FATIGUE IN PARENTS OF CHILDREN WITH AUTISM SPECTRUM DISORDER: THE ROLE OF PARENTAL AND CHILD FACTORS FOR MOTHERS AND FATHERS

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SUPERVISORY AND EXAMINING COMMITTEE

Sarah Elizabeth Ivens, candidate for the degree of Master of Arts in Clinical Psychology**,** has presented a thesis titled, ***Fatigue in Parents of Children with Autism Spectrum Disorder: The Role of Parental and Child Factors for Mothers and Fathers,*** in an oral examination held on August 28, 2015. The following committee members have found the thesis acceptable in form and content, and that the candidate demonstrated satisfactory knowledge of the subject material.

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Abstract

This study examined child and parental factors associated with fatigue in parents of children with Autism Spectrum Disorders (ASDs) by using the Middle-Range Theory of Unpleasant Symptoms (TOUS) model. The research was designed to 1) extend our understanding of fatigue in parents of children with a diagnosis of ASDs by investigating fatigue in both mothers and fathers, and 2) identify and examine the associations between psychological, physiological, parental situational, and child-based situational factors. Mothers (N = 78) and fathers (N = 34) of children with ASDs aged 2-12 years were recruited from across Canada. Participants completed a confidential questionnaire battery regarding their fatigue level, parenting self-efficacy, parenting satisfaction, sleep quality, depressive and anxiety symptoms, social support, marital satisfaction, level of physical activity, caregiving burdens, their child's sleep quality, and their child's behavioural problems. Fathers reported lower levels of fatigue than mothers. Fatigue was associated with psychological, physiological, and situational factors, including child-based situational factors, although child-based situational factors were predictive of fatigue in mothers but not fathers. Fatigue was negatively correlated with parenting self-efficacy and parenting satisfaction in both mothers and fathers. This study improves our understanding of a variety of factors that impact parental fatigue, allowing clinicians to better support parents and provide avenues for the development of interventions to help reduce parental fatigue. It also contributes to the existing literature by exploring how maternal and paternal experiences of children with ASDs differ and how parental fatigue is related to ASDs.

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Fatigue in parents of children with Autism Spectrum Disorder: The role of parental and child factors for mothers and fathers

1.0 Introduction

Parents are at greater risk for negative mental, physical, and emotional health outcomes than childless adults (Evenson & Simon, 2005). Research on parental wellbeing has focused on the role of parental factors, identifying important contributors such as marital quality (Kersh, Hedvat, Hauser-Cram, & Warfield, 2006) and employment (Strazdins et al., 2012) but few studies have explored child characteristics (e.g., having a developmental disorder) and their association with parental wellbeing (Abbeduto et al., 2004), despite reasons to believe that child characteristics are important correlates of parental wellbeing. Autism Spectrum Disorders (ASDs) have been identified as among the most stressful developmental disorders for families (Gray, 2006). ASDs involve deficits in social behaviours, deficits in communication, and repetitive interests (American Psychiatric Association, 2013a). Sleep disturbances (Malow, et al., 2014) and other problematic behaviours associated with children with ASDs, such as social withdrawal, stereotypic behavior, and inappropriate speech, are challenging for parents and have been found to be negatively associated with parental wellbeing (Estes et al., 2009). While much of the existing literature has focused on the negative health outcomes associated with stress and depression among parents of children with ASDs, recent research has identified fatigue in parents as another part of wellbeing that is of significant concern as it can be detrimental to both parental health and effective parenting practice (Cooklin, Giallo, & Rose, 2012; Dennis & Ross, 2005). Specifically, there is evidence that fatigue is correlated with parental mental health as well as parenting self-efficacy and

parenting satisfaction (i.e., Giallo et al., 2011; Dunning & Giallo, 2012). In fact, it has been suggested that parenting self-efficacy mediates the relationship between fatigue and parenting behaviours (Chau & Giallo, 2014). As such, it is important to understand fatigue in parents of children with ASDs and the correlates associated with it.

Emerging evidence suggests that parents of children with ASDs have higher rates of fatigue than parents of typically developing children (Giallo, Wood, Jellett, & Porter, 2011). Maternal variables such as poor sleep quality, a high level of need for social support, and poor quality of physical activity have been correlated with higher levels of fatigue in mothers of children with ASDs (Giallo et al., 2011). While these findings contribute to our understanding of parental fatigue within this population, there are significant limitations to our understanding of parental fatigue. First, the existing parental fatigue literature has focused on studying fatigue in parents of typically developing children under the age of two. While this is a time period where there is an increased risk of fatigue, as children age beyond the first 2 years of life, the demands on parents change and this may be reflected in their experience of fatigue. This may be especially true of parents of children with developmental disorders, as there are different parenting demands that arise over time than among typically developing children. Second, as much of the research has examined maternal fatigue and wellbeing, less is known about fatigue in fathers. However, the few studies that exist indicate that fathers do experience fatigue, though they have lower levels of fatigue than mothers (e.g., Loutzenhiser, McAuslan, & Sharpe, 2015), and that fathers attribute their fatigue to different parenting challenges than mothers (Giallo, Rose, Cooklin, & McCormack, 2013). This may be due to differences in how fatigue is experienced. For example, though both genders identify

sleep deprivation as a key factor in their fatigue, only mothers attribute fatigue to high daily demands and an inability to take breaks (Giallo et al., 2013). A greater understanding of parental fatigue could be obtained by examining whether fatigue is different for mother and fathers, and if so, how. While maternal fatigue is an important area of study, understanding how fatigue impacts both mothers and fathers is vital as fatigue may be problematic both for parents and their children. Third, most studies of factors associated with fatigue are atheoretical. As factors associated with fatigue tend to be identified without the benefit of a theoretical model, this risks missing potentially important factors, such as child characteristics. Although the research has primarily focused on parental characteristics and behaviours, it is thought that child variables (e.g., sleep quality and behavioural problems; Seymour, Wood, Giallo, & Jellett, 2012) are factors in parental fatigue as well, and this may be highly relevant in children with ASDs. Finally, as there is evidence that fatigue is associated with lower levels of parenting self-efficacy and lower levels of parenting satisfaction in mothers of typically developing children, it is important to explore whether this is also true about fathers, and how these parenting variables are related for parents of atypically developing children as well. This study will address these limitations by using a theoretical model of fatigue to identify and examine factors associated with fatigue in mothers and fathers of children ages 2-12 years with ASDs.

