.166	.007	.178	.076	-.398**	.122	-

\*Note. \* $p < .05$ . \*\* $p < .01$ .

The present study hypothesized that perceived social support (2a) and positive reframing (2b) would predict perceived SRG. In the MRA analysis, social desirability, the variable being controlled for, was entered into block one. The variables entered into block two were all the predictor variables (Active coping, Emotional support, Positive reframing, Acceptance, stress, and social support). Predictor variables were entered in random order into block two. The overall model significantly predicted perceived SRG,  $R = .603$ ,  $R^2 = .364$ ,  $F_{(7, 106)} = 8.662$ ,  $p < .001$ . There was a significant difference between model two when compared to model one,  $\Delta R^2 = .311$ ,  $\Delta F_{(6, 106)} = 8.6$ ,  $p < .001$ . Four variables were significant in predicting perceived SRG once social desirability was controlled for. As hypothesized, Positive reframing ( $p = .023$ ), and social support ( $p = .022$ ) significantly predicted SRG, but also Active coping ( $p = .043$ ) and stress ( $p = .042$ ) significantly predicted the general factor of SRG. For more information on the b-weights, beta weights, significance values, and confidence intervals for the hierarchical MRA please see Table 15.

**Table 15**

*Regression Coefficients for Coping Strategies, Social Support, and Stress Predicting Stress-Related Growth*

<b>Predictor</b>	<b>B</b>	<b>SE B</b>	<b><math>\beta</math></b>	<b>p</b>	<b>95% Confidence Interval</b>	
					<b>LL</b>	<b>UL</b>
Step 1						
Constant	140.18	5.86		.002	129.38	151.82
Social desirability	1.97	.79	.23	.023	.23	3.45
Step 2						
Constant	104.33	20.04		.002	61.23	154.91
Social desirability	.362	.732	.04	.654	-1.20	1.95
Active coping	3.29	1.59	.174	.043	-.039	6.462
Emotional support	.483	1.414	.032	.73	-2.00	3.07
Positive reframing	3.71	1.48	.24	.023	.434	6.90
Acceptance	.67	1.76	.03	.69	-2.294	4.107
Stress	-.48	.21	-.22	.042	-.908	-.031
Social support	.32	.14	.22	.022	.07	.61



### **Preliminary Analyses of the Couples Group**

The secondary goal of the present study was to investigate differences between mothers and fathers in the use of internal coping strategies, external support received, stress, and perceived SRG in the Couples Group. The dataset was examined for accuracy and completeness. For the Couples Group, less than 20 items were missed across all measures from the 27 couples, and Little's MCAR test of missing data indicated that the responses missing were completely random  $\chi^2(1090) = 0, p = 1.00$ . The Estimation Maximization method was again used to estimate the 20 missing cases.

Investigation of outliers indicated eight participants' responses (5 mothers and 3 fathers) exceeded 2.5 standard deviations from the mean across the 17 variables. The outliers were associated with scores that were again generally lower on a variable that had a high average. For example, the mean scores of Acceptance for mothers ( $M = 7.30$ ) and fathers ( $M = 7.40$ ) were high, and mothers and fathers who reported Acceptance scores of less than 5 were considered outliers. Despite these outliers potentially increasing the likelihood of a Type I error (rejecting the null hypothesis when the null should not be rejected), the exclusion of these outliers would decrease the power for the corresponding variables. It would also increase the likelihood of committing a Type II error (failing to reject the null hypothesis when it should be rejected). In addition to this, the outliers were analyzed for consistent and meaningful responses and the outliers did not appear to be answered randomly. Therefore, no responses were excluded from the Couples Group. For more information on the descriptive statistics of variables in the Couples Group please see Table 16.

**Table 16**

*Descriptive Statistics of Coping Strategies, Social Support, Stress, and Stress-Related Growth for the Couples Group*

Variables	Mothers			Fathers		
	<i>M</i>	<i>SD</i>	Range	<i>M</i>	<i>SD</i>	Range
Active coping	7.11	1.15	4-8	6.19	1.30	3-8
Emotional support	5.77	1.87	2-8	5.03	1.85	2-8
Instrumental support	5.78	1.60	2-8	4.89	1.93	2-8
Positive reframing	6.72	1.37	2-8	6.11	1.05	4-8
Planning	6.75	1.10	5-8	6.07	1.27	4-8
Acceptance	7.30	1.10	4-8	7.40	.97	4-8
Self-blame	4.63	1.71	2-8	3.52	1.65	2-8
<b>Social Support</b>	<b>59.49</b>	<b>18.83</b>	<b>19-83</b>	<b>61.56</b>	<b>12.82</b>	<b>33-84</b>
Significant Other	22.19	7.15	5-28	25.19	3.16	18-28
Family	19.04	7.64	4-28	20.74	6.72	4-28
Friends	18.27	6.99	4-28	15.63	7.11	4-28
<b>SRG</b>	<b>165.15</b>	<b>19.77</b>	<b>125.42-195.34</b>	<b>149.75</b>	<b>19.63</b>	<b>113-193</b>
Positive Effects	20.74	2.77	16-25	19.78	2.82	15-25
Spiritual Growth	11.63	5.73	4-20	7.33	4.67	4-19
New Possibilities	39.48	6.67	25-50	34.67	7.24	23-49
Appreciation	34.84	4.51	22-40	33.59	4.56	24-40
Greater Awareness	14.30	.91	12-15	13.81	1.04	11-15
Personal Growth	43.79	5.53	31-50	40.56	5.58	30-50
<b>Stress</b>	<b>48.07</b>	<b>9.88</b>	<b>31-67</b>	<b>43.76</b>	<b>9.89</b>	<b>21-58</b>

\*Note. *n* = 27 for both mothers and fathers; bolded terms are general factor scores

### **Preliminary Analyses for Differences in Coping, Social Support, Stress and SRG between Mothers and Fathers (Couples Group)**

After the investigation of outliers, the Couples Group was examined to ensure the assumptions of normality and homogeneity of correlated variance were not violated. The assumption of normality was examined by investigating the skewness, kurtosis, as well as significance tests (Shapiro-Wilks normality test) for each variable. The technique used to evaluate the homogeneity of correlated variance for each variable was the significance test known as the Pitman-Morgan test. The techniques used to test the normality and homogeneity of correlated variance assumptions may be seen in Table 17. A total of five variables (Active coping, Positive reframing, Acceptance, Familial support, and Greater Awareness) violated the assumption of normality. Despite non-normal distributions possibly increasing the likelihood of a Type I error, paired t-tests are generally robust to violations of normality (Field, 2009). Paired t-tests are less robust for violations of homogeneity of correlated variance. Despite SPSS having techniques to correct for violations of homogeneity of variance (independent observations), SPSS has no techniques to correct for violations of homogeneity of correlated variance. As a consequence of these assumptions being violated, the results of the paired t-tests should be interpreted with caution. In addition to this, these results warrant replication as the likelihood of committing a Type I error is high given the amount of paired t-tests that were conducted (experiment-wise error rate).

**Table 17***Tested Assumptions of Normality and Homogeneity of Correlated Variance for the Couples**Group*

Variables	Skewness	Normality			Correlated Variance	
		Kurtosis	Shapiro-Wilk's	<i>p</i>	Pitman-Morgan	<i>p</i>
Active coping	-1.13	<b>3.72</b>	.839	<b>.001</b>	.64	.53
Emotional support	.42	.41	.946	.170	.05	.95
Instrumental support	-.04	.05	.961	.391	.49	.63
Positive reframing	-1.55	<b>3.8</b>	.861	<b>.002</b>	1.36	.19
Planning	.408	-.310	.949	.208	.74	.47
Acceptance	-.333	1.31	.865	<b>.002</b>	.65	.52
Self-blame	.472	-.404	.944	.157	.18	.86
<b>Social Support</b>	-.47	-.59	.952	.228	1.01	.32
Significant Other	-.86	.12	.927	.058	2.12	<b>.04</b>
Family	.91	<b>2.64</b>	.917	<b>.033</b>	.35	.73
Friends	.14	.73	.948	.194	.04	.97
<b>SRG</b>	-.29	-.19	.977	.794	.02	.98
Positive Effects	-.13	-1.10	.939	.116	.05	.96
Spiritual Growth	.41	.52	.936	.097	.59	.56
New Possibilities	-.40	.29	.971	.623	.21	.83
Appreciation	-.43	.32	.974	.709	.02	.98
Greater Awareness	.44	-.38	.904	<b>.017</b>	.34	.74
Personal Growth	.14	-.44	.944	.149	.03	.97
<b>Stress</b>	.04	-.46	.980	.853	.998	.30

\**Note.* Values that violate the assumption are in boldface; Pitman-Morgan provides *t* value; bolded terms are general factor scores;  $n = 27$ ;  $df = 27$  (for Shapiro-Wilk's);  $df = 25$  (Pitman-Morgan).

### **Paired t-Test Analyses between Mothers and Fathers for Internal Coping Strategies, External Support, Stress, and Perceived SRG (Couples Group)**

**Research Question 2:** Do mothers and fathers of children with ASD differ in perceived social support from significant others, family, and friends? In the Couples Group, the present study hypothesized that mothers would report higher levels of perceived social support (2) when compared to fathers. This hypothesis was not supported by the results of the present study. There were no differences between mothers and fathers in perceived social support of the general factor,  $t_{(26)} = -.55, p = .59$ . In addition to this, when the three factors of social support were investigated separately (Significant Other, Family, and Friends), fathers reported higher perceived social support from their significant others when compared to mothers ( $M = -3.00, SD = 7.45$ ),  $t_{(26)} = -2.10, p = .046$ .

**Research Question 3:** Do mothers and fathers of children with ASD differ in their amount of caregiving stress? In the Couples Group, the present study hypothesized that mothers would report higher levels of perceived stress (3) when compared to fathers. This hypothesis was supported by the results as mothers reported more stress when compared to fathers ( $M = 4.31, SD = 9.88$ ),  $t_{(26)} = 2.27, p = .032$ .

**Research Question 4:** Do mothers and fathers of children with ASD differ in perceived SRG? In the Couples Group, the present study hypothesized (3) that mothers would report higher levels of perceived SRG when compared to fathers. This hypothesis was supported by the results as mothers reported higher levels of perceived SRG when compared to fathers ( $M = 15.40, SD = 20.38$ ),  $t_{(26)} = 3.93, p = .001$ .

**Research Question 5:** Do mothers and fathers of children with ASD differ in their use of coping strategies: Active coping, Instrumental support, Emotional support, Positive reframing,

Planning, Acceptance, and Self-blame? In the Couples Group, there were significant differences between mothers and fathers for four of the seven internal coping strategies and external support measured by the Brief COPE: Active coping, Planning, Self-blame, and Instrumental Support. Mothers ( $M = .93$ ,  $SD = 1.47$ ) reported higher levels of Active coping  $t_{(26)} = 3.28$ ,  $p = .003$ , and Planning ( $M = .68$ ,  $SD = 1.45$ ),  $t_{(26)} = 2.43$ ,  $p = .022$  when compared to fathers. Mothers also reported higher levels of Self-blame than did fathers ( $M = 1.11$ ,  $SD = 2.12$ ),  $t_{(26)} = 2.72$ ,  $p = .011$ . Last, fathers reported using lower levels of Instrumental coping compared to mothers ( $M = .89$ ,  $SD = 2.04$ ),  $t_{(26)} = 2.26$ ,  $p = .032$ . Although mothers reported higher levels of Emotional support than fathers, the difference was not significant ( $M = .73$ ,  $SD = 1.90$ ),  $t_{(26)} = 2.00$ ,  $p = .056$ .

**Research Question 6:** Do mothers and fathers of children with ASD differ in the sub-themes of the BFS-PCAS: New Possibilities, Personal Growth, Appreciation, Spiritual Growth, Positive Effects of the Child, and Development of a Greater Awareness? Exploratory analyses of the sub-factors of SRG indicated that mothers reported higher levels of Spiritual growth ( $p < .001$ ), New Possibilities ( $p = .007$ ), Greater Awareness ( $p = .03$ ), and Personal Growth ( $p = .006$ ) as a result of raising children with ASD when compared to fathers. The effect size of the differences between mothers and fathers that were significant ranged from .40 to .87 (low-end of medium to large). The results of all paired t-tests may be seen in Table 18.

**Table 18**

*Differences between Mothers' and Fathers' Mean Scores in Coping, Perceived Social Support, Stress, and Stress-Related Growth (Couples Group)*

Variables	$M_{diff}$	SD	95% Confidence Interval		$t$	$p$	Cohen's $d$
			LL	UL			
Active coping	.93	1.47	.35	1.51	3.28	.003**	.63
Emotional support	.73	1.90	-.02	1.49	2.00	.056	.38
Instrumental support	.89	2.04	.08	1.70	2.26	.032*	.44
Positive reframing	.61	1.69	-.05	1.28	1.90	.069	.36
Planning	.68	1.45	.10	1.25	2.43	.022*	.47
Acceptance	-.11	1.31	-.63	.41	-.44	.663	.08
Self-blame	1.11	2.12	.27	1.95	2.72	.011*	.52
<b>Social Support</b>	<b>-2.06</b>	<b>19.48</b>	<b>-9.76</b>	<b>5.64</b>	<b>-.55</b>	<b>.587</b>	<b>.11</b>
Significant Other	-3.00	7.45	-5.95	-.05	-2.10	.046*	.40
Family	-1.70	8.03	-4.88	1.47	-1.10	.280	.21
Friends	2.64	9.75	-1.22	6.50	1.41	.171	.27
<b>SRG</b>	<b>15.40</b>	<b>20.38</b>	<b>7.33</b>	<b>23.46</b>	<b>3.93</b>	<b>.001**</b>	<b>.76</b>
Positive Effects	.96	2.79	-.14	2.07	1.79	.085	.34
Spiritual Growth	4.29	4.91	2.35	6.24	4.54	<.001**	.87
New Possibilities	4.80	8.61	1.40	8.21	2.90	.007**	.56
Appreciation	1.25	6.14	-1.18	3.68	1.06	.300	.20
Greater Awareness	.48	1.09	.05	.91	2.30	.030*	.44
Personal Growth	3.22	5.60	1.01	5.44	3.00	.006**	.58
<b>Stress</b>	<b>4.31</b>	<b>9.88</b>	<b>.40</b>	<b>8.22</b>	<b>2.27</b>	<b>.032</b>	<b>.44</b>

\*Note.  $M$  scores that are positive indicated that mothers scored higher than fathers for that variable and  $M$  negative indicated that fathers scored higher than mothers. Bolded terms are general factor scores.

$n = 27$ ;  $df = 26$

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

## **Qualitative Analysis**

### **Thematic Analysis of Phone Interviews**

The 20 phone interviews were each conducted by the primary investigator and electronically recorded. They were then transcribed by the primary investigator and a trained research assistant. Each transcript was read in its entirety several times in order to ensure the accuracy of the transcriptions and also to better understand the growth experiences described by parents (Braun & Clarke, 2006). A hierarchical structure was created using each of the six interview questions as the main categories, followed by more specific categories as determined by the emerging themes from parent responses. These emerging themes were then further broken down based on parent responses into a number of sub-themes. The thematic analysis involved grouping the similar responses of parents together into their corresponding emerging themes and sub-themes. The thematic analysis results are as follows and are organized by interview questions followed by participant quotes which support the development of the thematic themes. The use of ellipsis (...) within a quote represents a pause in a parent's response. For a breakdown of the themes and sub-themes from the thematic analysis see Table 19.



**Table 19***Phone Interview Primary Themes and Sub-Themes*

<b>Interview Question</b>	<b>Primary Themes &amp; Sub Themes</b>
1) Challenging aspects of parenting a child with autism?	Barriers to support Waiting lists Financial Advocacy/Availability of resources Diagnosis and behavioural challenges Time constraints Learning curve No time for self-care Adhering to routines Change in stress over time Dealing with criticism
2) How has growth been a part of your parenting experience?	Journey to acceptance Positive life changes Improving relationships Beneficial impact on life Focusing on positives Positive characteristics of child Preparing for the future Celebrating small successes Rising above the challenges Learning things about themselves Growing in the face of challenges New empathy
3) Changes in perspective on life and perception of yourself?	Changing expectations of child Thinking about their future Appreciation for their abilities Change in perspective on life Change in perception of yourself Impact on Life Change in career/life goals Relationship with partner Process of adapting
4) Changes in parenting style?	Parenting neurotypical/child with autism Splitting attention Feelings of guilt Changing idea of parenting Siblings relationships Adapting to parent children with autism

**Table 13** (*continued*)

<b>Interview Question</b>	<b>Primary Themes &amp; Sub Themes</b>
5) Advice for parents of newly diagnosed children with ASD?	Acceptance and moving forward Learn new things about yourself Accepting diagnosis Using your resources Research Educate yourself and be involved Develop a Plan Get on waitlists Overwhelming Reaching out for support Live your life
6) Likert rating of current level of growth in parenting experience?	Please see Table 20 for breakdown of responses

### 1) What are the challenging aspects for you raising a child diagnosed with autism?

This question was designed to allow parents to expand on the parenting experiences which have caused them increased stress and have been the most challenging to deal with.