1.1 Fatigue in Parents

Fatigue is "a self-recognized state in which an individual experiences an overwhelming and sustained sense of exhaustion and decreased capacity for physical and mental work that is not relieved by rest" (Hossain, Reinish, Kayumov, & Bhuiya, 2003,

p. 224). It is persistent and significant, and negatively impacts cognitive, emotional and psychomotor functioning (Cooklin et al., 2012). Due to the association between fatigue and poor physical and mental health, poor cognitive functioning (e.g., diminished problem-solving abilities) and poor functional performance (e.g., difficulties in accomplishing the tasks of daily living), fatigue in parents is an important health concern to study (e.g., Hossain et al., 2003, Cooklin et al., 2012).

Researchers have attempted to distinguish the concept of fatigue from related constructs (e.g., tiredness, depression) in at least three ways. First, unlike tiredness, fatigue does not seem to be relieved by rest (Hossain et al., 2003). Second, fatigue is thought to always be a negative experience, while tiredness may be perceived as positive following a satisfying activity (Milligan, Parks, Kitzman & Lenz, 1997). Third, although fatigue is related to depression, there is empirical evidence to suggest that they are different constructs. In a study of mothers who had given birth within the past year, participants completed a measure of fatigue (The Fatigue Assessment Scale) and a measure of depression (The Depression subscale of the Depression Anxiety and Stress Scale) to analyze whether or not they were distinct (Giallo, Wade, Cooklin, & Rose, 2011). A two-factor model was found to fit the data better than a one-factor model, supporting the notion of distinct yet related constructs. More specifically, fatigue questions assessed exhaustion and energy while the depression questions were focused on mood and ahedonia.

1.2 What do we know about parents and fatigue?

There is evidence that parents in general are at a greater risk of higher levels of fatigue than childless adults (Evenson & Simon, 2005). Fatigue not only negatively

impacts parents' physical and mental health, but the problems associated with fatigue (e.g., impaired functioning, forgetfulness, reduced patience) negatively impact parenting. For example, fatigue has been associated with ineffective coping techniques in parents of typically developing children (i.e. self-blame and behaviour disengagement; Cooklin et al., 2012). One possible reason for this is that parents experiencing greater levels of fatigue may perceive their children's behaviour as more challenging (Cooklin et al., 2012). This could potentially lead to a feedback loop of problematic behaviour and outcomes as parents are less well-equipped to deal with children's problematic behaviour. Raising a child requires the ability to balance multiple roles, the flexibility to adapt to the child's changing needs, and the energy to effectively parent and respond to needs. The reduced mental and physical functioning that is a component of fatigue can make these behaviours more challenging. Furthermore, fatigue does not only impact the ability to parent; it has been found to also negatively impact the cognitions surrounding parenting, such as parenting satisfaction and parenting self-efficacy (i.e., Giallo et al., 2011; Dunning & Giallo, 2012). In fact, it has been suggested that these cognitions are the mechanism by which parenting behaviours are impacted (Chau & Giallo, 2014). In sum, parents experiencing higher levels of fatigue find parenting less rewarding and more challenging than parents who are less fatigued.

While fatigue and its impact on wellbeing has been studied, much of the work looking at fatigue levels in parents has been done on new parents of typically developing children, and primarily focused on mothers. However, it is important to expand our understanding of fatigue to include other groups of parents. As fatigue is a sense of exhaustion that negatively impacts one's ability to effectively function, it is an imperative

component of wellbeing to understand for all parents as it impacts their ability to fulfill and enjoy their role as a parent.

In terms of research on fatigue in new parents, there is evidence that they experience higher levels of fatigue after the birth of their child (e.g., Gay, Lee, & Lee, 2004). In a recent study, researchers found that new mothers reported moderate to high levels of fatigue (Giallo et al., 2015). Despite studies suggesting that fatigue remains a problem past the infant stage (e.g., Cooklin et al., 2012), little is known about fatigue past the age of two years. It is important to extend our knowledge of fatigue to parents of older children as fatigue may be of continued concern as children age. While the neonatal period is one of great change for parents, demands continue to evolve as the child ages and becomes more mobile and independent, yet remains very dependent on parents for both safety and meeting their needs. As the child ages and develops, their characteristics, temperament, and behaviours may influence parental fatigue, although this remains understudied (e.g., Seymour et. al, 2012).

As demonstrated above, challenges in parenthood continue to be associated with fatigue as children age. However, much of the research that has examined older children has predominantly focused on typically developing children. This research has found that fatigue is present in parents beyond the first two years of their child's life, and is associated with negative parenting experiences, such as more irritability in interactions with their child and ineffective coping styles (e.g., Cooklin et al., 2012).

The challenges involved in raising a child might be greater for children with developmental disorders. Some of the changes that occur as their child ages may be

especially difficult for parents of children with developmental disabilities, as these children are more likely than their typically developing peers to have impaired understandings of safety concerns, as well as a reduced ability to master self-care activities. There is evidence that these child problematic behaviours are associated with parental fatigue, which mediates the relationship between child problematic behaviours and stress in mothers of children with ASDs (Seymour et. al, 2012). As fatigue is marked by decreased mental and physical functioning, it risks negatively impacting parental abilities to successfully negotiate the particular challenges associated with ASDs (e.g., communication challenges, behavioural needs, safety concerns). As such, given the detrimental impact of fatigue and the additional physical health, mental health, and child wellbeing challenges associated with higher levels of fatigue, it is important to understand how the model of fatigue works in this particularly vulnerable group of parents.

Among parents with children with developmental disabilities, there is evidence that parents with children with ASDs find their children's behaviours particularly challenging (Gray, 2006). ASDs is the new diagnostic classification in the DSM-5 for four distinct but related disorders that were previously conceptualized in the DSM-IV as under the umbrella of Autism Spectrum Disorders (Autistic Disorder, Asperger's Disorder, Childhood Disintegrative Disorder, and Pervasive Developmental Disorder Not Otherwise Specified). They were combined into the construct of ASDs because the existing literature indicated that these four disorders are fundamentally related and should be conceptualized as different expressions of the same underlying phenomenon (American Psychiatric Association, 2013b).