***Barriers to Receiving Adequate Support.*** Over half of the parents reported that barriers they had faced in accessing support for their child with ASD and for their family were challenges in parenting children with ASD. Many mothers reported that the financial burden of affording services, accessibility of services, and lengths of waitlists were the biggest challenges. Ten mothers and five fathers also reported that having to advocate on behalf of their children in order to gain access to programs/services or obtain a diagnosis was challenging.

Difficult getting help, getting adequate help...there is literally nothing available and waiting lists are so long...you feel disheartened...if I had a child who was severely autistic, I don't know that I would have the fortitude to deal with it. (Mother 1)

Biggest issue I have is financial...you have to beg steal and borrow to afford it...I don't get paid for not working and looking after my son...there's no funding. (Mother 2)

I first noticed my twins because they were diagnosed before my son even though they are younger...remember looking at this toddler book and they had hit three or four of the twenty milestones for a 12 month old and they were about 14 months...ended up hiring private psychologist because they told me otherwise it was a six to 12 month wait...so when I finally got the diagnosis I went to AGENCY NAME and was like we need to start early intervention therapy and they looked at me like I was crazy. They were like well we will give you your respite and we'll give you like for appointments and stuff like that, sibling care and mileage and whatever but we're not giving you any therapy. So that took me about 14 months from they were eventually finally diagnosed to like finally get that in place for them. (Mother 9)

***Diagnosis and Behavioural Challenges.*** Half of parents noted that the process of receiving and accepting the diagnosis, and 80% reported that behavioural challenges associated with ASD were challenging aspects of raising children with ASD.

I had to change because when he was first diagnosed uh I probably cried oh probably like a week then it was just like um I felt devastated and then it was like just put one foot in front of then another and make it one day at a time. (Mother 7)

Lack of predictability...what kind of day you're going to have with respect to um mood, communication challenges on the child's part and just generally behaviourally...not being able to necessarily plan for...the variables which can throw the day off completely.

(Father 5)

Behaviours yes...being afraid of all sorts of things...about three or four loud sounds having himself explode as we say...very sensitive to sounds loud loud places um too much sensory input at once. (Father 1)

Some parents indicated issues between their children with ASD and their siblings were also challenging when parenting children with ASD.

There is also stress with his relationship with his brother...we work on trying to teach him appropriate ways to behave...work with his brother to explain the condition more to him so that he understands that you know he's not hated, it's just social difference or social unawareness that's why he is treated that way by his brother. (Father 2)

***Time Constraints.*** Nearly all parents reported that the increased time constraints associated with parenting children with ASD was a challenge. Most mothers reported parenting children with ASD was time consuming and gave next to no time for self-care. Several fathers reported that parenting children with ASD represented a huge learning curve for them.

I would say since having him...that my life changed dramatically and my social life is pretty much nil. I think it has been hard to find um at least in the beginning years it was hard to find other families to connect with...quit full time work and now full time am taking care of, educating and supporting my son. (Mother 3)

Time is another issue because there's not enough time in the day to do everything and so much time has to be spent on him and getting his needs met um that you just don't have time for anything else really it comes down to. (Mother 8)

He's got almost his own language. So to get inside his head is kind of a unique challenge in itself...it seems like it's really it's a whole new language, it's a whole new world he's in and trying to get inside his head and trying to get him to understand...even the basic things it just takes a while to understand how his mind works. (Father 8)

***Change in Stress over Time.*** Almost half of parents reported that as their children with ASD got older, the parents had similar levels of challenges to deal with but that these challenges

had changed over time. Some of these challenges included a lack of programs and resources for older children and worrying about future opportunities for their children with ASD.

I think the older he gets the worse it gets because um when he was three...there's lots of programs and he's almost six and now it's like well he's not eligible for this anymore and he's not eligible for that anymore and it's like what do you want me to do? (Mother 1)

Things got a little bit easier once we got picked up for services...like Early Intervention and with...that you get your speech therapist you get your OT you get like all these services until they're a certain age but...you're on for two months your off for four months...so every off I would keep it going...my sons doing amazing so it's he is not intense now but there's a lot of work to do and as a teenager now that he's 14 parents have to switch gears...it's the future right so what's going to happen is he going to get credits is he going to graduate high school is he going to have a future how do I get there and now that's my main focus. (Mother 2)

None of the parents interviewed reported that their stress reduced as their children got older but some said they had adapted to their situation through various coping and parenting strategies which made them feel better able to handle their stressful situations.

Yah absolutely...things that stressed me out a lot before stress me out less now...it's not because there has been sort of a total improvement or change in our situation. Um partly it's just sort of becoming accustomed to sort of dealing with uncertainty and the challenges that my daughter faces...family doctor referred me to a psychologist a couple of times just to sort of talk through some of these issues...a couple of new thinking strategies have helped me out a lot...certain thought patterns that I can nip in the bud faster than I was able to nip in the bud in the past. (Father 5)

***Dealing with Criticism.*** Seven mothers and three fathers reported that the issues they had getting support from their extended family and their lack of understanding about their child and family situation were a big challenge for them in parenting children with ASD. Criticism and judgement from others regarding their child's behaviours in public, their use of non-traditional therapies or treatment options, as well as others' criticism of the parents' parenting style with their children with ASD were also reported by parents as a challenge.

Family gatherings, family reunions, the holidays, all the kinds of special time that for both my husband and I were very important to us and family um are some of the worst times for our child so that's hard because the places that you normally draw support and

tradition from and kind of have that support network from are the most stressful for your kid and you need it the most, so I see that as a challenge...I think they at first...would be frustrated and think that we weren't disciplining well and then we would feel judged and so that was a bit of a struggle...I think people um think things are willful because they see CHILDS NAME...he can do appropriate skills, he is very verbal, he is bright in many ways. So when people see that they think that when he's not doing that and is acting out that it is on purpose. (Mother 6)

**2) Parents may experience growth through personal benefits from your situation, learning something new about yourself and making positive life changes. How has personal growth been a part of your experience raising a child diagnosed with autism?** Parents were asked to reflect on their growth experiences as a result of parenting children with ASD and how this had affected them personally. Despite the number of challenges previously mentioned, all parents reported at least two positive impacts of growth on them personally as a result of parenting children with ASD.

*Journey to Acceptance.* Several fathers and one mother reported making positive life changes, experiencing personal benefits, and/or learning something new about themselves. This occurred for many as a result of dealing with their children's diagnosis and how they adapted to deal with it afterwards.

Great humility you know...when having a kid you assume for whatever reason you know that the kid you know most people in my shoes are going to dream about their kid being perfect and going to Harvard and everything...there are people in way more difficult circumstances...so for me having lived a relatively not sheltered but blessed and lucky life here I was faced with some challenges and it sort of brings you back to reality what's important and what's not. (Father 9)

I had to get over my own thoughts because when I first met him I was like I can fix this you know and I can't fix this I just have to be able to work with him and to understand him better and help him with his frustrations. (Father 10)

*Positive Life Changes.* Almost half of parents reported experiencing growth through positive changes and seeing benefits from their situation as a result of raising children with ASD.

Become more patient...met some absolutely fantastic people...whole wide variety of experiences...from the AGENCY NAME here and serving on the board and I'm a board chair of that organization...CHILDS NAME has been active the last couple of years in the Special Olympics here in CITY...I don't think I would have necessarily had that experience otherwise, I don't know if I necessarily would have sought it out in the same way that having the personal need to it now has made me kind of push my boundaries more than I probably otherwise would have. (Father 7)

It has definitely extended my patience...as a person and a professional those are valuable skills to me and it also taught me that I have to be a lifelong learner and so just because I graduated college and got my teaching degree...it doesn't stop so I have since my child got diagnosed I went and got certified to be a special-ed teacher. (Mother 7)

Several parents also discussed how they felt their experience of raising children with ASD had helped them grow and improve their relationship with their partner through increased communication, feelings of closeness, working well together, and relying on one another. This sub-theme was reported by six fathers and three mothers.

As a team my wife and I were pretty tight before but um we're much more so...as a result of this experience...for us it's been one situation where you know it certainly has led to more friction for us over the years but it has also led to a lot more just sort of well-oiled machine. We work well together and that's sort of been one of the positives of all this...if we are going to make this work...a lot of communication was necessary...that sort of led to...positive and ancillary benefits in just a general sense of closeness and connectedness. (Father 5)

***Focusing on Positives.*** Parents reported growing from their parenting experiences by attempting to look at their situation and focus more on the positive attributes of their children with ASD, preparing their families for the future, and celebrating the small successes.

We're very lucky that he's very expressive so he tells us sometimes what he sees or like the questions he asks are amazing they make you think of things in a different way um they make you challenge other people's perceptions they make you think about the way we organize society in like a really intelligent way...and I think that's a real gift. (Mother 6)

You know it took baby steps it took quite a while to get him so that he could shower on his own independently but you know what he can do it now. (Father 1)

I mean he is our world but out there in the world it kind of opens your eyes...because seeing out there what the future is going to hold and imagining how our son and our

family fits in...hopefully if it's a pipe dream then we can live it out and do the best we can as a family. (Father 8)

***Rising Above Challenges.*** Ninety percent of parents discussed experiencing growth through pushing through the challenges which, in many cases, helped them learn something new about themselves and more effectively adapt to their situations.

I don't think that previously patience was my greatest virtue...wouldn't say it is perfect but it's gotten a lot better...I think having a child with autism he's really taught me a lot about um I think loyalty and supporting one another not just your own child but just as a community and really what's more...important in life you know. (Mother 3)

I think growth has been huge, I wouldn't trade it for anything...learning about him has made me learn about myself and really realize how much I take for granted as you know this is the way the world is instead of just this is how I perceive it to be so um I get emotional. (Mother 6)

I didn't know I had such patience...as a child...I was a quitter...now I have patience galore...I didn't realize I could be like a fighter, I've always been pretty passive but I've become like a big advocate for CHILDS NAME I don't let him get pushed over by people anymore and I don't get pushed over by people anymore. If he needs something I fight for it and he gets it. (Mother 8)

***New Empathy.*** Nearly half of parents reported growth in how they had developed new empathy and understanding for people in similar situations and those dealing with mental health issues.

Prior to this I had, had little to no empathy for uh I guess directly people with disabilities...families of people with disabilities...you're out in public and you see somebody with a disability...it's kind of like you know used to think maybe this person is being disruptive...don't think about toughness of their situation...used to be a little put out by fact they're being disruptive and now it's more real to me...say to myself well frick I've been there...they don't want to be disruptive they probably just want to peacefully go about their business. (Father 3)

I think for me it is being more understanding...my patience has definitely grown a lot the other thing is that I am more empathetic towards other kids or parents out there I am less judgmental. If I see a child throwing a tantrum before you would wonder you know like how is the discipline in the family but now I have a better understanding of um kids might have special needs that make them behave the way that they do so I don't jump to conclusions or judge people. (Mother 4)



**3) How has your perspective on life and the perception of yourself changed from parenting a child diagnosed with autism and what brought about this change?** This question was concerned with how parents' views on life and on themselves had adapted as a result of parenting children with ASD. Most parents reported several changes in perspective which had occurred in their life.

*Changing Expectations of Child.* Almost half of mothers reported how their perceptions changed in regards to previous expectations they had of what it would be like to be a parent.

I am kind of still going through like the different levels of mourning or whatever because you sort of have this image of what you're going to be like as a parent, what your child is going to be like. So I think a part of me is still kind of getting over a lot of those things that aren't happening right now, like I would picture me taking my girls to dance lessons...it's kind of tough when I have friends over and I've sort of secluded myself from having play dates and stuff because when they come over and their daughter is two years old...year younger than my girls and she is singing that like *Frozen* song...I don't even know what my girls' voice really sounds like. (Mother 9)

Several parents noted that in the process of adjusting their expectations they attempted to focus on positives and the strengths and abilities of their children with ASD. Many of these parents however still expressed worries about what the future held for their children with ASD.

CHILDS NAME is articulate and smart beyond measure...doesn't always come across in a socially useful way...but the insight and candor, you know the thought processes are bewildering at point you know...CHILDS NAME has a sense of reasoning that is so simplistically smart that at times I am absolutely amazed. (Father 9)

I worry a lot about the world in general and um how a child like mine may succeed in it and I've seen how people can treat people that are a little different or somebody who might not move as fast as you want them to...I see that these kids have so much to contribute...yes some of them are going to need a lot of help probably for the rest of their life...with a kid with autism...you have to point them in the right direction and then you can see them take some steps...I'm 40 years older than he is and I worry a lot about not being here...want to make sure that I have done everything that I possibly can in the event that I'm not here much longer...especially if you don't have a support system you almost wonder who is going to be there for my child and love him and nurture him and help him succeed. (Mother 3)

***Change in Perspective on Life.*** Ninety percent of parents reported that raising children with ASD had changed their overall perspective on life in ways such as realizing what is most important and having a greater awareness of the challenges faced by those with mental health issues and people in general.

Million times more aware of um other people's parenting...challenges they might be facing...more aware of sort of disability...and mental health issues in the community generally...it's now like admiration as opposed to a sense of a little bit of fear...person is having superhuman effort in many cases to keep it together and to you know sort of function at the level that they're functioning. (Father 5)

Made me a lot more accepting and it's made me a lot more flexible. I think I always had kind of an idea of what things would look like when I had a family and it doesn't look anything like that but it's still totally perfect. (Mother 5)

See now that my glass is half full not half empty. I try to see positive things...don't take anything for granted in life just every day is a happy day now, lucky to be alive and have roof over my head and my son is healthy and is able to go to school and have a great day. (Mother 7)

***Change in Perception of Yourself.*** Seven fathers and three mothers reported seeing a change in their perceptions of themselves as a result of parenting children with ASD.

As we started to discuss after marriage...starting a family I always had a fear of like what if I had a child with...a disability...I used to be honest with myself and say I am more than sure that I don't know if I would have the strength...patience...emotional reserves to you know properly raise a child with those kinds of needs...helping my daughter and accepting and loving her for exactly who she is has helped me realize that you, you find the strength...helps you connect to things more spiritually and to see the bigger picture...if these things happen for a reason and it helps you to grow and helps make you a better person and realize you are capable of things you didn't think you could do...I feel that's definitely been true in my situation. (Father 4)

***Impact on Life.*** Several mothers and one father reported having to adjust some of their life and career goals in order to put in the time required parenting children with ASD.

It's a lot more involvement as opposed to a regular kid and um a lot of personal self-sacrifice and you have to give up a lot. Like career what what's that? No that's not going to happen because you're going to be at home to take care of him and support his needs and...if the school calls you know what you gotta go get him, you can't just leave a regular job like that. (Mother 1)

Several parents reported feeling as though the changes they experienced in their perspective on life and the perception of themselves was organic in nature and occurred naturally over a period of time rather than it being a conscious cognitive adjustment.

We have a really good parent support community here in CITY so meeting people who had a lot of things in common and having discussion with people about you know where their kids are at and what the future holds for their kids and knowing some people with older children with Asperger's that had already thought of these things and having sort of discussions with them sort of lead me to that questioning so change didn't really just happen and wasn't like I necessarily sat down to think about the future I guess like it was more of an organic experience. (Father 2)

**4) How has your parenting style changed since having your child with autism? In what ways has your idea or approach to parenting changed?** For those parents who were parenting both a neurotypical child(ren) and a child(ren) with ASD, they were asked to discuss how they felt their parenting style had been adapted for both kids. For those parents who had only their child(ren) with ASD, they were asked how they thought their idea or approach to parenting had changed since having their children.

*Parenting Neurotypical Child vs. Child with ASD.* All parents interviewed who had at least one child with ASD and at least one neurotypical child reported they had noticed an adjustment in their parenting style between their children.

We've got almost two separate uh parenting skills where certain things will work with my daughter and I just cannot approach it the same way with my son...we have to put so much more work into our son. (Father 6)

With my one son I can be a lot less consistent and structured...I can't do that with my ASD son it just doesn't work for him to have kind of loopy goopy we will see how things go and no consequences for things um so I have to be a lot more explicit in parenting and have rules to try to follow them and consistent in my own emotional regulation which is really hard...my other son can recover well from changes or kind of roll with it...with ASD...it can be a bigger setback if I don't deal with things as well. (Mother 6)

A few parents noted the difficulties they had with trying to fairly split their attention between their children with ASD and their neurotypical children and expressed some feelings of guilt with regards to this.

We try not to make it look like it's different but in a way it really is...you try to treat every child the same but at some point you can't and you have to give extra attention to the child who is slightly less fortunate...don't want to make it sound like he is the poorer, weaker child but sometimes requires us to take the extra minute with him...at times it can seem like you're not doing anything right...again you just try and make it look like it's the same but really it isn't and you have to admit that to yourself and to everyone else around you that this is the way it's going to be normal in our family from now on. (Father 8)

***Changing Idea of Parenting.*** Eight fathers and five mothers reported adjusting their original pre-child idea of parenting once they had a child diagnosed with ASD.

I was raised in a really old school type of manner so I had a lot of I guess...punitive sorts of ways of parenting before...has no affect absolutely on children with autism...became important to figure out what caused the unexpected behaviour rather than reacting to it and thinking back on what part I had played in it...try not to react in the heat of the moment because...when he is heated he is shut off...we will separate you know for five minutes...sit down and then come back and talking about it kind of thing. (Father 2)

Had no experience prior...so it changed in every possible, imaginable way you know...you've got to be more flexible, you've got to be more open minded...I was a guy who was used to understanding and controlling things and being critically invested in the results and a lot of that changed for me. (Father 9)

***Sibling Relationships.*** Almost half of parents discussed interesting dynamics they had observed within the siblings relationships between their children with ASD and their neurotypical children.

I would class them as normal brother sister you know they have their moments...the fights and issues with his social well awkward things at times...but then again you'll turn around and he will defend his sister in a school yard setting and vice versa...my daughter will do the same thing to protect her brother too. (Father 6)

At times we may wish that it was different, it's not and this is how we have to move ahead...it does require them to um to assume roles that they might not otherwise have to in another family...younger brother...has to watch out for his older brother and almost kind of babysit his brother...older sister...expectation on her in terms of helping out in

the family...we haven't tried to I guess pile it on too far because that's not really fair to them but they do know that um it's going to be a part of their lives forever that they are going to have to be used to looking after their brother. (Father 7)

*Adaptations for Parenting Children with ASD.* Almost half of fathers and two mothers provided some insights into adaptations they had made or things they had used to help them in making the necessary adjustments to their parenting style for parenting children with ASD.

Preparation time...you don't just throw something at them and say oh we are going to do this now...and expect them to be happily ready to go. You have to build down time...into a day...allow him enough time to be at home, sit and rest for a while before heading out the door. (Father 1)

**5) What advice do you have for parents whose children have just been diagnosed with autism?** Parents responded to this question by providing advice to other parents about how to deal with their children receiving a diagnosis of ASD. They gave suggestions as to things which helped, provided words of encouragement, and suggested things parents should ensure they do upon receiving the diagnosis.

*Acceptance and Moving Forward.* Nearly half of parents described ways for newly diagnosed parents to work towards acceptance of their situation and how to move forward positively.

Number one accept it...I guess most people and other parents we've talked to always have a little bit of that denial but accept it and go I guess jump in both feet um you know it's not a curse to me it's just a different learning experience you know my son sees things that uh you know I can only dream of...it's a journey and you know don't get disheartened jump into it with both feet because they are quite the tour guide. (Father 6)

*Research.* Over 70% of mothers advised newly diagnosed parents to begin researching information about ASD and the services/resources available as well as to sign-up for waitlists as soon as their children received a diagnosis.

Get on the lists just the first thing I did after we found out...got on every single waiting like just like right away because it's uh it's a tough education process to get to the point where you um where you have any idea what's going on. (Mother 1)

Research, do all the research you can because you're going to be the only advocate your child has...you need to know your stuff and get it right. (Mother 8)

**Overwhelming.** Five mothers and one father reported the experience of parenting children with ASD can be overwhelming and advised newly diagnosed parents to let themselves go through their own process of acceptance, take time to educate themselves, and never give up hope.

Let yourself feel what you feel. You're not necessarily going to grieve but you might grieve, you're not necessarily going to cry but you might cry...can't stop yourself from feeling those things and it doesn't do you any good to fight them because then you just bottle it up and eventually it's going to break...scary how many resources there are because it's kind of overwhelming at first. (Mother 5)

Find your own answers...every kid is worth it...you just find your answers, you find your inner peace and you get to the finish line somehow...you don't want to give up because there is so much a human being can do even with walls up around them...yes you're going to make mistakes and yes you're going to feel like you want to give up...you're going to find an answer somehow there is always one out there. (Father 8)

**Reaching Out For Support.** Over half of parents advised newly diagnosed parents to ensure they reached out for support from their partner, family, friends, support groups, etc.

Connecting with other parents who are in the same boat...very powerful because when you find this out it's very alienating...you feel alone...tell your own family, your extended family. (Father 4)

Seek out some support, whether it's through a service provider...an advocacy agency just to know that um you're not alone out there and that there are other people who you can lean on...going to be the same kinds of experiences that you can learn from and hopefully there may even be some pitfalls that you can avoid. (Father 7)

**Live Your Life.** Several parents wanted to pass on to parents of newly diagnosed children with ASD that the most important thing to do was to not let ASD stop them from living their life.

Don't give up hope, it's not a death sentence...it's not an easy road at all...you see some positive benefits from it...be committed and invest time in your child. (Mother 3)

Benefit from the benefits and take from your kids as much as you can. The frustrations will be there...I've heard of people you know who...are all bent up that it is a problem or it needs to be swept under the carpet or hidden. But it needs to be out there, we need to

enjoy our children and our families, we need to be um we need to be advocates for change in a way that people approach people with disabilities. (Father 10)

**6) On a scale from 1 to 10 with 1 being “I have achieved the minimum amount of growth” and 10 being “I have achieved the maximum amount of growth” where would you place yourself when thinking about parenting your child with autism?** Participants were asked to rate themselves on the Likert scale based on how much growth they had achieved to this point in their parenting experience. On average, fathers rated themselves as having achieved a level of growth of 7.4 thus far in their parenting experience, while mothers rated their level of growth as 6.5. For a breakdown of these responses see Table 20.

**Table 20**

*Amount of Growth Experienced by Parents over Time as a Result of Parenting Their Children*

*With Autism*

<b>Mothers</b>	<b>Fathers</b>
9: "Really been a lot of growth...actually credit my son with that..."	8: "Have to assume there is more growth ahead...being ok with it all is where I see the massive growth potential."
8: "There is always room for growth."	8: "With this experience consider it a bad day if haven't learned something new..."
8: "Grown a lot, learned a lot but I haven't learned everything I can."	8: "Come a long way but would never profess to have mastered it...constant learning process."
7: "Don't know it all...stuff I could be doing...I'm always open and speaking to people..."	8: "Learned an awful lot...taken advantage of opportunities presented to me...make myself better for me, my family and my community."
7: "Do as much as I can right now...as I grow and learn there's always a possibility to improve."	7: "Always room for growth...hope to keep growing, changing and getting better."
7: "Room to grow but I feel like we are a good chunk there and through difficult beginning."	7: "Some days are more of a challenge...feel you could have done more...it's a journey."
7: "Still think I have a ways to go and feel that I want to reach the top...not there yet."	6: "Done a lot so far...long way to go with autism, still lots that I can learn."
5: "Learned a lot...long way to go...one of the biggest gifts...ability to understand where other disabled people are coming from."	6: "Still have a lot of things to be learned."
5: "Learned a lot from all the services and programs...have a lot to learn yet."	5: "I'm about half-way there...making strides."
2: "I am still working all of this stuff out so hopefully will eventually get higher..."	3: "Definitely grown...way more to go...still working on things...gone a bit of a distance, still a far way to go."

\**Note.* Likert rating scale responses to question six of the phone interviews with 1 being "I have achieved the minimum amount of growth" and 10 being "I have achieved the maximum amount of growth".



**Summary of Qualitative Results**

In their phone interview responses, parents were given the opportunity to expand on their experiences in parenting children with ASD. They discussed the challenges, changes in perceptions, growth experienced, adjustments in parenting style/idea, and provided beneficial advice for parents whose children have been newly diagnosed with ASD. Although there were a variety of responses provided in the individual interviews, several themes and sub-themes emerged from the interview process. For more information on the themes and subthemes from the phone interview see Table 19 above.

### Discussion

The purpose of the present study was to identify the specific factors associated with stress-related growth (SRG) of mothers and fathers who are raising children with autism spectrum disorder (ASD). Additionally, the study sought to investigate any potential differences in these factors between mothers and fathers of children with ASD. Although SRG has been studied extensively with different populations such as cancer survivors (Connerty, & Knott, 2013; Slezackova et al., 2012), survivors of war (Gallaway et al., 2011; Tedeschi, 2011), and those dealing with bereavement (Currier et al., 2013; Currier et al., 2012), very few have investigated the growth parents experience when raising children with ASD (Zhang et al., 2015).

The theoretical framework used for the present study was the Organismic Valuing Theory (OVT) as defined by Joseph and Linley (2005). The OVT described the process of growth as an individual process based on the type of stressor and the amount of internal and external resources an individual has. It also states that individuals strive to become more fulfilled and actualized after experiencing a stressful or traumatic event.

The present study investigated the internal (Active coping, Positive reframing, Planning, Acceptance) and external (Emotional, Instrumental and social support) resources possessed by mothers and fathers raising children with ASD. Similar to previous studies (Helgeson, Reynolds, & Tomich, 2006), the present study found that these factors were in concordance with the OVT in regards to their relationship and prediction of SRG. That being said, in the present study the relationship between stress and SRG and the process of growth as a conscious, cognitive decision did not follow the theorized trajectory as outlined by OVT.

The OVT states that SRG occurs as a result of individuals experiencing moderate levels of stress as a result of a trauma and their core beliefs being shattered. Within the framework of

OVT, SRG is described as having a curvilinear relationship with stress (Joseph, 2011). The present study found a negative, linear correlation between stress and SRG. A possible explanation for this finding could be that parents experience *chronic stress* as a result of the daily challenges of raising children with ASD rather than one-time traumatic events which may result in post-traumatic stress or growth later. Despite the limitation of the present study having a restricted range for both stress and SRG scores, the theme of prolonged stress was evident in the qualitative interviews.

The stress changes...some things are much different than they used to be. You know he used to have a lot of meltdowns, a lot of emotional issues...I think the more challenging things now that he's older are things um as far as transitioning into adulthood...teaching him how he's going to get around one day on his own with transportation, etc. (Mother 3)

Both the OVT theory (Joseph & Linley, 2004) and Transformational Model (Tedeschi & Calhoun, 2004) theorize that individuals who report more growth over a period of time will also report lower levels of stress. Due to the continuous and diverse stress parents experience raising children with ASD, the relationship between growth and stress over time may be more complex. Park and Fenster (2004) described three different ways in which SRG develops for individuals. One way was that SRG occurred as more of a conscious process which people engage in through “religious participation (Tedeschi & Calhoun, 1996), personal resources and cognitive appraisals” (Cain Spannagel, 2011, p. 30). In the present study, many parents indicated they had found ways to cognitively adapt their coping strategies and thereby adjust effectively to their situations. However, the process in which they engaged in this adaptation was reported as being more of an organic process which occurred naturally over time rather than a cognitive, mental decision to change.

You don't really have a choice...it was like uh getting hit by...a train...the only thing that matters is my son I just want him to be happy...whatever happens to make that a reality that's what we're gonna do so I don't remember sitting there thinking...I have to be more

patient or I have to be more whatever I feel like it just happened naturally I think um either to accommodate...to deal with it. (Mother 1)

### **Internal and External Factors that Predict Stress-Related Growth (Independent Group)**

Based on the OVT model, the primary goal of the present study was to determine which factors significantly correlate and predict perceived SRG. A secondary goal was to address the limitations of the measurement of growth for cross-sectional studies (Bitsch et al., 2009), and investigate whether perceived SRG is similar to coping strategies or a unique factor that assess something different. Before the primary goal was investigated, the secondary goal was analyzed in order to gain a better understanding of the relationships between the internal coping strategies, external social support, stress and perceived SRG.

**Preliminary Analysis 1:** Does perceived stress-related growth (SRG) share significant common variance with Active, Positive reframing, Planning, and Acceptance coping, as well as Emotional support, Instrumental support, and support received from family and friends (Bjork & Byron, 2014)?

The present study found that Positive reframing coping and perceived SRG are different types of resilience people use in order to reduce the negative effects of stress. Tedeschi and Calhoun (1995) supported this finding in suggesting that SRG is not simply a form of coping but rather Positive reframing coping provides a crucial framework for individuals as they strive to experience growth. Positive reframing is central to the OVT model. As previously mentioned, after individuals experience a stressful situation they re-establish their worldviews by either assimilating or accommodating the information. Individuals who positively accommodate or positively reframe this information are more likely to report higher levels of growth (Joseph & Linley, 2005). Positive reframing coping or positive reappraisal is the process of reframing a

stressful situation in a positive way to manage the possible negative cognitions and emotions associated with the situation (Folkman & Moskowitz, 2004).

Preliminary Analysis 1 also investigated the similarities of other strategies in reducing stress, such as Active coping, Planning, Acceptance, Instrumental support, and Emotional support from the Brief COPE and the general factor of perceived social support from the MSPSS. Positive reframing along with Active, Planning, and Acceptance coping were similar in that the four strategies were associated with internal coping strategies. Both Emotional and Instrumental support were similar to the general factor of perceived social support in that the three strategies were associated with external support received from others. Whereas Instrumental support, was similar to both internal coping strategies and external support. A possible reason for this was the two specific questions which were asked on the Brief COPE for instrumental coping. For example, participants were asked to respond to “I’ve been getting help and advice from other people” and “I’ve been trying to get advice or help from other people about what to do”. Receiving advice and help from others falls under the category of social support; however, implementing the advice given to the parents requires them in many cases to also implement internal coping strategies such as active coping (Ito & Brotheridge, 2003).

**Research Question 1:** To what extent does social support, different coping strategies, and stress predict perceived SRG?

**Social Support.** The present study hypothesized (*Ia*) that social support received from significant others, family, and friends would predict SRG. The results supported this hypothesis as perceived social support was significantly, positively correlated with and predicted SRG. Perceived social support was the only external support factor that predicted SRG. Previous studies have found that parents of children with ASD who are satisfied with the amount of social

support available to them report lower levels of stress and higher levels of growth (Tobing & Glenwick, 2006; Samios, et al., 2009). For the present study, the general factor of perceived social support was used. This included support from significant others, family and friends. Examples of support received from friends and significant others were illustrated in the qualitative interview.

I have met a lot of really great people you know because my children have autism through you know supports um like I've started a group on Facebook for CITY special needs mom and met a lot of great ladies through there. (Mother 9)

I think my wife and I have become closer while dealing with this it's something we've you know had to work at and it's almost like a hobby. I don't know how else to explain it but you know it's something that we research and work on and communicate over so it's been a benefit to our relationship which I know is not necessarily common but it has been a good thing for us I guess that way. (Father 2)

Xue et al. (2014) conducted a study that investigated factors that promoted adaptation in family functioning of 65 parents from Singapore raising children diagnosed with ASD. The researchers found the most effective strategy in improving adaptation and family functioning was coping through family integration/optimism (e.g., doing things as a family). Zhang et al., (2015) found that perceived social support in the form of peer example was helpful in promoting growth and overcoming the stressful experiences.

**Positive Reframing Coping.** The present study hypothesized (*Ib*) that Positive reframing coping would predict SRG. The results supported this hypothesis as Positive reframing was significantly positively correlated with and predicted perceived SRG. In fact, Positive reframing was found to be the strongest predictor of SRG when compared to stress, social support, Active and Acceptance coping, and Emotional support. Previous research has frequently found Positive reframing to be the strongest predictor of SRG for children, adolescents, and adults (Meyerson, Grant, Carter, & Kilmer, 2011; Hastings, Kovshoff, Brown, et al., 2005;

Urcuyo et al., 2005). Positive reframing coping was also illustrated in the in-depth qualitative interview.