ASDs have been identified among the most stressful developmental disorders for families (Gray, 2006). ASDs are pervasive, meaning that the children will not stop having the diagnosis, and its chronic nature can be stressful for parents. ASDs are characterized by impairments in reciprocal social activities and communication, as well as restricted and/or repetitive patterns of behaviour, interests, or activities (American Psychiatric Association, 2013a), all of which can result in additional parenting challenges. ASDs are associated with intellectual delays, language delays, decreased self-care abilities, and higher rates of assisted living. There is also a great deal of co-morbidity between ASDs and various medical challenges, including seizure disorders, sleep disorders, gastrointestinal disorders, metabolic disorders, and hormonal dysfunction (Bauman, 2010), leading to more complex support and wellbeing needs. Furthermore, as children age, the discrepancy between the expected course of parenting demands and the reality of raising a child with a diagnosis of ASDs, whose adaptive behaviours tend to show a decline (Fisch, Simensen & Schroer, 2002), becomes more pronounced, which may be especially challenging for parents. In fact, there is evidence that parents of children with ASDs have higher rates of fatigue than parents of typically developing children (Giallo et al., 2011). Thus, it is important to study fatigue in parents of children with ASDs as they age, as there is evidence that suggests that fatigue continues to be of concern.

Much of the research examining fatigue in parents of children with ASDs has primarily focused on mothers. In fact, parental fatigue in general, as with many parenting constructs, has been studied more extensively in mothers than fathers. This discrepancy is likely due to several factors, including changing gender roles and challenges in recruitment for research. Parenting literature has tended to focus on mothers as the

primary caregiver of the child, reflecting gender roles and expectations in the parenting dyad. Parenting expectations and norms have been changing in the general population, with increased paternal involvement in child care and a larger maternal work force (Hoffman, 2011). Parenting researchers have also been challenged because of the relative dearth of fathers who participate in studies (e.g., Phares, Fields, Kamboukos, & Lopez, 2005). With mothers being the majority of participants and fathers often responding in comparatively low numbers, researchers have had to choose between considering both mothers and fathers as the same group in their analyses, or excluding fathers because there are not enough of them in the study to conduct an appropriate statistical analysis on them as a group. As a result of these two factors, the parenting literature tends to focus on mothers, or on parents without differentiating between mothers and fathers. In fact, in a review of developmental psychopathology literature, it was found that 45.0% of the studies only examined mothers, and an additional 28.2% of the studies did not differentiate between mothers and fathers (Phares et al., 2005). Only 24.7% of the studies considered mothers and fathers separately. This may be problematic due to findings that suggest fundamental differences in mothers and fathers in their role as parents. Differences between how genders experience parental challenges, such as parental fatigue, are vital to understand as they may impact outcomes of fatigue, such as parenting satisfaction and parenting self-efficacy.

Little research has examined whether fathers and mothers experience fatigue differently in the general population. One study that has explored this question found that among preschool aged children, mothers experience more fatigue than fathers (Cooklin et al., 2012). However, the pattern of fatigue seems less clear in the perinatal population,

which has been more thoroughly examined. For example, before a child's birth, pregnant mothers report increasing amounts of fatigue, but fathers do not (Elek, Hudson, & Fleck, 1997). However, there is no difference between the fatigue levels of mothers and fathers of newborn babies (Gay, Lee, & Lee, 2004) and newborn twins (Damato & Burant, 2008). A longitudinal study examining 108 mother/father couples before and up to six months after their child's birth found that though mothers tended to be more fatigued than fathers, the birth of their child seemed to increase paternal fatigue more than maternal fatigue (Loutzenhiser, McAuslan, Sharpe, 2015). These differences and nuances in fatigue levels suggest that factors contributing to and maintaining fatigue may be dynamic and vary according to parenting role and phase. As periods of parenting that have been better studied show the relationship between gender and paternal fatigue is not simple, it must be acknowledged that fatigue in older children may also be nuanced. Given the health and parenting problems associated with fatigue, how fathers and mothers experience fatigue and how their experiences differ are important areas of enquiry.

While no published studies were found comparing fatigue levels in mothers and fathers of children with ASDs, related research on typically developing parents suggests that mothers and fathers' experiences of fatigue may differ and that there may be different contributors to fatigue levels for mothers and fathers (Giallo et al., 2013). This suggests that there may be gendered differences in how fatigue develops and is experienced, perhaps due to differences in caregiving demands and expectations. Furthermore, there may be additional pressures involved in raising a child with a diagnosis of ASDs, as there tend to be particular challenges in regards to their child's

sleep habits and caregiving needs. Whether or not this would result in disparate fatigue scores in fathers and mothers of children with ASDs remains to be determined. Research comparing fatigue levels in mothers and fathers of children with other challenges, such as chronic illnesses (e.g., diabetes), identifies higher levels of fatigue in mothers than fathers (Knafl & Zoeller, 2000).