Growth has been a huge part of it...I sort of re-evaluated everything in my life and I've made changes to try and be healthier and be happier and...recently I have gone through a layoff and...I am changing my career to actually work with kids with special needs and autism. (Father 2)

As previously mentioned, Positive reframing is central to the OVT model in achieving growth as a result of experiencing a stressful event. According to OVT mothers and fathers raising children with ASD may engage in higher levels of positive reframing if they engage in positive cognitive processes but also develop autonomy, competence and relatedness. Zhang et al., (2015) conducted a qualitative study on the growth experienced and the most effective coping strategies and promoting growth. The researchers found that self-efficacy enhancement was one of the most important and helpful internal coping strategies for parents. This may be achieved by parents actively seeking out information for and assistance with their situation from professionals, other parents, and family.

**Active Coping.** The present study did not hypothesize Active coping to predict perceived SRG. That being said, Active coping was one of two internal coping strategies which significantly predicted SRG. Previous research which assessed the relationship between Active coping and SRG found that higher levels of active coping are associated with higher levels of SRG (Urcuyo et al., 2005; Bjorck & Byron, 2014). Parent's responses for the qualitative interview demonstrated the importance of active coping in raising children with ASD.

I decided that I needed to do something about it so I went to the library and I got books and educated myself. Put many hours into learning and researching about what was happening. And I got one it's...an autobiography...it's parents that are telling stories about their kid and that's where I went and I've read up on all the books that I could find of people writing about their kids, their experience just living their life with their child. So after all of that I felt like I was good to go and I knew what I was looking for. (Mother 8)

Zhang et al. (2013) conducted a study investigating the relationship between coping, rumination, and PTG in mothers of children with ASD. The researchers used positive coping and negative coping in predicting PTG. They found that positive coping predicted SRG but negative coping did not. Although not all items assessing positive coping were associated with active coping several were (e.g., trying to find different resolutions of the problem).

**Stress.** The present study found a significant, negative correlation between stress and perceived SRG and lower levels of stress predicted higher levels of SRG. This finding was contrary to what previous studies have found (Butler et al., 2005) as well as the framework of the OVT (Joseph & Linley, 2011) which theorized moderate levels of stress would predict higher levels of SRG. Due to the limited number of studies that have investigated the relationship between stress and SRG for mothers and fathers raising children diagnosed with ASD, these findings warrant replication.

A possible reason for this finding was that the present study focused on parents who were experiencing chronic stress as a result of parenting children with ASD and are required to deal with challenges on a daily basis for prolonged periods of time (Pisula, 2011). In the past, the OVT has been applied more with individuals dealing with posttraumatic stress from frightening, distressing events or traumatic experiences from a one-time event. For example, Butler et al. (2005) found a curvilinear relationship between stress and SRG from a large sample of participants following the terrorist attacks of 9/11/01. On the contrary, research that has investigated SRG with individuals who are experiencing chronic stress may not report a curvilinear relationship between stress and perceived SRG. The presence of chronic stress may result in other behavioural health issues. Gallaway et al. (2011) conducted a study on the relationship between PTG and behavioural health issues such as, post-traumatic stress,



adjustment reaction, depression, suicide ideation, and alcohol abuse. The researchers found that the soldiers who reported lower levels of growth reported higher suicide ideation.

**Emotional and Instrumental Support.** Emotional and Instrumental support was assessed via the Brief COPE. Although the present study did not have a specific hypothesis in regards to the relationship between Emotional and Instrumental support with SRG, both were found to be positively correlated with perceived SRG. That being said, Emotional support was not found to predict SRG when compared to social support, Positive reframing, stress, and Active coping. Parents in the qualitative interviews illustrated the importance of receiving instrumental and emotional support from others as a result of raising children with ASD.

My mom is fantastic and um everybody you know has tried to accommodate and understand and you know my mom reads everything and goes to the education sessions and um I think he's her favorite. And she is actually one of the only people that I can that we would leave him with and we leave him with her for a week at a time. (Mother 6)

And then the autism support here in town also um right after we started they had a bunch of parent sessions where you would go in and there was a different topic each week for about 7 weeks running and you know you learnt some good information but a big part of it was there's other parents sitting around the table and you get to talk about what you're going through related to the topic. (Father 3)

**Planning.** The present study found that Planning had a significant positive relationship with perceived SRG. Planning as a coping strategy may be seen as a sub factor of active coping. The decision to include this coping strategy in the present study, in addition to active coping, was based on previous research, for example by Kuhaneck et al. (2010), which has investigated planning as a distinct coping strategy in raising children with ASD. Kuhaneck and colleagues found planning to reduce the overall stress parents' experience, but not necessarily increase their growth. Zhang et al., (2015) found that planning and anticipating the difficulties of the day were effective coping strategies in promoting growth and reducing stress. Qualitative responses provided by parents in the present study illustrated the importance of planning to reduce

problematic behaviour. It was also reported how this practice can increase the stress experienced by parents due to the time constraints associated with planning.

Very rigid um routines that upset him if we don't follow them...if we know we are going to be late we have to prepare him...I have to really structure my time so that I help him with his routines in as much as I try to help him be flexible...also because he is on a gluten free, dairy free, egg free diet. So it affects me because it complicates things...I have to you know pre-plan things in advance and that takes a lot...of my time. (Mother 4)

**Acceptance.** Acceptance was found to be positively related to perceived SRG. Despite this relationship, Acceptance was not found to predict SRG when compared to social support, Positive reframing, stress, and Active coping. In the present study, parents reported Acceptance as the coping strategy they implemented the most in raising their children with ASD. DePape and Lindsay (2014) conducted a meta-analysis of qualitative studies of parents experiences raising children diagnosed with ASD. They found acceptance to be extremely important as parents transitioned between diagnosis, family life adjustment, navigating the system, parental empowerment, and moving forward. The importance of parents accepting their children's' ASD diagnosis and positively moving forward, was also illustrated in the qualitative responses.

We are learning to be more patient, we are learning to change our expectations and um you know you do mourn a bit the child that you thought you were going to have um and then you say you know what no my kid is awesome just the way he is so we are going to deal with whatever comes up and we're going to just help him be the best that he is because it's really not his fault that this has happened...you just gotta make the best of it. (Mother 1)

**Social Desirability (Independent Group).** The present study investigated the relationship of seven possible confounding variables that may be significantly related to SRG: gender, age, marital status, income, level of education, time since diagnosis, and social desirability. The only variable that had a significant relationship with SRG was social desirability. Mothers and fathers who reported more SRG were more likely to respond to items in a more socially desirable manner when compared to mothers and fathers who reported less SRG.

This finding is consistent with previous research that has found social desirability to be positively related to SRG (Bitsch et al. 2009; Frazier et al. 2009). There may be several different reasons why individuals may respond to items in a more socially desirable way. Reynolds (1982) indicated that individuals may report higher scores of social desirability based on denial and attributional components. These factors may further be broken down into self-deception and impression management. Paulhus (1984) found that impression management was the primary reason for higher social desirability scores. Despite these findings, recent research on elevated social desirability scores have focused more on individual differences, such as personality, gender, well-being and circumstance. Soubelet and Salhouse (2011) found that adults ranging from 18 to 93 years of age who reported higher social desirability scores also reported more positive affect and life satisfaction. Social desirability has also been found to predict subjective well-being (Brajša-Žganec, Pilar, Ivanović, & Lipovčan, 2011).

A possible explanation for the positive relationship between social desirability and SRG from an OVT perspective is associated with the availability of parents' internal coping strategies and external support. There were illustrations of positive reframing in the qualitative data. Positive reframing is associated with finding positives despite the challenges. Those parents of children diagnosed with ASD who adjusted their thought processes to make the best of a difficult situation were more likely to report SRG (Zhang et al., 2013) and had higher positive affect and well-being (Motaghedi & Haddadian, 2014). As a result, parents raising children with ASD who are more likely to report SRG may also report higher levels of socially desirable responding.

### **Differences between Mothers and Fathers in Coping Strategies, Social Support, Stress and SRG (Couples Group)**

**Research Question 2:** Do mothers and fathers of children with ASD differ in perceived social support from significant others, family, and friends?

The present study hypothesized (2) that mothers would report higher levels of social support from their significant others, families, and friends when compared to fathers. Differences between perceived social support from significant other, family, and friends were investigated together and separately. In the present study, no differences were reported between mothers and fathers for total perceived social support and social support received from friends and family. However, contrary to previous research (Johnson & Simpson, 2013) and the hypothesis (2), fathers reported more support from their significant others as compared to mothers. A possible reason for mothers reporting less support from their significant others in the present study could be the differences in parents' perceptions and expectations about family functioning in raising children with ASD (Knafl & Deatrick, 2003). Johnson, Frenn, Feetham, and Simpson (2011) found that mothers had a larger discrepancy between "what is" and "what should be" family functioning roles in parenting children with ASD when compared to fathers. Brobst et al. (2009) found that mothers also reported less support from their significant others when their children with ASD engaged in more challenging behaviours when compared to mothers raising children with developmental disabilities.

**Research Question 3:** Do mothers and fathers of children with ASD differ in their amount of caregiving stress?

The present study hypothesized (3) that mothers would report higher levels of parenting stress when compared to fathers. This hypothesis was upheld by the results as the present study

found that mothers reported more stress than fathers. This is similar to previous research that has compared stress levels between mothers and fathers raising children diagnosed with ASD (Baker-Ericzen et al., 2005; Davis, 2008). Some possible reasons could be that mothers spend more time caregiving for their children, and may be more susceptible to becoming stressed or negatively impacted from very stressful events in comparison to fathers (Gray, 2003). Another possible reason could be the differences in ideas of parenting expectations as previously mentioned (Johnson et al., 2011). Mothers may report higher levels of stress if they feel their significant other is not providing enough support to them in raising their child with ASD. This may also be associated with possible difficulties within the spousal relationship (Ramisch, 2012).

**Research Question 4:** Do mothers and fathers of children with ASD differ in perceived SRG?

The present study hypothesized (4) that mothers will report higher levels of perceived SRG when compared to fathers. This hypothesis was upheld by the results of the present study, as mothers reported more perceived SRG than fathers. Despite differences between mothers and fathers not being expected in the development of the original Stress-Related Growth Scale measure (SRGS; Park et al., 1996), previous research has found women to report higher levels of growth across different stressful events when compared to men (Vishnevsky et al., 2010; Park et al., 1996). Kayfitz et al. (2010) found mothers reported more positive experiences in raising children with ASD, although positive experiences may not necessarily result in growth. A possible reason why mothers have reported higher levels of growth could be a greater reliance on obtaining support from other people and agencies to assist with the challenges of parenting children with ASD (Altiere & von Kluge, 2009).

**Research Question 5:** Do mothers and fathers of children with ASD differ in their use of coping strategies: Active coping, Instrumental support, Emotional support, Positive reframing, Planning, Acceptance, and Self-blame?

There were no specific hypotheses in the present study for the differences in coping strategies between mothers and fathers. The specific coping strategies which were investigated include: Active coping, Emotional support, Instrumental support, Positive reframing, Planning, Acceptance, and Self-blame. Mothers reported higher scores in Active coping, Planning and Self-blame, and Instrumental support when compared to fathers. There were no differences between Emotional support, Positive reframing, and Acceptance. Previous research has found that mothers parenting children with ASD were more likely to seek professional help when compared to fathers (Little, 2003). In addition to this, mothers have also been found to be more likely to join support groups (van Kraayenoord, 2002; Mandell & Salzer, 2007) and participate in parent training (Flippin & Crais, 2011) when compared to fathers. This may be associated with mothers reporting higher scores of Active coping and Instrumental support. Although previous research has found that men are more likely to turn to instrumental and individual coping strategies when compared to women (Fayerberg, 2011), the present study found that mothers reported higher levels of Instrumental support. The questions from the present study's online questionnaire which measured Instrumental support included: "I've been getting help and advice from other people" and "I've been trying to get advice or help from other people about what to do". A possible reason for mothers reporting higher levels of Instrumental support could be that mothers are more likely to reach out to external resources where they can receive support and advice about their situation. Mothers also reported higher scores of Planning and Self-blame when compared to fathers. Previous research has found that Planning may be seen as a sub factor

of Active coping (Woodman & Hauser-Cram, 2012). Pisula (2011) discussed how parents of children with developmental disabilities including ASD, often have a component of self-blame where they feel responsible in some way for their child having a mental health disorder.

**Research Question 6:** Do mothers and fathers of children with ASD differ in the sub-themes of the BFS-PCAS: New Possibilities, Personal Growth, Appreciation, Spiritual Growth, Positive Effects of the Child, and Development of a Greater Awareness?

There were no specific hypotheses in the present study for the differences in the sub-themes of perceived SRG for mothers and fathers. To investigate perceived SRG in greater detail between mothers and fathers, the present study looked at the six sub factors of SRG in the BFS-PCAS: Positive Effects, Spiritual Growth, New Possibilities, Appreciation, Greater Awareness, and Personal Growth. Mothers reported higher scores in Spiritual Growth, New Possibilities, Greater Awareness and Personal Growth when compared to fathers. A possible reason for the differences these factors may be associated with mothers being more likely to attend support groups than fathers (Flippin & Crais, 2011). Another reason could be the reliance on internal coping strategies for the mothers raising children with ASD (Zhang et al., 2015).

### **Qualitative Interview Findings**

The qualitative data in the present study was investigated using thematic analysis (Braun & Clarke, 2006). The qualitative section provided parents an opportunity to expand on their responses provided in the online questionnaire about the challenges and growth they experienced as a result of parenting children with ASD. The in-depth phone interviews also investigated the cognitive and parenting adaptation of parents over time as a result of raising a child with ASD, and provided an opportunity for parents to share advice with parents whose children have recently been diagnosed with ASD. Questions one and two from the phone interviews, pertaining

to challenges and growth in parenting respectively, are addressed individually as these were the central focus of the present study. Questions three, four and five regarding change in perceptions/perspective, parenting style adaptations, and advice for parents of newly diagnosed children with ASD respectively, are discussed together as they were more indirectly related to stress and growth.

**Challenges.** Parents in the present study reported on a broad number of challenges which had occurred for them during their experience parenting children with ASD. One of the major themes which arose on this issue was barriers to receiving support for their child with ASD and their family. Several mothers reported feeling these challenges in the forms of a lack of access to resources, having to advocate to receive services, length of time on waitlists, and the financial costs of accessing resources. This is similar to Pisula's (2011) findings where parents raising children with ASD often experience unsatisfactory professional support.

You know it's really expensive...almost feel as though you are on your own as you have to pay so much out of your pocket but what choice do you have because if you don't pay then your child suffers as don't get the services and programs right...so I mean that's I mean the first problem is that there's just nothing to help these kids. And I mean so far he has had 13 weeks of speech therapy, 8 weeks of ABA and he was diagnosed two years ago so everything else we have to pay for ourselves and we have to find our own resources. So that's just you know so unfair because it's such a problem and I mean I understand why there is a waiting list I understand but still when it's your kid you know it's like I want it now. (Mother 1)

Another major theme was the behavioural issues and communication difficulties with their children with ASD. Although there were a number of parents who reported this, many also stated that as their children got older and received more supports, these challenging behaviours decreased and were now no longer a major challenge for them. Once the behavioural issues and communication difficulties reduced and/or the mothers and fathers implemented strategies that reduced the amount of stress experienced, different stressors and challenges arose. Some of these



stressors included less supports available for their older children with ASD and worries about their children's future.

We are just worried about how he is going to get out there in the world, what the future holds for him with jobs, life and we aren't going to be around forever and we want to prepare him for the day that he's going to be all grown up and...maybe not completely on his own but at least on his own enough that he won't have...live the life of a child when he is an adult. (Father 8)

Finally, several mothers reported time constraint issues such as the time consuming needs of the parenting role and lack of time for self-care to be major challenges for them. Mothers raising children with ASD have been found to report higher levels of burnout when compared to mothers of children with intellectual impairments (Weiss, 2002).

Saying to my caseworker here on Wednesday you know I am burning out and I think sometimes I come across like I am handling it too well and I don't show much emotion. (Mother 9)

**Growth.** Parents in the present study reported on a number of areas in their life where growth had been a part of their experience parenting children with ASD. One of the major themes which arose on this issue was parents' journey to acceptance of their children's ASD diagnosis. Several fathers and one mother reported that accepting their children's ASD diagnosis was essential to moving forward and making positive life changes in their situation.

I think one of the things we would have liked someone to have told us is don't stress about the diagnosis and don't try and fix it right away. Take some time to learn about it and investigate the services that are available to you. You grow, you learn and you work towards acceptance because you can't fix it, you just accept it. (Father 2)

Another major theme for growth was the development of new empathy and understanding for people in similar situations and to those dealing with mental health issues. This theme was similar to the BFS-PCAS measure of Personal Growth in becoming less judgmental, more open-minded, and more compassionate towards others. This theme may also be categorized within the

New Possibilities subscale in the BFS-PCAS under involvement in advocacy for people with disabilities.

Feel like I have had a lot more patience... find that I can sympathize and empathize with other families a lot more now that I kind of understand what a lot of other families are going through. I used to be that person in the grocery store thinking God take that kid home he's done...he's screaming...now I just think I wonder if there's something that I can do to help them you know it's you don't realize what other people are going through until you go through it yourself and it has really helped me kind of tame my own issues a little. (Mother 5)

The other major themes parents reported in the growth area involved making positive life changes, rising above the challenges, and focusing on positives. This theme included four components of the BFS-PCAS measure: New Possibilities, Personal Growth, Appreciation, and Positive Effects of the Child.

You know education make yourself aware um read, learn about what you're facing so that you can react to it as positively as possible and really focus on the...phrase it in a positive manner. Everyone has gifts and everyone has deficits, your deficits just belong in a certain category and you know because of these deficits you have wonderful gifts in other areas...I would encourage parents to look into and spend time trying to find their gifts and celebrate the gifts, celebrate the successes and don't focus on...your setbacks and troubles but really celebrate the little successes every time you can. (Father 2)

Bitsch et al. (2009) indicated the necessity to investigate the extent to which participants have achieved the maximum amount of growth possible in dealing with their stressful experience. The final question of the phone interview used a 10-point Likert scale from one "I have achieved the minimum amount of growth" to 10 being "I have achieved the maximum amount of growth" in order to investigate the extent to which parents experienced growth as a result of parenting children with ASD. Despite the limited sample size, fathers rated their level of growth between three to eight and mothers rated their level of growth between two to nine. Most importantly, all parents who participated in the phone interviews, stated that although they had achieved some

level of growth, parenting a child with ASD was a lifelong journey and they all had room to continue growing and learning from their experience.

**Change in Perspective, Parenting Style, and Advice.** All parents in the phone interviews indicated that parenting their children with ASD resulted in a change in their perspective on life and the perception of themselves. The goal of this question was to gain information regarding the change in cognitive constructs of mothers and fathers in raising children with ASD. More importantly, the question also looked to determine the degree to which parents' cognitions were either positive or negative in nature as a result of parenting children with ASD. This follows the OVT framework where an individual is confronted by a stressful event and is forced to re-evaluate their assumptive world and integrate the new information they have gathered on their stressful event (Joseph & Linley, 2005). A major theme parents reported was how they had to change the expectations they had of their children based on them now being diagnosed with ASD. This meant re-evaluating what was now possible in their children's future and ensuring they recognized and appreciated what their children were capable of rather than being upset about what they could do if they were neurotypical children.

I worry a lot about the world in general and um how a child like mine may succeed in it and I've seen how people can treat people that are a little different or somebody who might not move as fast as you want them to...I don't see the world through...rose colored glasses by any means...on the other hand there's a side that I see that these kids have so much to contribute and... its taught me...my perspective on life that if you give someone like my son a chance...if we just slow down a little be a little kinder you know as a human race then...a lot of good things can come out of that because he has a lot to offer.  
(Mother 3)

Other themes which arose were parents needing to adjust their perceptions of themselves and their perspectives on life. For many mothers these adjustments also caused them to re-evaluate other aspects of their lives including life and career goals. This is often seen in families who are not able to access adequate support services for their children with ASD and the parents are

thereby required to spend more time caregiving (Montes & Halterman, 2008). Of the participants who completed the in-depth phone interview, three mothers and one father reported being affected by employment decisions.

I found that for my life and the things that I wanted that I have settled...and I do not for one second resent him or the experience at all it's just um I feel that I settled for things that I wanted for myself...I had a very aspiring career and I had the two kids...so I took time off from my career for that and then I never went back um I started driving a school bus instead because that was more flexible for CHILDS NAME and it was a better routine for him...now I just started actually trying to build up my career again but I don't know how long that's going to go as it depends on how CHILDS NAME and his schooling goes. (Mother 8)

The parent reports on change in perspectives and adjustment to their situation was for the most part positive. However, a few parents expressed difficulties in seeing some of the “silver-linings” in dealing with their situation and being able to fully overcome all of the negative aspects.

The experience of raising a child with ASD is difficult and is often misunderstood... I love my daughter and appreciate what she brings to the world but if I had a choice of whether or not to have a child with ASD I would choose no ASD in a heartbeat...I have done quite a bit of grieving and therapy to help me deal with my daughter's condition. I accept it and it is true that when she achieves things I am happier to see it than I would otherwise if she was an NT [neurotypical] child but if I had a way of taking away the ASD right now or never having it to begin with, there would be no question what I would do. I often compare it to being born in war-torn Ethiopia. Say for example that that was your upbringing. Say you were born in Ethiopia; you survived war, famine and being an orphan. Yes, you are a stronger person for it but would you ever have chosen that? I wouldn't. In my personal view the positives do not outweigh the negatives. (Email from mother who completed the online questionnaire; see Appendix N for permission to use email)

For parents in the present study who were parenting multiple children, they found they had to make adjustments in their parenting style based on whether they were parenting their children with ASD or their neurotypical children. This in many cases resulted in different sibling relationship dynamics and issues with parents trying to fairly split their attention between their multiple children. Parents also reported having to change their general ideas or approaches to parenting from what they thought about parenting before having children. This also supports the

ideas presented by OVT where individuals integrate new information they have gathered from their stressful events into their previous assumptions (Joseph & Linley, 2005).

I think before we had kids I would have been a much more laissez faire easy going dad um were it not for my experience of raising a child with autism. So certainly um I'm much more likely to try to sort of anticipate...what will happen next if we you know...go to the museum...what do I have to think about. Where are the bathrooms...what kinds of things might be triggers that sort of thing...it certainly has changed my parenting approach in that...I'm a much more organized and planned by necessity and I think that spills over into the second child as well who probably doesn't need as much micromanaging and helicopter parenting as the first one does but I think in many ways I become a bit of a helicopter parent for both of the kids. (Father 5)

Parents in the present study provided advice they would like to pass on to those parents whose children have been recently diagnosed with ASD. A major theme reported by parents was the process of accepting your child's ASD diagnosis and how to move forward afterwards.

Receiving an ASD diagnosis can be shocking, devastating, and also a relief for parents who have been dealing with the uncertainties arising from their children's behaviours (Altiere & von Kluge, 2009). Parents in the present study suggested that as part of their acceptance process they were able to learn many new things about themselves. They also noted the importance of using the resources they had available to them and reaching out to receive support for their child, themselves, and their family.

I would urge someone...be hopeful...I did a lot of research myself and got myself informed. Like you need to allow yourself to grieve...but don't do it too much...obviously it is a shock when you are told your child has autism but then the next thing is what's next, what can I do for him and the one thing I told myself is that I am going to make sure my child achieves you know to his full potential. I don't want to hold him back or anything so whatever is out there I am constantly doing that. (Mother 4)

Another theme reported by parents was to warn those parents of children newly diagnosed with ASD that this experience can be very overwhelming. Several mothers reported ways to deal with this which included researching the available resources as much as possible and getting onto wait lists as soon as their child received their diagnosis. A few fathers also stated that although the

experience was difficult and could be overwhelming, it was important to not let ASD stop them and their family from living their life.

You gotta go out into the world and you have to um try and experience what you can with your kids and still try and have like a real family life...it's hard because there are going to be times that um you're going to feel judged but um in the end I really do think that it's worth it again with the experiences that you have, the people that you meet, I think that you'll find far more benefit in the end than not. (Father 7)

### **Strengths of Present Study Research Design**

There were a number of aspects with the present study which allowed for expansion on previous research and investigation into areas of study which have not been looked at by many researchers in the past. Within the last couple of years, more studies have been conducted on the SRG of parents raising children diagnosed with ASD (Strecker, Hazelwood & Shakespeare-Finch, 2014; Zhang et al., 2013). Zhang et al. (2015) conducted a qualitative study on the PTG experienced by mothers as a result of raising a child with ASD. The researchers were also interested in specific coping strategies that promote growth. The theoretical model used for this study was Tedeschi and Calhoun's (1995) model of PTG. As previously mentioned, this model may be used to measure growth achieved by individuals who have experienced a stressful event; however, parents of children with ASD may experience aspects of growth this theory does not account for (i.e. greater awareness of developmental disabilities, specifically ASD, and the difficulties these families experience) (Samios et al., 2009). This theme of greater awareness was illustrated by qualitative findings.

I'm like a million times more aware of um other people's parenting in terms of you know sort of what challenges they might be facing...much more aware of sort of disability and intellectual disability and mental health issues in the community generally...Pre-autism pre-child I would think ok I'm just going to steer clear...I mean lately...thought to myself I know what you're going through now I've got a much clearer idea of what you're all about...it's just being much more aware that that slightly odd person is having a superhuman effort in many cases to keep it together and to you know sort of function at the level that they're functioning. (Father 5)

The present study investigated growth, coping strategies, and social support experienced by fathers. This is compared to previous studies that have investigated growth with solely mothers (Zhang et al., 2015) or studies that did not develop research questions and hypotheses specifically for fathers (Phelps et al., 2009). The present study also incorporated the recommendations proposed by Bitsch et al. (2009) to improve the validity of reported growth. These recommendations included investigating the extent to which participants achieved maximum growth as a result of the stressor. This was done by including questions that measure negative well-being to confirm growth is real and not illusory, and by asking open-ended questions about growth.

An open-ended question was used in the phone interviews of the present study which examined the change of perceptions in mothers and fathers as a result of raising children with ASD. Some of the responses provided by parents were changes in their cognitive constructs and coping strategies. These excerpts were important for the OVT as information was provided about whether parents re-evaluated their assumptive world by assimilating, or positively or negatively accommodating as a result of parenting children with ASD. The open-ended question also provided information that is difficult to measure via quantitative methods. For example, the ability to quantitatively measure the change of coping strategies used by parents over time is difficult without implementing a longitudinal research design (Bjorck & Byron, 2014). When parents responded in regards to the challenges they experienced and the degree to which their perspective on life had changed as a result of parenting children with ASD, they also discussed how their coping strategies have changed over time.

### **Limitations of the Present Study**

There were several limitations to the present study. An extensive effort was made to recruit an equal number of mothers and fathers to participate in the present study. However, there were an overwhelmingly higher number of mothers who completed the online questionnaire in comparison to fathers. Efforts were also made to recruit participants internationally including from Canada, United States of America, United Kingdom and Australia, but many of the respondents who participated were from Ontario and Alberta, Canada. These two characteristics of the participants may lead to difficulties with generalization of the findings. In addition to this, there were a large majority (>90%) of parents in the present study who reported growth as a result of parenting children with ASD. The parents who volunteered to participate in the present study may have been parents who felt they had achieved growth as a result of parenting children with ASD. Whereas, parents who felt they did not experience growth may not have volunteered to participate. This may have also resulted in a restricted range of scores on the PSS, BFS-PCAS, and the Acceptance subscale of the Brief-COPE. Based on the restricted range of the sample, the results of the present study may not be an accurate representation of SRG, coping strategies, social support, and stress of mothers and fathers raising children with ASD.

There were also limitations of the measurement of SRG and coping strategies. The participants' recollection of their perceptions of growth experienced was retrospective. Previous research has found the perception of growth may be illusory and a coping strategy rather than actual growth experienced (Zoellner & Maercker, 2006). In addition, the OVT theory posits the importance of cognitive adaptation as a result of the stressor. The present study did not assess this quantitatively but qualitatively to an extent. The coping strategies investigated in the present study only had two questions pertaining to each coping strategy as part of the Brief COPE. The



limited scope of these questions did not allow for an extensive investigation of the intricate details of each individual coping strategy.

The final limitation of the study was that the measures were not counterbalanced. Since there was no counterbalancing, some of the findings of the study may be a result of order effects (Kazdin, 2003). This is evident, by the results of the Marlowe-Crowne Social Desirability Scale (MCSDS) Revised-Form C, which was placed after the BFS-PCAS on the online questionnaire, which had a higher average score (6.8) than other studies that have used this measure (Bäckström & Björklund, 2013). Andrews and Meyer (2003) conducted a meta-analysis on the norms of the MCSDS Revised-Form C and found the average to be 5.37 across seven studies. Despite previous research that has found self-reported growth to be influenced by social desirability (Bitsch et al., 2009), if the measures had been counterbalanced, the average score of social desirability may have been lower.

### **Implications for Parents and Professionals**

Findings from the present study provide important insights into the positive and negative aspects parents experience as a result of parenting children with ASD. The present study provides helpful perspectives and strategies for parents who are raising children diagnosed with ASD. The majority of research on parents raising children with ASD has focused on the negative aspects (Plant & Sanders, 2007; Pisula, 2011). Although stress and challenges were investigated, the present study also focused on the potential for positive experiences and benefit finding. The responses of parents in the interviews provided advice on effective strategies and ways of coping while still remaining hopeful about the future for their children with ASD and their families. This study also provides parents with reassurance that the experience and difficulties they are having in parenting children with ASD is similar to that of other parents. The advice provided by parents

who completed the interviews to parents of newly diagnosed children with ASD, was also similar to what previous research has found (Xue, Ooh, & Magiati, 2014; Zhang et al., 2013). Three out of the four major qualitative themes regarding advice for newly diagnosed parents were associated with either internal coping strategies or external support. Parents of children with ASD have formed a community to support one another; if formal support is not readily available for families of children with ASD, other families of children with ASD are willing to assist. All parents in the interviews also reported that as part of their parenting experience they were required to change their perspectives and adjust their parenting style. Strategies that were effective one day may not be effective another day so it is important for parents to remain flexible and use strategies that work for that particular day. Last, the majority of parents in the present study reported growth despite the challenges and felt as though they were continuing to grow in their parenting experience.

Despite the majority of parents indicating they experienced growth, the extent of growth experienced was associated with the use of adaptive coping strategies, availability of external support, and lower levels of stress. A recurring theme from the qualitative interview was the idea that stress associated with raising children with ASD changes as the children get older. The majority of parents interviewed indicated that the programs available for their young children with ASD were very helpful; however, there were very few programs available for their children when they become a teenager or young adult. In addition to this, all parents interviewed indicated they had concerns and were stressed about future challenges that may arise for their children with ASD. Roux and Goring (2015) conducted a study on the transition to adulthood for teenagers with ASD. The researchers found that 58% of young adults with ASD had paid employment between 16 to approximately 23 years of age, 36% had completed some form of

post-secondary education, and one in five young adults with ASD ended up living independently. Autism related organizations should develop more programs to foster independent living skills and job skills for individuals diagnosed with ASD. In addition to this, society and businesses should work to provide more job opportunities for this group and educate themselves on the skills young adults with ASD possess.

The findings of the present study also provide beneficial information to practitioners and service providers about the inner workings of parents raising children with ASD and their families. These insights can assist service providers in knowing what is most important for parents and what supports should be provided. With more knowledge about the impact of SRG and the development of growth, practitioners can work towards amplifying the strengths of parents associated with promoting their growth. This may allow service providers to develop more effective strategies and promote the development of growth-oriented support programs. Last, a major theme parents discussed in the qualitative interview when asked to expand on the challenges of parenting children with ASD was availability of resources. Within this theme, half of the parents talked about the need for advocating for their children to practitioners and within the schools. Practitioners and schools need to address the issues of parents as this will likely reduce stress and give parents more peace-of-mind (AL Jabery, Arabiat, AL Khamra, Betawi, & Jabbar, 2014). Motaghedi and Haddadian (2014) conducted a study on growth appraisal and stress on mental health outcomes of parents of children with ASD. The researchers found that parents who reported more growth and less stress had better overall mental health. They also found that parents who reported more growth also reported less stress.

### **Future Directions**

More research is required in the area of SRG for parents of children with disabilities, particularly ASD due to the chronic stress experienced by these caregivers (Pisula, 2011). Previous studies have also found mothers who are raising children with ASD report higher levels of burnout when compared to parents raising children with developmental disabilities (Elci, 2004; Weiss, 2002). Although the present study included a measure on caregiving stress, the questions were not specific for raising children with ASD. Future studies should include questions specific to raising children with disabilities and the degree of burnout parents are experiencing at the present time.