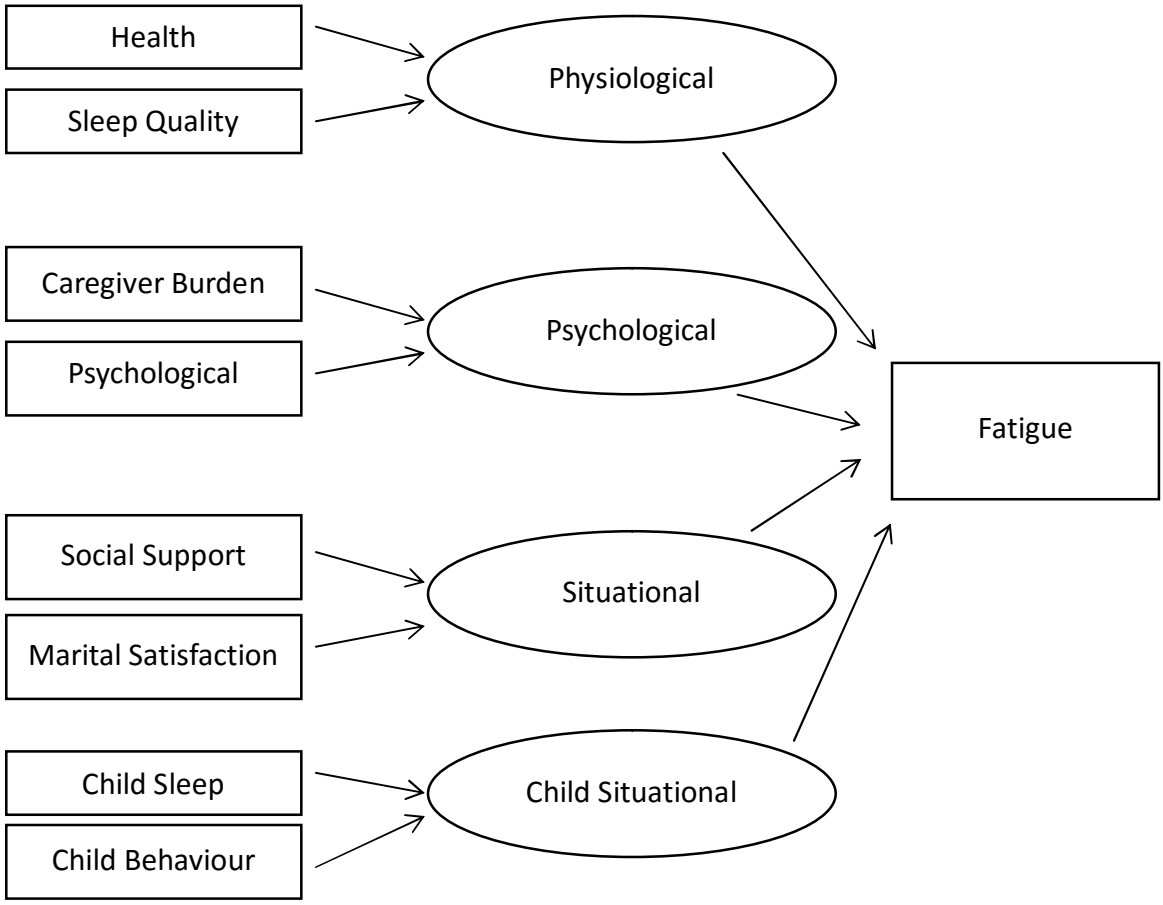
In sum, parents are at risk to experience more fatigue than childless adults, and higher fatigue levels are associated with negative parenting outcomes. However, much of the research has focused on parents of infants and preschool aged children, typically developing children, and the experience of fatigue for mothers. Furthermore, the research has tended to focus on parental correlates of fatigue, though there is evidence that suggests that child characteristics play a role in parental fatigue. This study examined fatigue in both mothers and fathers of children with ASDs ages 2-12 years in terms of both parental and child factors in order to expand our understanding of parental fatigue.

1.2 What do we know about factors associated with fatigue?

In order to develop a comprehensive understanding of fatigue in parents, we need to investigate factors associated with the development and maintenance of fatigue. However, few studies have examined factors associated with fatigue within a theoretical framework. This is problematic because without a framework, it is possible to miss important variables, such as child characteristics. The Middle-Range Theory of Unpleasant Symptoms (TOUS; Lenz et al., 1997) may be an effective framework to identify and understand variables associated with fatigue. This theoretical model, designed to provide a framework for understanding and managing symptoms, was originally used to study childbearing fatigue in mothers (Pugh & Milligan, 1993).

However, researchers have extended its use to study fatigue in both mothers and fathers (Elek, Hudson, & Fleck, 2002). The TOUS model is composed of the symptoms experienced by the individual, the factors that affect the experience of the symptoms, and the results of the experience. From this perspective, three types of factors: physiological, psychological, and situational/environmental are hypothesized to influence parental fatigue (Figure 1). Although the TOUS model provides the opportunity to examine direct and indirect associations amongst the three types of factors and fatigue, as will be discussed below, most researchers have focused on the role of physiological factors (e.g. Lee & Zaffke, 1999) with mothers.

Figure 1:
TOUS model of fatigue



1.2.1 Physiological Factors of Fatigue. Physiological factors that have been identified as related to maternal fatigue tend to be correlates that are inherently focused on understanding fatigue in mothers who have recently given birth, such as low iron, folic acid, ferritin and hemoglobin levels, (Lee & Zaffke, 1999), maternal age and length of labour (Troy & Dalgas-Pelish, 1997), as well as maternal sleep disturbance (Rychnovsky, 2007). However, to understand parental fatigue in a larger context that also includes fathers, general health may be a more appropriate correlate to examine. Poor self-reported general health has been found to be associated with fatigue in other populations (e.g., Fortier-Brochu, Beaulieu-Bonneau, Ivers, & Morin, 2010; Kocalevent, Hinz, Brähler, &

Klapp, 2011) Research has also shown that self-assessed measures of general health are correlated with fatigue levels in mothers of children with ASDs (Giallo et al., 2011). Whether this is because fatigue prevents one from engaging in positive general health behaviours, such as exercising or eating well, or because physical inactivity and a poor diet results in fatigue is unknown. The lack of energy emblematic of fatigue and inactivity are likely maintaining each other, as are the benefits and habits of a person's diet.

Sleep disturbances have been found to be associated with fatigue in other populations (i.e., Fortier-Brochu, Beaulieu-Bonneau, Ivers, & Morin, 2010; Giallo et al., 2015), and may be an especially important correlate of fatigue among parents of children with ASDs. Among these parents, parental sleep quality is frequently negatively impacted (e.g., Giallo et al., 2011). In a study looking at the experiences of both mothers and fathers of children with ASDs who later moved into group homes, parents reported exhaustion associated with their children's severe sleep disturbances, with some parents reporting sleeping for only a few hours every night (Benderix, Nordström, & Sivberg, 2006). The lack of sleep for both the parents is problematic, and both mothers and fathers report that poor sleep quality contributes to higher levels of fatigue (Giallo et al., 2013). Thus, both general health and sleep quality may be important correlates of fatigue in parents of children with ASDs.

1.2.2 Psychological Factors of Fatigue. Among the psychological factors associated with fatigue, depression is the most frequently studied. The relationship between the two has been well established, with depressive symptoms being correlated with fatigue in the general population (e.g., Alapin et al., 2000) and mothers specifically

(e.g., Dennis & Ross, 2005). Fatigue has been associated with several other psychological factors, predominantly anxiety symptoms (e.g., Alapin et al., 2000) and emotional distress (National Comprehensive Cancer Network, 2003).

Having a child with a diagnosis of ASDs may be particularly problematic to the wellbeing of parents (Gray, 2006) and that it uniquely contributes to the psychological stress factors of fatigue. Parents of children with ASDs have been found to have higher levels of depression, anxiety and stress. Specifically, problematic behaviours of children with ASDs are associated with higher levels of parenting stress and psychological distress among mothers (Estes et al., 2009). There is evidence that mothers may be experiencing more psychological distress than fathers. For example, in a recent study comparing 19 dyads of mothers and fathers of children with ASDs, mothers reported higher levels of both anxiety and depression than fathers (Foody, James, & Leader, 2015). However, as both mothers and fathers report that anxiety and stress are problematic, it is important to look at psychological functioning in both.

Another factor that may be related to the elevated fatigue levels in parents of children with ASDs is the caregiver burden they experience. While all children require caregiving efforts from their parents, children with ASDs may pose particular challenges for parents, including additional time demands and challenging behaviours (Estes et al, 2009) that may impact the burden felt by caregivers. In fact, the majority of families of children with ASDs experience high levels of caregiver burden after the diagnosis of their child, implying that the diagnosis itself comes with additional stresses, such as knowing that the challenges will be chronic (Stuart & McGrew, 2009). In this study, the challenges that were associated with increased caregiver burden were the severity of the child's

symptoms, additional demands, lack of social support, and coping strategies that do not directly address their child's needs. In another study, mothers identified high daily demands and an inability to take a break as instrumental in their fatigue (Giallo et al., 2013). While few studies have examined how caregiver burdens of atypically developing children impact fathers, in a recent study comparing 19 dyads of mothers and fathers of children with ASDs, mothers reported higher levels of parenting responsibility (Foody et. al, 2015). Though this suggests that caregiver burden may differ in mothers and fathers, how it is related to fatigue remains to be seen. As such, both psychological functioning and caregiver burden may be important correlates of fatigue in parents of children with ASDs.

1.2.3 Situational Factors of Fatigue. In terms of parental situational factors associated with fatigue, a high need for social support has been correlated with higher levels of fatigue in mothers of children with ASDs (Giallo et al., 2011). This augmented need begins in the early years following the diagnosis of a child with ASDs, which are marked with a high use of coping strategies, such as social support, religion, service provider use, and involvement in support groups (Gray, 2006). However, while these parents tend to need a higher quantity of social support, they also tend to have a more difficult time meeting this need. Parents of children aged 10 -11 years old with ASDs reported hesitation to socialize, both in leaving the home and inviting people over, due to the difficulties around their child's problematic behaviours and their child's need for routine and consistency (Benderix et al., 2006). As the quantity of social support activities that parents are able to engage in is lower than they may want, parents are at

risk of being isolated and having fewer supports in dealing with the challenges associated with ASDs.

There is evidence that suggests that marital satisfaction may be lower for parents of children with ASDs than their typically developing peers. In one study, the divorce rate for parents of children with ASDs was found to be 23.5% whereas it was only 13.8% in a matched comparison group (Hartley et al., 2010). As divorce and separation have been associated with fatigue (Kocalevent et al., 2011), examining marital satisfaction might provide important information about fatigue. It has been suggested the fatigue is a response to chronic tension, and that this may be the mechanism by which divorce and separation are associated with fatigue (Kocalevent et al., 2011).

1.2.4 Child-Based Situational Factors of Fatigue. In examining situational correlates of fatigue, the focus tends to be on parental factors, with those involving the child being largely ignored. This is problematic, as it has been suggested that child factors, including child age and ability (e.g., having a developmental disability) contribute to fatigue (Seymour et al., 2012). A child is an important part of a parent's situation, and can impact the parent through abilities/disabilities, changing needs at different ages, and their behaviours, among other variables. Child situational factors can be thought of as risk factors for parental fatigue, and yet their influence remains underexamined. There is evidence that a diagnosis of ASDs may be another child-based situational variable that impacts the parenting experience (Gray, 2006; Stuart & McGrew, 2009). However, although child-based situational factors may be an important component of fatigue, they remain a relatively unexamined area of parental wellbeing.

Child behaviour challenges have been suggested independently as a factor of fatigue in parents of children with ASDs (Seymour et al., 2012). These additional behavioural challenges include requiring specific routines, aversions to specific stimuli, self-harm behaviours, and inappropriate behaviours toward other people (American Psychiatric Association, 2013a). Parents of children with ASDs have reported that the constant need to be prepared for those behaviours is challenging (Benderix et al., 2006). Violent behaviour from their child, for example, has been found to be especially problematic for parental wellbeing (Gray, 2002). Parents need to be aware and respond to these behavioural challenges that can be persistent and very problematic, which may contribute to their levels of fatigue. While few studies have examined how difficult behaviours of atypically developing children impact fathers, a recent study examining the risk factors that are associated with mental health of fathers of children with an intellectual disability found that the father's report of their child's problematic behaviours were significantly correlated with paternal stress, depression, and anxiety (Giallo et al., 2015).

Child sleep quality has also been identified as a possible contributor to parental fatigue. The association between parental sleep quality and child sleep quality (Chu & Richdale, 2009) is particularly problematic with this population as children with ASDs tend to have more problematic sleep than their typically developing peers. For example, children with ASDs aged 30 months to 69 months were found to sleep 17 to 30 minutes less each night than typically developing children, and were more likely to wake up at least three times during the night (Humphreys et al., 2014). This pattern of problematic sleep may contribute to parental fatigue, especially as this finding was persistent over the

course of years. As such, it is important to consider child sleep quality in addition to parent sleep quality. In sum, both child problematic behaviours and child sleep quality can be thought of as child-based situational factors that are likely to be associated with fatigue in parents of children with ASDs.