Within the past several years more research has been conducted on the relationship between SRG, psychological functioning, and wellbeing (Frazier et al., 2009; Gunty et al., 2011). Future studies should also include analyses of psychological functioning (e.g. depression and anxiety) in addition to coping and stress. Lastly, recent research on parents of children with ASD (Chiang & Wineman, 2014; Dardas & Ahmad, 2015) and growth (Teodorescu et al., 2012) has focused on quality of life of the participants. Future studies should further investigate the relationship between growth and quality of life for parents raising children diagnosed with ASD. Given that the present study found internal coping strategies to be different from perceived SRG, a possible research question could investigate if SRG mediates the relationship between coping strategies and quality of life.

A recurring theme from parents during the phone interview was the idea that it takes a “village” to raise a child diagnosed with ASD. This was most prevalent when parents discussed the social support they received from their family and community. The responses were mixed in regards to how helpful mothers and fathers viewed their extended family in understanding their

situation and providing them with caregiving support. As the present study investigated the SRG of biological, step, and adoptive mothers and fathers raising children with ASD, future studies should investigate the SRG of extended family members, such as grandparents, aunts, uncles, and siblings.

Despite the present study implementing techniques to improve the validity of reported SRG, a cross-sectional research design is unable to assess if participants have grown over time as a result of the stressor(s). Future studies should use a longitudinal research design to assess actual growth, cognitive changes over time, psychological functioning, and changes in the use of coping strategies.

### **Conclusion**

The present study investigated the factors associated with the stress-related growth (SRG) of parents raising children diagnosed with autism spectrum disorder (ASD). A large majority of parents raising children with ASD in the present study reported experiencing SRG. In the Couples Group, 100% of the mothers and 92% of the fathers reported they have experienced growth as a result of parenting children with ASD. In the Independent Group, 93.9% of the parents reported they have experienced growth as a result of parenting children with ASD. Similar numbers were associated with parents who believe they will continue to experience growth. The factors which were found to be associated with SRG were Positive reframing, social support, stress, Active coping, Emotional/Instrumental support, Planning and Acceptance. The present study also investigated the differences between mothers and fathers in stress, use of different coping strategies, perceived social support and perceived SRG. Fathers were found to report more social support from significant others, while mothers reported higher levels of Instrumental support, stress, Active coping, Planning, and perceived SRG. No differences were

found between mothers and fathers for Positive Reframing, social support from family and friends, Emotional support and Acceptance. Within the qualitative phone interviews, all parents identified challenges and areas of growth within their parenting experiences. However it is important to note that for some parents, dealing with the challenges of raising their children with ASD posed difficulties for them in seeing the “silver-linings” in their situation.

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## Appendix A

### Recruitment Flyer

Parents needed for research study on personal growth of parents of children with autism spectrum disorder (ASD)



Are you the parent of a child who has been diagnosed with autism? We are investigating the coping strategies used by parents and the personal growth experiences they have in raising children with ASD.

For participating you will be offered a \$5 Gourmet Coffee eGift.



#### ELIGIBILITY FOR STUDY:

- ☞ Biological, step- or adoptive mothers and fathers
- ☞ Raising children who have been clinically diagnosed with Autism

#### PARTICIPANTS WILL BE ASKED TO:

- ☞ Complete a screening questionnaire for autism for your child
- ☞ Complete an online survey
- ☞ If you choose to, participate in a phone interview

**TO PARTICIPATE IN THIS STUDY, PLEASE CONTACT THE PRIMARY RESEARCHER (Mitchell Loep) TO RECEIVE THE SURVEY LINK and PASSWORD!!**

**For more information, please contact by email or phone:**

Mitchell Loep, B.A., M.A. Candidate

[loep@uwindsor.ca](mailto:loep@uwindsor.ca)

(XXX) XXX-XXXX **OR** (XXX) XXX-XXXX



**\*\*ALL INFORMATION IS KEPT CONFIDENTIAL AND YOU MAY WITHDRAW YOUR PARTICIPATION PRIOR TO SUBMITTING THE SURVEY AND AT ANY TIME DURING THE PHONE INTERVIEW\*\***

*This research is being supervised by:* Marcia Gragg, Ph.D., University of Windsor  
Department of Psychology, 401 Sunset Drive, Windsor, Ontario, N9B 3P4

This study has been reviewed and approved by the Research Ethics Board at University of Windsor. If you have questions regarding participant rights and ethical conduct of research, contact the University of Windsor Research Office at (705)748-1011 ext. 705

## Appendix B

### Letter of Information and Consent to Participate in Research



Title of Study: **Stress-Related Growth of Parents Raising Children with Autism**

You are asked to participate in a research study conducted by Mitchell Loep, B.A., from the Psychology Department at the University of Windsor as part of the requirements for his M.A. in Child Clinical Psychology. Dr. Marcia Gragg, Ph.D., C. Psych., is supervising the study.

If you have any questions or concerns about the research, please feel to contact:  
Mitchell Loep at (XXX) XXX-XXXX/(XXX) XXX-XXXX ([loep@uwindsor.ca](mailto:loep@uwindsor.ca)) or  
Dr. Marcia Gragg at (519) 253-3000, ext. 2227 ([mgragg@uwindsor.ca](mailto:mgragg@uwindsor.ca))

#### **PURPOSE OF THE STUDY**

This study will look at the stress-related growth of mothers and fathers raising children with autism. I hope to determine some of the qualities which make parents stronger and lead to more positive experiences in parenting children with autism. I would also like to look at the differences in mothers' and fathers' parenting experiences.

#### **PROCEDURES**

If you volunteer to participate in this study, you will be asked to:

- 1) Provide responses to various questions in an online questionnaire. This will take approximately 30-40 minutes.
- 2) If you choose to, participate in a 20 minute phone interview to discuss your parenting experience in more detail. Twenty participants will be randomly selected by the primary researcher from those who have indicated their interest in completing the phone interview. Due to the limited number of participants required for the phone interview, not all indicating their interest will be contacted.

#### **POTENTIAL RISKS AND DISCOMFORTS**

There are no major risks associated with participation in this study. When thinking about stressful periods of time in your parenting experience, you may at some point experience minor emotional discomfort and possible anxiety.

#### **POTENTIAL BENEFITS TO PARTICIPANTS AND/OR TO SOCIETY**

You will not likely directly benefit from participating in this study. However, your participation could help provide helpful parenting information to other parents of children with autism. This study may also give you a chance to think about some of the positive parenting moments you

have had how it has impacted your life. It is our goal that this research will be published in a scientific journal.

### **COMPENSATION FOR PARTICIPATION**

To thank you for completing the survey you will be offered an electronic \$5 Starbucks gift card.

If you volunteer for the phone interview, you may be one of the 20 randomly chosen participants (10 mothers and 10 fathers). To thank you for completing the phone interview you will be offered another electronic \$5 Starbucks gift card.

### **CONFIDENTIALITY**

All of the information you provide will be confidential and will be not shared without your permission. Your completed questionnaires will be given a survey number to make sure your responses are anonymous. If you choose to participate in the phone interview with the researcher you will be asked to enter your contact information (phone number and email) on the online questionnaire. The researcher, Mitchell Loepp, will store the data obtained from this study in a secure location for seven years.

### **PARTICIPATION AND WITHDRAWAL**

If you volunteer to be in this study, you may withdraw at any time before submitting your online survey without any consequences. You may also not answer any of the questions and still remain a participant in the study.

Once you have started the survey if you no longer wish to participate, you may simply exit the browser. However, once you submit your survey, you will no longer be able to withdraw your information. As it is only identified by a survey number there will be no way to identify your completed questionnaire from other participants.

If you are contacted for the phone interview and no longer wish to do so, you may simply tell the researcher and your contact information will be destroyed after the completion of this study. At any point during the phone interview and once all responses have been given, you may still request to withdraw your participation until the termination of the phone interview. Once the interview is over all of your identifying information will be removed and there will be no way to identify your completed phone interview from other participants.

The investigator may also withdraw you from this research if circumstances arise which warrant doing so.

### **FEEDBACK OF THE RESULTS OF THIS STUDY TO THE PARTICIPANTS**

The results of this study will be posted on-line. You may also contact the primary investigator, Mitchell Loepp or the research supervisor, Dr. Marcia Gragg, using the contact information provided on this letter.

Web address: [www.uwindsor.ca/autism](http://www.uwindsor.ca/autism) Date results will be available: May 31, 2015

**SUBSEQUENT USE OF DATA**

The information obtained from this study may be used in future studies. Your information will remain confidential and identified only by the survey numbers associated with your questionnaires.

**RIGHTS OF RESEARCH PARTICIPANTS**

As mentioned, you may withdraw your participation at any time without consequences. If you have questions regarding your rights as a research participant, contact:

Research Ethics Coordinator  
University of Windsor,  
Windsor, Ontario  
N9B 3P4,  
(519) 253-3000, Ext. 3948  
email: [ethics@uwindsor.ca](mailto:ethics@uwindsor.ca)

**RESEARCH PARTICIPANT CONSENT**

I understand the information provided for the study **Stress-Related Growth of Parents Raising Children with Autism** as described. My questions have been answered to my satisfaction, and I agree to participate in this study. I have been given a copy of this form.

Yes I agree to participate in this study

## Appendix C

### Qualitative Analysis Phone Interview Script & Questions

(Loepp & Gragg, 2013)

Hi, may I speak with *(parent's name)* please?

Hi, *(parents' name)* this is Mitchell Loepp from the University of Windsor. On the survey you completed for my study you agreed to be contacted for a phone interview. In your email you said this was a good time to contact you. Is now still a good time for the interview?

- If **NO LONGER INTERESTED IN INTERVIEW**—That is fine. Thank you very much for completing the online questionnaire and assisting with this study. [*End phone call, and remove the participant's name from the call sheet*].
- If **NO**—Is there another time that would be better for us to call you? (*Arrange another day and time to complete the interview and verify their contact information*). Thank you for your time and we will talk to you (*repeat scheduled interview time*). [*Note on the contact sheet the new arrangement for the scheduled interview AND any necessary changes to contact information*].
- If **YES**—Thank you that would be great!

I would like to record our interview if possible. Information about this was emailed to you in the “Consent to Electronically Record the Phone Interview” form. Have you had a chance to read through this form?

- If **NO**—Ok would you like me to read the form over with you or would you prefer to read it to yourself? [*Will read through Consent to Electronically Record form or allow participant to read it themselves*].
- If **YES**—Ok do you have any questions about the electronic recording? [*Answer participant questions*].

Based on what we have discussed about the consent form for electronically recording this interview:

- Do you agree to allow your phone interview with me to be electronically recorded?
  - If **NO**—That is ok, I will NOT record our session. I will do my best to record your answers in writing.
  - If **YES**—Great thank you very much, this will help to accurately record answers. [*Ask participant if there are any questions about the “Consent to Electronically Record” form*].

I am from the Psychology Department at the University of Windsor and this study is my M.A. thesis in Clinical Psychology. It looks at the positive experiences of parents raising children with autism. We would like to know about your parenting role, growth experiences and the impact of parenting children with autism on your personal well-being. Dr. Marcia Gragg is supervising this

study and if you have any questions or concerns, please feel free to contact her at [mragg@uwindsor.ca](mailto:mragg@uwindsor.ca).

You were emailed the Letter of Information and Consent to Participate form. Did you print or save a copy of this for your records? Do you have any questions about this letter?

- If **YES**—Answer their questions and if they did not already print a copy from the on-line survey, offer another email copy to be sent to them.
  
- If **NO**—If they did not already print a copy of this letter, offer an email copy to be sent to them.

This interview will take approximately 20 minutes and I am wondering if it would be possible to take yourself to a quiet location so there are fewer distractions for you while we complete this interview.

There are no foreseeable physical or psychological risks in taking part in the research. Although there will be no direct benefit, your participation will provide valuable information about the experiences and stress-related growth of parents raising children with autism. The results of this research study will be posted on-line. The web-address is on the Letter of Information and Consent to Participate form [*which they have either printed off from the on-line survey or which you emailed to them prior to the phone interview*]. It is a goal of ours that the findings of this research study will be published in a scientific journal.

To thank you for participating, you have the option of receiving an additional \$5 Starbucks eGift card. You will be sent this gift card within a week of completing this phone interview.

Before we begin, I want to reassure you that your identifying information will remain completely confidential. A separate identification number will be used to identify your online questionnaire and the (*electronic recording OR transcript*) for your interview. Your name and the name of your child will not appear in any reports associated with this study. The interview (*electronic recording OR transcript*) will be kept secure for 7 years by the researcher Mitchell Loepp.

You may end the phone interview at any time by telling me you no longer wish to participate and you may refuse to answer any questions without consequences of any kind. After the phone interview, you will be asked if your responses can be used in this research project and at that time you may still withdraw your participation. We may wish to use your information from this study in future research studies and if so it will remain confidential.

This study has received approval through the Research Ethics Board at the University of Windsor. If you have any questions regarding your rights as a research participant, please feel free to contact the Research Ethics Coordinator at the University of Windsor whose contact information is on the Letter of Information and Consent to Participate form [*which they have either printed off from the on-line survey or which you will be emailing to them after the phone interview*].

Before starting the phone interview I would like to remind you that there are no right or wrong answers. I simply want to hear more about your experiences in parenting a child with autism. Do you have any questions before we get started with the phone interview?

- If **YES**—Answer their questions [*Start the interview going through the 6 interview questions*]
  - If **NO**—[*Start the interview going through the 6 interview questions*]
- 1) What are the challenging aspects for you raising a child diagnosed with autism? How are you personally affected by these?
  - 2) Parents may experience growth through personal benefits from your situation, learning something new about yourself and making positive life changes. How has personal growth been a part of your experience parenting a child with autism? Please provide any specific examples.
  - 3) How has your perspective on life/perception of yourself changed from parenting a child with autism? What brought about this change?
  - 4) How has your parenting style changed since having your child with autism? How has having a child with autism changed your views on parenting?
  - 5) What advice do you have for parents whose children have just been diagnosed with autism? What advice do you wish someone had given you regarding growth and coping in your situation?
  - 6) On a scale from 1 to 10, with 1 being “I have achieved the minimum amount of growth” and 10 being “I have achieved the maximum amount of growth” where would you place yourself when thinking about parenting your child with autism? Think of possible areas of growth such as personal character, appreciation of life or positive impacts. Please explain.

[*Ask if the participant has any questions once phone interview is over. Inquire whether they are willing to allow their responses to be used as part of this research study or if they would like to withdraw their participation.*]

[*Once they have provided their consent to use their responses in the research project, offer the additional \$5 electronic gift card for Starbucks.*]

[*If interested in the electronic gift card, confirm their email address once phone interview has been completed and inform them it will be emailed to them within a week of the phone interview being completed. Thank participant for their assistance with study. End call.*]



**Appendix D****Consent for Electronic Recording of Phone Interview**

Research Participants Identification Number (Survey #): \_\_\_\_\_

Title of the Project: **Stress-Related Growth of Parents Raising Children with Autism**

I give my permission to have my phone interview with the Primary Researcher electronically recorded.

I know my involvement in this phone interview is voluntary. I may withdraw at any time by asking to stop the recording. Any identifying information provided in this phone interview will not be shared with anyone. These recordings will remain confidential and filed by number only. The transcripts will be stored in a locked cabinet.

The Researcher and/or Research Assistants will listen to the electronic recordings and type out the interview. Once the recordings have been transcribed and checked for accuracy they will be deleted.

There are no anticipated risks of my involvement in this interview. I know confidentiality will be respected. The recordings will be for professional use only.

Do you     (participant survey ID#)     agree to allow your phone interview with the Primary Researcher to be electronically recorded on this date     (dd/mm/yy)    ?

## Appendix E

### Agency Permission to Recruit Participants Email



To (*Name of Individual*),

I am asking for your help to recruit parents from (*Name of Organization/Facebook Group*) to participate in my research study. Biological, step- or adoptive mothers and fathers that are raising children ages 3 years, 0 months, to 17 years, 11 months who have autism are eligible. Parents will be given a link to an on-line survey asking them about their parenting experiences. The survey will take 30-40 minutes. To thank them for completing the survey, they will be offered a \$5 electronic gift card for Starbucks.

This study is for my Master's Thesis, "*Stress-Related Growth of Parents Raising Children with Autism*". Dr. Marcia Gragg, C. Psych. is supervising my study. I have obtained approval from the Research Ethics Board at the University of Windsor for this study which I have attached to this email.

Parents will also have the option to participate in a 20-minute phone interview. These parents will be offered another \$5 Starbucks eGift card for completing the interview.

If you agree to help, I would ask you to;

- post a link to the study on your FACEBOOK GROUP and/or WEBSITE
- if possible email parents on your contact list the link and password to the study

There is a response box below for you to use in your reply if you like. Please feel free to also ask any questions. Thank you for your time and I look forward to hearing from you.

Sincerely,

Mitchell Loep, M.A. Candidate,  
Child Clinical Psychology, University of Windsor  
[loep@uwindsor.ca](mailto:loep@uwindsor.ca)

#### Response Box

- We (*AGENCY NAME*) **agree** to help Mitchell Loep recruit participants for his M.A. thesis study "*Stress Related Growth of Parents Raising Children with Autism*" on this date (*TODAYS DATE*).
- No thank you, I prefer not to recruit parents for this study.

## Appendix F

### Demographic Questionnaire

(Loepp & Gragg, 2013)

Please answer the following questions about you and your family:

**1. Your relationship to your child with Autism**

- a) Biological Mother raising child with Autism
- b) Biological Father raising child with Autism
- c) Step-Mother raising child with Autism
- d) Step-Father raising child with Autism
- e) Adoptive Mother raising child with Autism
- f) Adoptive Father raising child with Autism
- g) Other

**2. What is the age of your child with autism:** \_\_\_\_\_ (Years, Months)

**3. Your Gender:** a) Male b) Female c) Other (*Please specify*): \_\_\_\_\_

**4. Your Age:**

- a) 18-24
- b) 25-34
- c) 35-44
- d) 45-54
- e) 55-64
- f) 65 or above

**5. Please complete the following demographic information**

**Country:** \_\_\_\_\_ **Province/State:** \_\_\_\_\_ **City:** \_\_\_\_\_ **Other:** \_\_\_\_\_

**6. Your marital status:**

- a) Single
- b) Married and living with partner
- c) Living with partner
- d) Separated
- e) Divorced

**7. Your annual household income:**

- a) Under \$20,000
- b) \$20,000 - \$30,000
- c) \$30,000 - \$40,000
- d) \$40,000 - \$50,000
- e) \$50,000 - \$75,000
- f) \$75,000 - \$100,000
- g) \$100,000 - \$150,000

h) \$150,000 or more

**8. Your current employment status:**

- a) Full-Time
- b) Part-Time
- c) Unemployed
- d) Retired
- e) Leave of absence

**9. Your highest level of education:**

- a) Less than High School
- b) High School graduate (includes equivalency)
- c) Technical School
- d) Some College/Some University (no Degree/Diploma)
- e) University or College Degree
- f) Graduate Degree or Professional Degree

**10. What is the gender of your child with Autism:** a) Boy b) Girl c) Other, please specify: \_\_\_\_\_

**11. How old was your child when they were first diagnosed:** \_\_\_\_\_ (Years, Months)

**12. State the age, gender and any psychological disorders for each of the children you have raised (please include your child with Autism in this total)**

Child	Gender (Male/Female)	Age (Years)	List any psychological disorders child is diagnosed with
Child with Autism.			
Child 2.			
...			

**13. Which race or ethnicity do you and your child identify with (they may be different)?**

Race or Ethnicity	You	Your child with Autism
a) Aboriginal		
b) African American		
c) Arab		
d) Chinese		
e) Filipino		

f) Japanese		
g) Korean		
h) Latin American		
i) South Asian (Bangladeshi, East Indian, Pakistani, etc.)		
j) Southeast Asian (Cambodian, Indonesian, Vietnamese, etc.)		
k) West Asian (Afghan, Iranian, etc.)		
l) White/Caucasian		
m) Other		

**14. Parents of children with disabilities can experience increased stress in the form of extra demands and caregiving pressures resulting from the needs of their children. Growth can be experienced in variety of ways including finding benefits from your situation, learning something about yourself and making positive life changes. Do you feel you have experienced growth as a result of parenting a child diagnosed with autism?**

- YES       NO

**15. Do you feel you are likely to experience more personal growth throughout your experience of parenting a child with Autism?**

- YES       NO

**16. Would you agree to participate in a 20-minute phone interview with the researcher to provide more information on your experiences with stress-related growth? If yes, please provide your email address and phone number below. This will assist with the identification of your demographic information. This information will not be connected to your survey responses.**

- YES       NO

Email: \_\_\_\_\_

**17. Thank you for taking the time to complete this online questionnaire, you are now finished. We appreciate you sharing your experiences about parenting a child with autism. Would you like to receive an electronic \$5 Starbucks gift card as a token of our appreciation for your participation in this study? Please provide us with your preferred email address so that we may send you your gift card.**

- YES       NO

Email: \_\_\_\_\_

**Appendix G**

**Social Communication Questionnaire**

(Rutter, Bailey & Lord, 2003)

\*Due to copyright agreements and permissions the items of the SCQ will not be presented below.

**Appendix H****Brief COPE**

(Carver, 1997)

\*Brief COPE was available in the public domain.

**These items deal with ways you've been coping with the stress in your life while raising your child diagnosed with autism. There are many ways to try to deal with problems. These items ask what you've been doing to cope with this one. Obviously, different people deal with things in different ways, but I'm interested in how you've tried to deal with it. Each item says something about a particular way of coping. I want to know to what extent you've been doing what the item says (how much or how frequently). Don't answer on the basis of whether it seems to be working or not—just whether or not you're doing it. Use these response choices. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can.**

**1 = I haven't been doing this at all****2 = I've been doing this a little bit****3 = I've been doing this a medium amount****4 = I've been doing this a lot**

<b>1.</b> I've been turning to work or other activities to take my mind off things.	1	2	3	4
<b>2.</b> I've been concentrating all my efforts on doing something about the situation I'm in.	1	2	3	4
<b>3.</b> I've been saying to myself "this isn't real".	1	2	3	4
<b>4.</b> I've been using alcohol or other drugs to make myself feel better.	1	2	3	4
<b>5.</b> I've been getting emotional support from others.	1	2	3	4
<b>6.</b> I've been giving up trying to deal with it.	1	2	3	4
<b>7.</b> I've been taking action to try to make this situation better.	1	2	3	4
<b>8.</b> I've been refusing to believe that it has happened.	1	2	3	4
<b>9.</b> I've been saying things to let my unpleasant feelings escape.	1	2	3	4
<b>10.</b> I've been getting help and advice from other people.	1	2	3	4
<b>11.</b> I've been using alcohol or other drugs to help me get through it.	1	2	3	4
<b>12.</b> I've been trying to see it in a different light, to make it seem more positive.	1	2	3	4
<b>13.</b> I've been criticizing myself.	1	2	3	4
<b>14.</b> I've been trying to come up with a strategy				

about what to do.	1	2	3	4
<b>15.</b> I've been getting comfort and understanding from someone.	1	2	3	4
<b>16.</b> I've been giving up the attempt to cope.	1	2	3	4
<b>17.</b> I've been looking for something good in what is happening.	1	2	3	4
<b>18.</b> I've been making jokes about it.	1	2	3	4
<b>19.</b> I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping or shopping.	1	2	3	4
<b>20.</b> I've been accepting the reality of the fact that it happened.	1	2	3	4
<b>21.</b> I've been expressing my negative feelings.	1	2	3	4
<b>22.</b> I've been trying to find comfort in my religious or spiritual beliefs.	1	2	3	4
<b>23.</b> I've been trying to get advice or help from other people about what to do.	1	2	3	4
<b>24.</b> I've been learning to live with it.	1	2	3	4
<b>25.</b> I've been thinking about what steps to take.	1	2	3	4
<b>26.</b> I've been blaming myself for the things that happened.	1	2	3	4
<b>27.</b> I've been praying or meditating.	1	2	3	4
<b>28.</b> I've been making fun of the situation	1	2	3	4



## Appendix I

### Multidimensional Scale of Perceived Social Support

(Zimet, Dahlem, Zimet, & Farley, 1988)

\*MSPSS was available in the public domain.

**Instructions: We are interested in how you feel about the following statements. Read each statement carefully. Indicate how you feel about each statement.**

Circle the “1” if you **Very Strongly Disagree**

Circle the “2” if you **Strongly Disagree**

Circle the “3” if you **Mildly Disagree**

Circle the “4” if you **are Neutral**

Circle the “5” if you **Mildly Agree**

Circle the “6” if you **Strongly Agree**

Circle the “7” if you **Very Strongly Agree**

<b>1.</b> There is a special person who is around when I am in need.	1	2	3	4	5	6	7
<b>2.</b> There is a special person with whom I can share my joys and sorrows.	1	2	3	4	5	6	7
<b>3.</b> My family really tries to help me.	1	2	3	4	5	6	7
<b>4.</b> I get the emotional help and support I need from my family.	1	2	3	4	5	6	7
<b>5.</b> I have a special person who is a real source of comfort to me.	1	2	3	4	5	6	7
<b>6.</b> My friends really try to help me.	1	2	3	4	5	6	7
<b>7.</b> I can count on my friends when things go wrong.	1	2	3	4	5	6	7
<b>8.</b> I can talk about my problems with my family.	1	2	3	4	5	6	7
<b>9.</b> I have friends with whom I can share my joys and sorrows.	1	2	3	4	5	6	7
<b>10.</b> There is a special person in my life who cares about my feelings.	1	2	3	4	5	6	7
<b>11.</b> My family is willing to help me make decisions.	1	2	3	4	5	6	7
<b>12.</b> I can talk about my problems with my friends.	1	2	3	4	5	6	7

## Appendix J

### Benefit Finding Scale for Parents of Children with Asperger's Syndrome

(Samios, Pakenham, & Soffronoff, 2009)

\*BFS-PCAS was available in the public domain and permission obtained from authors to adapt the Likert rating system and terminology to suit parents of children with ASD.

**Sometimes people who have a child with a disability of some type find benefits from this situation. For example, some people feel they learn something about themselves or others. Have you found any benefits from having a child with ASD?**

YES       NO

**Please rate how much you have experienced each item below as a result of parenting a child with ASD.**

- 1 = I have not at all experienced this**  
**2 = I have experienced this to a small degree**  
**3 = I have experienced this to a moderate degree**  
**4 = I have experienced this to a great degree**  
**5 = I have experienced this to a very great degree**

<b>1.</b> I have become involved in helping other parents.	1	2	3	4	5
<b>2.</b> I have become involved in advocacy for people with disabilities.	1	2	3	4	5
<b>3.</b> I have become more tolerant.	1	2	3	4	5
<b>4.</b> I have learned more about myself.	1	2	3	4	5
<b>5.</b> I take nothing for granted.	1	2	3	4	5
<b>6.</b> I have become more spiritual.	1	2	3	4	5
<b>7.</b> I have experienced intellectual stimulation from spending time with my child with ASD.	1	2	3	4	5
<b>8.</b> I appreciate my child for what he/she is.	1	2	3	4	5
<b>9.</b> I see things from a different point of view.	1	2	3	4	5
<b>10.</b> I have become interested in helping children with special needs.	1	2	3	4	5
<b>11.</b> I have become more perceptive.	1	2	3	4	5
<b>12.</b> I have become more compassionate toward others.	1	2	3	4	5
<b>13.</b> I have grown as a person.	1	2	3	4	5
<b>14.</b> I have learned there is something special about everyone.	1	2	3	4	5
<b>15.</b> I have learned to be happy with what I have.	1	2	3	4	5
<b>16.</b> I have a better understanding of spiritual					

matters.	1	2	3	4	5
<b>17.</b> I have developed new interests.	1	2	3	4	5
<b>18.</b> I have learned to see the world from a different perspective.	1	2	3	4	5
<b>19.</b> I have become more patient.	1	2	3	4	5
<b>20.</b> I have become more open-minded.	1	2	3	4	5
<b>21.</b> I have learned that a happy child is all that is important.	1	2	3	4	5
<b>22.</b> I have learned that children with ASD can be extremely loving.	1	2	3	4	5
<b>23.</b> I am more aware of problems people with disabilities face.	1	2	3	4	5
<b>24.</b> I have learned to share knowledge and resources.	1	2	3	4	5
<b>25.</b> I have improved my coping skills.	1	2	3	4	5
<b>26.</b> I have devoted more time to my children.	1	2	3	4	5
<b>27.</b> I have learned that there are people worse off than me.	1	2	3	4	5
<b>28.</b> I accept people for who they are.	1	2	3	4	5
<b>29.</b> I have found new faith.	1	2	3	4	5
<b>30.</b> I have become closer to my family.	1	2	3	4	5
<b>31.</b> I have met new people.	1	2	3	4	5
<b>32.</b> I have become more independent.	1	2	3	4	5
<b>33.</b> I have become less judgemental.	1	2	3	4	5
<b>34.</b> I have discovered inner strength.	1	2	3	4	5
<b>35.</b> I have learned not to jump to conclusions about people.	1	2	3	4	5
<b>36.</b> I have learned to love family unconditionally.	1	2	3	4	5
<b>37.</b> My faith has been strengthened.	1	2	3	4	5
<b>38.</b> I have learned that there are positive aspects of ASD.	1	2	3	4	5
<b>39.</b> I have a greater understanding of children with disabilities.	1	2	3	4	5
<b>40.</b> I have changed my life goals for the better.	1	2	3	4	5

## Appendix K

### Parental Stress Scale

(Berry & Jones, 1995)

\*PSS was available in the public domain.

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

**1 = Strongly disagree**

**2 = Disagree**

**3 = Undecided**

**4 = Agree**

**5 = Strongly agree**

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

<b>15.</b> I feel overwhelmed by the responsibility of being a parent.	1	2	3	4	5
<b>16.</b> Having child(ren) has meant having too few choices and too little control over my life.	1	2	3	4	5
<b>17.</b> I am satisfied as a parent.	1	2	3	4	5
<b>18.</b> I find my child(ren) enjoyable.	1	2	3	4	5

## Appendix L

### Marlowe-Crowne Social Desirability Scale-Revised (Form C)

(Reynolds, 1982)

\*MCSDS-Revised (Form C) was available in the public domain.

**Instructions:** Listed below are a number of statements concerning personal attitudes and traits. Read each item and decide whether the statement is *true* or *false* as it pertains to you personally. It is best to answer the following items with your first judgment without spending too much time thinking over any one question. Please circle “True” if the statement is true, and circle “False” if the statement is false to you personally.

- |   |      |       |
|---|------|-------|
| 1. It is sometimes hard for me to go on with my work if I am not encouraged.  | TRUE | FALSE |
| 2. I sometimes feel resentful when I don't get my way.  | TRUE | FALSE |
| 3. On a few occasions, I have given up something because I thought too little of my ability.                        | TRUE | FALSE |
| 4. There have been times when I felt like rebelling against people in authority even though I knew they were right. | TRUE | FALSE |
| 5. No matter who I'm talking to, I'm always a good listener.  | TRUE | FALSE |
| 6. There have been occasions when I took advantage of someone.  | TRUE | FALSE |
| 7. I'm always willing to admit it when I make a mistake.  | TRUE | FALSE |
| 8. I sometimes try to get even rather than forgive and forget.  | TRUE | FALSE |
| 9. I am always courteous, even to people who are disagreeable.  | TRUE | FALSE |
| 10. I have never been irked when people expressed ideas very different from my own.                                 | TRUE | FALSE |
| 11. There have been times when I was quite jealous of the good fortune of others.                                   | TRUE | FALSE |
| 12. I am sometimes irritated by people who ask favors of me.  | TRUE | FALSE |
| 13. I have never deliberately said something that hurt someone's feelings.  | TRUE | FALSE |

## Appendix M

### Completion and Termination Pages for Online Questionnaire

#### Termination Page for Parents Who Did Not Meet Demographic Inclusion Criteria or Receive a Cut-off Score on the SCQ



Thank you for taking the time to complete this survey. We appreciate your assistance with this research study. Feel free to contact the primary researcher (Mitchell Loep; [loep@uwindsor.ca](mailto:loep@uwindsor.ca)) or research supervisor (Dr. Marcia Gragg; [mgragg@uwindsor.ca](mailto:mgragg@uwindsor.ca)) if you have any comments, questions or concerns.

#### On-Line Questionnaire Completion Page



Thank you for taking the time to complete this survey. We appreciate your assistance with this research study.

Research on stress related growth (SRG) has been well documented across specific populations including survivors of natural disasters, bereavement, and war veterans. However, very little research has been conducted on the potential of SRG for parents raising a child with autism. Stress-related growth is an ongoing process and defined as the perception of growth after encountering single or multiple stressful experiences. The objective of this study is to identify specific factors associated with increased growth and the differences or similarities between mothers and fathers raising children with autism with these factors: stress, coping, perceived social support, age, and gender.