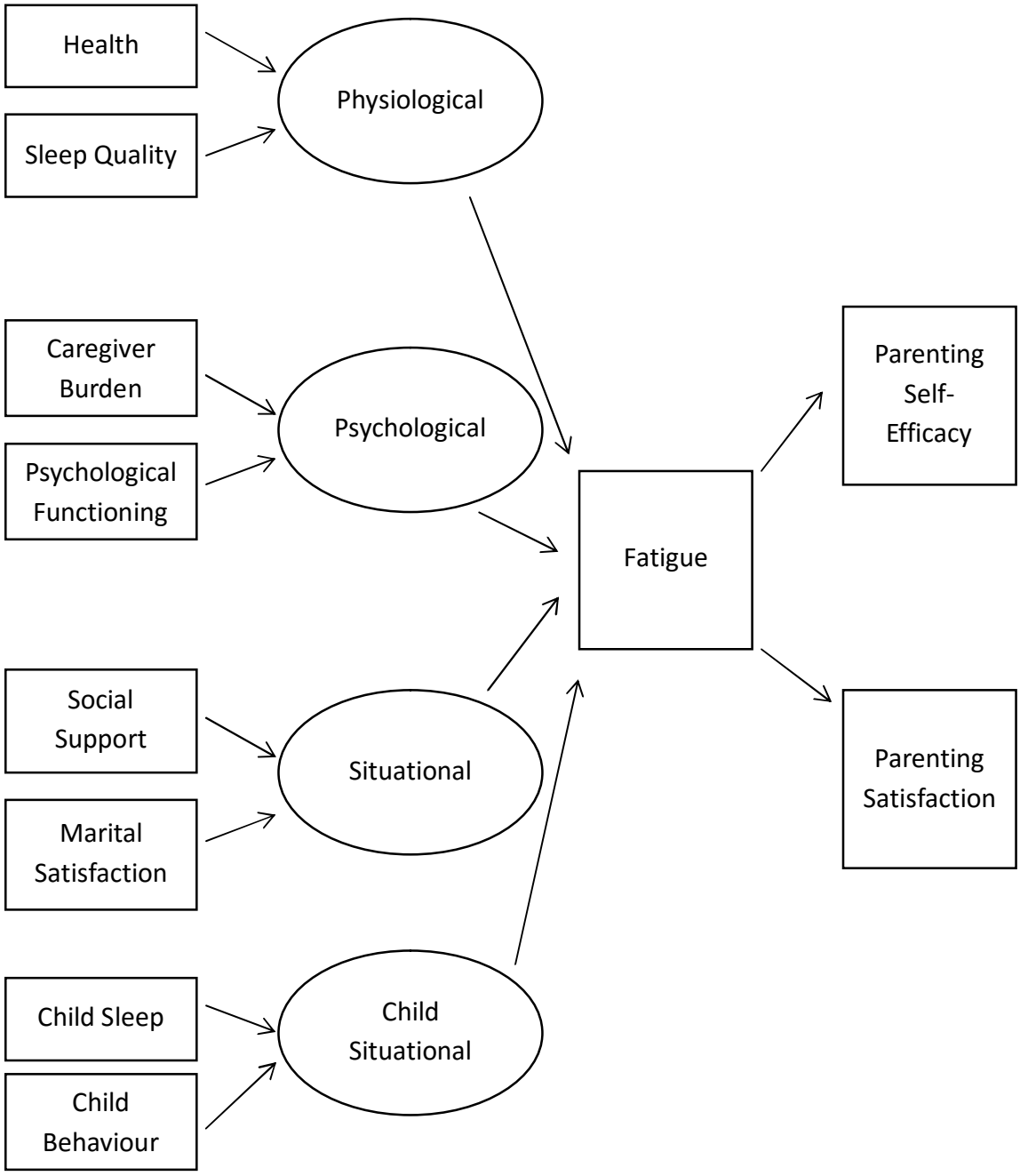
Preschool and school aged children with ASDs and their parents provide a useful view of the situational challenges facing this community. As the average age of diagnosis of ASDs is 3.1 years of age (Mandell, Novak, & Zubritsky, 2005), examining parents of children between 2 and 12 years of age captures families as they are adjusting to the diagnosis and its implications for parenting, as well as families that have been coping with the diagnosis for years. Parents of younger children are unlikely to have had their children diagnosed, and parents of older children are likely to be impacted by more confounding variables that are not being examined in this study, such as special education programs at school and community services.

1.3 Parental Outcomes of Fatigue

Not only does the TOUS model suggest that psychological, physical, and situational factors all contribute to fatigue, but it also suggests that parents will experience negative outcomes of fatigue (Lenz et al., 1997; Figure 2). As has been discussed, fatigue is detrimental in terms of wellbeing and parenting behaviours. Two important parenting outcomes that are associated with fatigue are parenting self-efficacy and parenting satisfaction. Parenting self-efficacy has been defined as the "expectation caregivers hold about their ability to parent successfully" (Jones & Prinz, 2005). It refers to how well a parent believes they are performing as a parent and how well they are able to cope with the demands of parenting. It is an important component of the parenting

experience because it is positively associated with parenting competence, parenting style (e.g., parental warmth and discipline styles), and child functioning (e.g., behavioural outcomes; Jones & Prinz, 2005; Ohan, Leung, & Johnston, 2000). Parenting satisfaction is a self-perception about one's role as a parent and "the quality of positive affect associated with parenting such as enjoyment or pleasure" (Dunning & Giallo, 2012). Parenting satisfaction is an important component of the parenting experience to understand as lower levels are correlated with negative outcomes for the parent, such as higher levels of psychological distress (Rogers & Matthews, 2004).

Figure 2:
Proposed fatigue model with observable, latent, and outcome variables



Parenting self-efficacy is of particular importance among parents of children with ASDs. Fatigue is associated with reduced parenting self-efficacy in mothers of children with ASDs (Giallo et al., 2011) and as higher levels of fatigue have been found within

this population than in the general population, this relationship is concerning. There is evidence that lower levels of maternal self-efficacy is associated with several problematic correlates, such as a lower sense of agency, increased guilt, and reduced wellbeing (Kuhn, & Carter, 2006). Behavioural challenges associated with ASDs may be detrimental for parenting self-efficacy for some parents, as higher levels of challenging behaviours have been associated with lower levels of parenting self-efficacy for fathers, although not for mothers (Johnston & Mash, 1989).

In addition, parenting self-efficacy has been found to mediate the relationship between fatigue and parenting behaviours. In a recent study, Chau and Giallo (2014) found that higher fatigue levels in parents were associated with lower confidence in their ability to fulfill their role as a parent, and that lower parenting self-efficacy was in turn associated with low warmth and high hostility in parent-child interactions. The researchers suggest that as fatigued parents have less mental energy to draw on, it is more difficult for them to respond positively in difficult situations with their child. Furthermore, parents who have less faith in their ability to parent may be less likely to engage in warm activities with their child (e.g., hugging and praising).