Feel free to contact the primary researcher (Mitchell Loep; [loep@uwindsor.ca](mailto:loep@uwindsor.ca)) or research supervisor (Dr. Marcia Gragg; [mgragg@uwindsor.ca](mailto:mgragg@uwindsor.ca)) if you have any comments, questions or concerns.

## Appendix N

## Permissions for Measures and Figures and Participant Emails

Social Communication Questionnaire Permission

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October 20, 2014

Mr. Mitchell S. G. Loepp  
BA, M.A. Candidate  
University of Windsor  
Department of Psychology  
Chrysler Hall South, Room 173  
401 Sunset Avenue  
Windsor, Ontario  
N9B 3P4

Re: Social Communication Questionnaire (SCQ) - Lifetime Form

Dear Mr. Loepp:

This acknowledges WPS's receipt of your payment of the license fees for the authorized, customized use of SCQ material. Under separate cover by mail, you will soon receive a paid-in-full receipt that will formally serve as your license to administer and score SCQ "Lifetime" material via a secure, password-protected online environment, as part of your registered scholarly study, examining the stress-related growth of mothers and fathers raising children with autism.


Our authorization is subject to the provisions of my letter to October 10<sup>th</sup>, and extends to you sole administration of up to three hundred (300) SCQ uses in the described study, with no authorization for continued or commercial use, for any purpose, without the prior, written approval of WPS.

In keeping with the terms of my letter of October 10<sup>th</sup>, the following is the reprint notice that must appear on each viewing/reprint of the SCQ:

**SCQ © 2003 by Western Psychological Services. Format adapted by M. Loepp, University of Windsor, for use in specific investigation, by permission of the publisher, WPS, 625 Alaska Avenue, Torrance, California 90503, U.S.A. All rights reserved. No additional reproduction may be made, whether in whole or in part, without the prior, written authorization of WPS ([rights@wpspublish.com](mailto:rights@wpspublish.com)).**

Thank you for your research interest in the SCQ, and for your consideration of copyright. We look forward in due course to learning of the results of the study. Please let me know if you need anything else of WPS.

Sincerely yours,



Sandra I. Ceja  
Rights & Permissions Assistant  
WPS Rights & Permissions  
e-mail: [sceja@wpspublish.com](mailto:sceja@wpspublish.com)

SC:sc



**Benefit Finding Scale for Parents of Children with Asperger's Syndrome Permission**  
Public Domain

Mitchell Loepp <[loepp@uwindsor.ca](mailto:loepp@uwindsor.ca)> July 13/13

Dr. Samios,

Hello my name is Mitchell Loepp and I am a Master's student at the University of Windsor in Ontario, Canada. I am currently completing my Master's thesis on the stress-related growth of mothers and fathers raising a child diagnosed with autism and I am interested in using the BFS-PCAS. I was wondering if this measure is available for public use? I originally emailed your colleague Dr. Pakenham and he indicated he would send my email on to you.

Thank you for your time and consideration and I look forward to hearing from you.

Kind regards,  
Mitchell Loepp

Christina Samios <[csamios@bond.edu.au](mailto:csamios@bond.edu.au)> August 1/13

Dear Mitchell,

I am sorry for the delays in responding. I am at the airport now and will be back at work Monday morning. I will send a more detailed email then, but for now I will say that I certainly do think the items could be adapted for use with parents who have a child with Autism. Testing the psychometrics of the items used with parents of classic autism would be very interesting.

I am sure I have a word copy of the scale on my work computer but if you wanted to you could certainly use the items as presented in the published article.

Your research sounds very interesting. I will write to you again on Monday.

Kind regards,  
Christina

**Brief COPE Permission**  
Public Domain

You are welcome to use all scales of the Brief COPE, or to choose selected scales for use. Feel free as well to adapt the language for whatever time scale you are interested in. Following is the BRIEF COPE as we are now administering it, with the instructional orientation for a presurgery interview (the first time the COPE is given in this particular study). Please feel free to adapt the instructions as needed for your application

Carver, C. S. (1997). You want to measure coping but your protocol's too long: Consider the Brief COPE. *International Journal of Behavioral Medicine*, 4, 92-100.

<http://www.psy.miami.edu/faculty/ccarver/sclBrCOPE.html>

**Marlow-Crowne Social Desirability Scale-Revised-Form C Permission**

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<http://primarycarecore.org/PDF/348.pdf>

**Multidimensional Scale of Perceived Social Support Permission**

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<http://www.parqol.com/page.cfm?id=123>

**Parental Stress Scale Permission**

Public Domain

<http://www.personal.utulsa.edu/~judy-berry/parent.htm>

**Parenting Sense of Competence Scale Permission**

Public Domain

<http://www.excellencepourenfantsados.ca/node/788?id=187>

**Permission to Use Figure 1**

Mitchell Loeppl <[loeppl@uwindsor.ca](mailto:loeppl@uwindsor.ca)> February 21/14

Hi Dr. O' Leary and Dr. Ickovics,

My name is Mitchell Loeppl and I am currently working on my Masters Thesis at the University of Windsor in Ontario, Canada. In my study I am investigating stress-related growth of parents raising children diagnosed with autism. I purchased a copy of the book "What Doesn't Kill Us: The New Psychology of Posttraumatic Growth" by Dr. Stephen Joseph. I wrote to him requesting to use a copy of a figure from his book titled "Three Trajectories of Adjustment Following Adversity" [p. 69] in my masters thesis. He replied to me and let me know this figure was attributed to you and suggested that I get in touch with you.

I have found a similar figure in your article "Resilience and Thriving: Issues, Models and Linkages" [1998, p. 246]. The figure in Dr. Stephen's book is a modified version of your original figure "Potential Responses to Trauma". I was not able to locate a copy of your 1995 article to check the figure in there as well. I would be looking to use Dr. Stephen's version which would still be cited as being Copyright 1995 by V. E. O'leary and J. R. Ickovics as is outlined in his book. I am writing to you to see if I would have your permission to use this figure in my masters thesis.

Thank you very much for taking the time to consider this and I look forward to hearing from you.

Mitchell Loeppl

Virginia O'Leary <[veoleary@gmail.com](mailto:veoleary@gmail.com)> February 22/14

Dear Mitchell:

Indeed you have our permission to use the figure in your thesis. I will send you a copy of the 1995 article as an attachment, but it may take me a bit to find it.

Best wishes,

Virginia

Virginia E. O'Leary, Ph.D.  
Professor Emerita  
Auburn University

Mitchell Loepp <[loepp@uwindsor.ca](mailto:loepp@uwindsor.ca)> March 3/14

Hi Dr. Joseph,

Thank you very much for your response and I greatly appreciate you granting me the permission to use your figure ["Trauma, Recovery & Growth" book Organismic Valuing Theory of Growth Through Adversity (Schematically Represented) , pg. 13] in my Masters thesis. I have written to O'Leary and Ickovics as you kindly suggested and they have also granted me permission to use the other figure. I was wondering if I could still be granted permission by you to use the figure ["What Doesn't Kill Us" book (Three Trajectories of Adjustment Following Adversity, pg. 69)] as it is displayed in your book, based on the permission I was granted by O'Leary and Ickovics. Thank you very much Dr. Joseph and I look forward to hearing from you again.

Kind Regards,  
Mitchell Loepp

Stephen Joseph <[Stephen.Joseph@nottingham.ac.uk](mailto:Stephen.Joseph@nottingham.ac.uk)> March 3/14

Dear Mitchell, yes you are welcome to reproduce the figures from my book in your thesis,  
Best wishes,  
Stephen

**Permission to Use Figure 2**

Mitchell Loepp <[loepp@uwindsor.ca](mailto:loepp@uwindsor.ca)> February 17/14

Hi Dr. Joseph,

My name is Mitchell Loepp and I am currently working on my Masters Thesis at the University of Windsor in Ontario, Canada. In my study I am investigating stress-related growth of parents raising children diagnosed with autism. I purchased a copy of your book "What Doesn't Kill Us" and have read your book "Trauma, Recovery & Growth" a number of your articles, particularly on Organismic Valuing Theory.

I am wondering whether I would be allowed to have permission to use one figure from your "What Doesn't Kill Us" book [Three Trajectories of Adjustment Following Adversity, pg. 69] and one figure from your "Trauma, Recovery & Growth" book [Organismic Valuing Theory of Growth Through Adversity (Schematically Represented), pg. 13] in my Masters thesis.

Thank you very much for taking the time to consider this and I look forward to hearing from you.

Mitchell Loepp

Stephen Joseph <[Stephen.Joseph@nottingham.ac.uk](mailto:Stephen.Joseph@nottingham.ac.uk)> February 17, 2014

Dear Mitchell, that sounds like a really interesting study.

You are welcome to reproduce the figure from the trauma, recovery and growth book.

However, the figure in the WDKU book is one that is attributed to O'Leary and Ickovacs so you may need their permission,

All best

Stephen

Professor Stephen Joseph  
School of Education  
University of Nottingham,  
Nottingham NG8 1BB, UK

**Permission to Use Participant's Email for Study**

Mitchell Loepp <[loepp@uwindsor.ca](mailto:loepp@uwindsor.ca)> March 10/15

Hi PARTICIPANT NAME,

I have now completed my phone interviews and have been meaning to email you again. I was waiting to send you a message in case my last randomly selected mother interviewee candidate wasn't able to do an interview with me. As I am now done the interviews I wondered whether you would allow me to include the information from your previous email in my interview information analysis. I feel like you raised some really great points and with your permission I was hoping to include your insights and experiences in my analysis of interview themes. Obviously your email would be included in a general pool of phrases and themes from my interviews and there would be no identifying information included about you/your email/your child, etc.

I completely understand if you are not comfortable with this and I will not include it in my interview analysis. Let me know your thoughts and thank you again for all of your help and for sharing with me PARTICIPANT NAME.

Mitchell

PARTICIPANT NAME <PARTICIPANT EMAIL ADDRESS> March 11/15

Congratulations on finishing up the interview process. Yes, you have my permission to use excerpts of my email, as long as no identifying information is included in any way. Wishing you all the best, PARTICIPANT NAME.

Mitchell Loepp <[loepp@uwindsor.ca](mailto:loepp@uwindsor.ca)> March 11/15

Perfect thank you so much PARTICIPANT NAME and yes any forms of identifying information will be completely removed and it will look like it is an excerpt from the interviews. Thank you again I really appreciate it!

## Appendix O

### Organizations, Facebook Groups and Web Forums Where Participants Were Recruited

#### Organizations:

- The Ability Hub
- AdoptOntario
- Adoption Council of Ontario
- Adopt 4 Life
- Alexander Society for Special Needs
- Answer Inc. Autism Awareness and Support Agency
- A.S.E.R.T. Program with the University of Calgary
- Autism Companion
- Autism Connections Fredericton
- Autism Nova Scotia
- Autism Now
- Autism Oklahoma
- Autism Ontario
- Autism Ontario, Chatham-Kent Chapter
- Autism Ontario, Durham Chapter
- Autism Ontario, Grey Bruce
- Autism Ontario, London Chapter
- Autism Ontario, North Halton
- Autism Ontario, North Bay and Area Chapter
- Autism Ontario, Ottawa Chapter
- Autism Ontario, Sarnia Lambton Chapter
- Autism Ontario, Simcoe County
- Autism Ontario, Waterloo
- Autism Ontario, Windsor-Essex
- Autism Partnership
- Autism Path
- Autism Queensland
- Autism Resources Miramichi
- Autism Services through the Regina Qu'Appelle Health Region
- Autism Services Incorporated Windsor/Essex Co.
- Autism Speaks
- Autism Speaks Canada
- Autism Society Alberta
- Autism Society of Edmonton Area
- Autism Society of Prince Edward Island
- Brooklyn Blue Feather Elementary School
- Canadian Therapeutic Riding Association
- Center for Autism Services Alberta
- Centre d'apprentissage en thérapie équine Québec

- Chaleur Autism and Asperger Family Centre Inc.
- Claro Kelowna & Nanaimo
- Community Association for Riders with Disabilities
- Community Autism Centre Inc.
- Dads 4 Special Kids
- Extend-A-Family
- Family Respite Services Windsor-Essex
- Geneva Centre for Autism
- Halifax Association for Community Living
- Hinchinbrook Farm Society
- Kerry's Place Autism Services
- Janus Academy
- Learning Disabilities Association of Newfoundland and Labrador
- Learning Disabilities Association of Prince Edward Island (LDAPEI)
- Los Angeles Families for Effective Autism Treatment
- Manitoba Families for Effective Autism Treatment
- NWT Disabilities Council
- Organization for Autism Research (O.A.R.)
- P.E.I. Department of Education & Early Childhood Development Autism Services
- Restigouche Autism Center
- Society for Treatment of Autism
- Special Equestrians Therapeutic Riding Association (SpEqTRA)
- Spectrum Intervention Group
- Summit Centre for Preschool Children with Autism
- Texas Autism Research and Resource Center (T.A.R.R.C.)
- Walking in My Shoes
- Windsor Essex County Special Stars Soccer League

#### **Facebook Groups:**

- A Day in the Life of a Autism Dad
- Autism Awareness and Support- Windsor/Essex
- Autism Mommas, Daddies, Fam & Friends
- Autism Parents- USA
- Autism Talk
- Autism: Uncensored
- Autism With a Side of Fries
- Connecting Autism Parents, Edmonton
- McClain Special Needs Advocacy
- Surfer's For Autism

#### **Listserves, Web Forums and Blogs:**

- A list for parents, professionals, and persons with autism/PDD in the Ottawa-Carleton region created to exchange information and resources, as well as to offer support (Yahoo Group)

- ASPIES Central-Asperger's & Autism Community
- Autism Support Ottawa (Yahoo Group)
- AutismWeb Forum
- Los Angeles Families For Effective Autism Treatment (Yahoo Group)
- Patient Talk



## Appendix P

### Confidentiality Agreements

#### **Research Assistant**

**Project Title:** Stress-Related Growth of Parents Raising Children with Autism

**Principal Investigator:** Mitchell Loepp, B.A., M.A. Candidate  
University of Windsor

I, *(name of research assistant)*:

1. Will keep all the research information pertaining to the identification of participants which is shared with me confidential by not discussing or sharing the research information in any form or format with anyone other than the Principal Investigator and the Supervisor;
2. Understand that all the material I will be asked to transcribe is confidential;
3. Will keep all research information in any form or format secure while it is in my possession and not allow third parties to access it;
4. Will return all research information in any form or format to the Principal Investigator when I have completed the research tasks and will not keep any copies;
5. After consulting with the Principal Investigator, will erase or destroy **ALL** research information and other relevant files in any form or format regarding this research project from my computer.

**Research Assistant:**

(Print name)	(Signature)	(Date)
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**Principal Investigator:**

(Print name)	(Signature)	(Date)
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If you have any questions or concerns about this study, please contact the Supervisor:

Dr. Marcia Gragg, Ph.D, C. Psych

Department of Psychology, 401 Sunset Drive, Windsor, Ontario, N9B 3P4

(519) 253-3000, ext. 2227

[mgragg@uwindsor.ca](mailto:mgragg@uwindsor.ca)

This study has been reviewed and approved by the Research Ethics Board at University of Windsor. If you have questions regarding participant rights and ethical conduct of research, contact the University of Windsor Research Office at (705)748-1011 ext. 7050

**Parent Advisor****Project Title:** Stress-Related Growth of Parents Raising Children with Autism**Principal Investigator:** Mitchell Loepp, B.A., M.A. Candidate  
University of WindsorI, *(name of parent advisor)*:

1. Will not share any research information (e.g., results, phone interview trends) in any form or format with anyone other than the Principal Investigator;
2. Will use the Parent Advisor Recruitment Script provided in order to assist the Principal Investigator with the recruitment of participants;
3. Will relay to potential participants only information which is on the recruitment flyer and the Parent Advisor Recruitment Script;
4. Will not share any information with the potential participants about the questions of the online questionnaire or the phone interview or any other information about this study, beyond what is on the recruitment script;

**Parent Advisor:**

(Print name)	(Signature)	(Date)
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**Principal Investigator:**

(Print name)	(Signature)	(Date)
--------------	-------------	--------

If you have any questions or concerns about this study, please contact:

Dr. Marcia Gragg, Ph.D., C. Psych

Department of Psychology, 401 Sunset Drive, Windsor, Ontario, N9B 3P4

(519) 253-3000, ext. 2227

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**Vita Auctoris**

NAME: Mitchell Scott Garry Loepp

PLACE OF BIRTH: Winnipeg, Manitoba

YEAR OF BIRTH: 1987

EDUCATION: Austin O'Brien  
2003-2005

Concordia University College of Alberta  
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2012-2015 M.A.