The existing evidence suggests that in general, fathers report lower levels of parenting self-efficacy than mothers. However, as all but one existing measure of parenting self-efficacy have been created for and validated with mothers, perhaps they did not adequately measure parenting self-efficacy in fathers (Sevigny, 2013). In examining parenting self-efficacy in both mothers and fathers, it is important that the measurement tool be appropriate for both groups as gender differences and norms may impact how parents view their ability to appropriately and effectively fulfill their role as a

parent. The Fathering Self-Efficacy Scale (Sevigny, 2013) is the only scale that measures this construct that was developed for fathers and validated with a male sample. However, as the questions drew from existing measures of parenting self-efficacy that are used for mothers, the scale will likely still be appropriate for mothers.

Parenting satisfaction has been shown to be correlated to fatigue as well as parenting self-efficacy in parents of typically developing children aged 0-5 (Cooklin et al., 2012). In a recent study of 1022 mothers of typically developing children aged 0-6, fatigue was shown to be associated with both parenting self-efficacy, and parenting stress, though mediated by parenting stress (Dunning & Giallo, 2012). The aforementioned higher levels of parenting stress in parents of children with ASDs gives reason to believe that parenting satisfaction may be negatively impacted by the additional challenges of raising a child with ASDs. Furthermore, reported challenging behaviours from the child have been associated with lower levels of parenting satisfaction in both mothers and fathers (Johnston & Mash, 1989; Ohan, Leung, & Johnston, 2000; Rogers & Matthews, 2004), and the additional behavioural challenges that children with ASDs present make this correlate an important one. There is evidence that fathers of typically developing children may experience higher levels of parenting satisfaction than mothers (Rogers & Matthews, 2004), but the types of differences amongst mothers and fathers of children with ASDs remain to be seen.

1.4 Summary and Aims of the Study

This research had three goals. First, to explore the extent to which parents of children ages 2-12 who have been diagnosed with ASDs report fatigue. Second, to identify the factors associated with fatigue using the TOUS model and focus on child-

based factors. Finally, this study sought to better understanding of the relationship between fatigue and parenting, through its focus on parenting self-efficacy and parenting satisfaction.

By understanding both parental and child situational factors that are associated with fatigue, more avenues for clinically addressing parental fatigue become possible. This research hopes to inform future studies addressing possible preventative measures and interventions focused on child-based situational factors, in addition to psychological, physiological, and parent-based situational factors, to reduce parental fatigue levels.

1.5 Research Questions

Research Question 1: Among parents of children with ASDs aged 2 to 12 years, do mothers report higher levels of fatigue than fathers? It was hypothesized that mothers would report higher levels of fatigue than fathers.

Research Question 2: Are psychological, physiological, and situational variables associated with fatigue levels in parents? According to the TOUS model, psychological factors, physiological factors, and situational factors were hypothesized to be associated with higher fatigue levels in mothers and fathers. It was also hypothesized that child-based situational variables would contribute to fatigue over and above the psychological, physiological, and parental situational factors.

Research Question 3: Are the same psychological, physiological, and situational variables associated with fatigue in mothers and fathers of children with ASDs? As there is little research comparing correlates of fatigue in mothers and fathers, this research question was primarily explorative.

Research Question 4: Are higher fatigue levels associated with lower Parenting Self-Efficacy and Parenting Satisfaction for mothers and fathers? Higher levels of fatigue were hypothesized to be associated with lower levels of parenting self-efficacy and lower levels of parenting satisfaction among both mothers and fathers.

2.0 Method

2.1 Research Ethics

Ethics approval was gained for this research project from the University of Regina Research Ethics Board and the Regina Qu'Appelle Health Region Research Ethics Board.

2.2 Recruitment Strategy

Parents were recruited online through a variety of means, including email lists, twitter posts, Reddit posts, Facebook groups, Facebook advertisements, Craigslist advertisements and UsedRegina advertisements. Recruitment also took place through flyers (Appendix A) that were placed in a number of facilities and organizations such as Regina Qu'Appelle Health Region's Child and Youth Services, and information placed on the Autism Society Canada and Autism Society Alberta websites and newsletters, and at the University of Regina. In order for interested participants to receive more information on the study, these flyers had a telephone number, email address, and website where the researchers could be reached. As an incentive to participate, there were three draws for a $50.00 gift certificate. These gift certificates were drawn after 40 participants, 80 participants, and at the end of the data collection period.

Due to the well-documented discrepancy between the number of fathers and mothers who participate in similar research projects (i.e., 12.1% fathers in Cooklin et al., 2012), additional effort was made to target male participants. The graphic chosen for the

poster (Appendix A) used an image of a male in an attempt to make the survey more welcoming to men. Furthermore, the information provided to potential participants regarding the study specifically mentioned that the researchers were especially interested in responses from fathers in an attempt to encourage fathers to respond in higher numbers than they tend to in similar parenting research. Finally, advertisements on Facebook were directed at fathers who had expressed interest in ASDs, and parenting groups that specifically targeted fathers were contacted to request that they promote the questionnaire to their contacts.

As this study focused on parents of young children with a diagnosis of ASDs, only parents with at least one child with ASDs between the ages of 2 and 12 years were eligible participants. All parents were required to be residents of Canada in order to participate, and were required to have access to a computer from which they could complete the online survey.

2.3 Participants

Using the recruitment strategy described above, 167 parents began the study. Of these, 123 completed the entire study. Five of these 123 participants were excluded from the analyses because their data was suspicious (i.e., appeared that the participant had responded twice, responses were inconsistent and appeared to be falsified). Ten of these 123 participants were couples, and so the mothers in these couples were omitted from all analyses in order to preserve the independence of the data (n = 5 women dropped). One individual reported a gender of "other", and thus was omitted from the analyses as it was unclear if they should be included in the mother or father group. Therefore, the final sample size for this research study was 78 mothers and 34 fathers. Table 1 contains the

demographic information from mothers and fathers who participated in this study. Mothers ranged in age from 28 to 54 years with an average age of 39.32 years (*SD* = 6.35), while fathers ranged in age from 30 to 53 years, with an average age of 41.29 years (*SD* = 5.46). The majority of mothers and fathers were legally married or in common-law relationships (n = 91) and they were predominantly Caucasian. Mothers reported significantly higher levels of education than fathers $t(110) = 2.165$, $p = .033$, and reported lower family income levels, $t(110) = -2.312$, $p = .023$. Fifty percent of the fathers who participated reported that they lived in Saskatchewan, while mothers within our sample were more distributed across Canada.

Table 1:
Participant Demographic Information

	Females (*n* = 78)	Males (*n*= 34)
Province of Residence		
Alberta	9 (11.5%)	2 (5.9%)
British Columbia	25 (32.1%)	9 (26.5%)
Manitoba	3 (3.8%)	1 (2.9%)
New Brunswick	1 (1.3%)	0
Nova Scotia	4 (5.1%)	0
Ontario	18 (23.1%)	3 (8.8%)
Quebec	2 (2.6%)	2 (5.9%)
Saskatchewan	16 (20.5%)	17 (50.0%)
Employment Status		
Part-time Work	18 (23.1%)	1 (2.9%)
Full-time Work	25 (32.1%)	31 (91.2%)
Unemployed	32 (41.0%)	1 (2.9%)
Student	6 (7.7%)	2 (5.9%)
Ethnicity		
Aboriginal	4 (5.1%)	1 (2.9%)
Asian	2 (2.6%)	1 (2.9%)
Caucasian	70 (89.7%)	31 (91.2%)
Other	4 (5.1%)	1 (2.9%)
Highest Level of Education		
Less than high school	1 (1.3%)	1 (2.9%)
High school	12 (15.4%)	9 (26.5%)
Bachelor's Degree	19 (24.4%)	10 (29.4%)
Technical school certificate / diploma	30 (38.5)	11 (32.4%)
Master's Degree	13 (16.7%)	3 (8.8%)
Doctoral Degree or Post-Doctoral Degree	3 (3.8%)	0
Marital Status		
Married	56 (71.8%)	27 (79.4%)
Common-Law	5 (6.4%)	3 (8.8%)
Divorced	12 (15.4%)	4 (11.8%)
Single	6 (7.7%)	0
Partner's Gender		
Female	1 (1.8%)	30 (100%)
Male	54 (96.4%)	0
Other	1 (1.8%)	0
Total Family Income		
< $20,000	8 (10.3%)	2 (5.9%)
$20,000 -$40,000	12 (15.4%)	3 (8.8%)
$40,000-$60,000	14 (17.9%)	3 (8.8%)
$60,000-$80,000	16 (20.5%)	4 (11.8%)
> $80,000	28 (35.9%)	22 (64.7%)

Table 2 contains the demographic information about children of participants. On average, mothers in this study had 2.24 (*SD* = 1.34) children while fathers had 2.12 (*SD* = 0.81) children. With respect to their child with ASDs, when asked how old their child was when diagnosed with ASDs, the mode response was 3 years, with a mean age of 3.96 (*SD* = 2.15). Mothers reported that their child with a diagnosis of ASDs was a mean age of 6.86 years (*SD* = 2.90), while father's reported that their child with a diagnosis of ASDs was a mean age of 7.32 (*SD* = 3.08).

Table 2:
Parental report of child with ASDs demographic information

	Females (*n* = 78)	Males (*n* = 34)
Number of children with ASDs diagnosis		
1	67 (85.9%)	29 (85.3%)
2	11 (14.1%)	5 (14.7%)
Child's communication		
Predominantly nonverbal	13 (16.7%)	9 (26.5%)
Somewhat verbal, but only understood by those familiar with my child	11 (14.1%)	6 (17.6%)
Somewhat verbal, and understood by those people who have just met my child	12 (15.4%)	6 (17.6%)
Predominantly verbal	42 (53.8%)	13 (38.2%)
Presence of other diagnoses with child		
Yes	33 (42.3%)	15 (44.1%)
No	45 (57.7%)	19 (55.9%)

2.5 Procedure

The battery of questionnaires that comprised the survey was provided to participants through Qualtrics and made available through a link on the Child and Family Research Group's website. Qualtrics is a web-based platform from which participants can anonymously complete questionnaires and/or surveys.

The survey began with a consent form in which participants were informed about the current study, how the information gathered would be used, and possible benefits and

drawbacks of participating (Appendix B). In order to continue on the survey, participants were required to agree to participate in accordance with the consent form. Contact information was provided on the consent form to enable participants to request more information if it was desired.

Mothers and fathers then completed a confidential self-report questionnaire battery. Parents were asked to complete a series of demographic questions (e.g., age, sex, education, employment) about themselves and their children. They were then asked questions about their fatigue level, parenting outcomes (i.e., parenting self-efficacy and parenting satisfaction), psychological factors (i.e., depression and anxiety symptoms and caregiver burden), physiological factors (i.e., sleep quality and general health), and situational factors (i.e., social support, marital satisfaction, child sleep quality and child behavioural problems). Internal reliability for the measures used in this study were at least acceptable, ranging from Cronbach's Alpha of .66 to .95. The battery of questionnaires took approximately 25 minutes to complete (Appendix B).

2.6 Measures

2.6.1 Demographics. Parents were asked a series of questions regarding their demographics and their child's demographics. In terms of parental demographics, questions targeted their age, gender, province of residence, ethnicity, employment status, highest level of education, marital status, partner's gender (if applicable), and total family income. In terms of child demographics, questions assessed the number of children in the family, how many of them had received a diagnosis of ASDs, how old the child was when diagnosed with ASDs, the child's current age, the child's communication abilities, and whether or not the child had received any additional medical diagnoses.

2.6.2 Fatigue. The Fatigue Assessment Scale (Michielsen et al., 2003) was used to measure fatigue. It is a 10-item self-report measure of fatigue. Reliability for this measure was excellent within this sample (Cronbach's alpha = .91), which is consistent with prior research (Michielsen et al., 2003). It has also demonstrated high correlations with other fatigue scales such as the Checklist Individual Strength (Vercoulen, Alberts, & Bleijenberg, 1999) ranging from .60 to .76 (Michielsen et al., 2003). It was chosen for this study because gender biases do not impact use of the Fatigue Assessment Scale, a concern that has been raised with other fatigue measures (Michielsen et al., 2003).

Each question is scored on a 5-point Likert scale, where the respondent can indicate agreeing with the statement never (1), sometimes (2), regularly (3), often (4), or always (5). The questions refer to a wide range of symptoms of fatigue (e.g., "I get tired very quickly", "I have problems thinking clearly", and "I don't do much during the day"). Two questions are reverse scored (i.e., "I have enough energy for everyday life" and "When I am doing something, I can concentrate quite well"), and all the items are summed together to obtain the scale score. The range of possible scores is 10-50.

2.6.3 Parenting Self-Efficacy. Parenting self-efficacy was measured using the 20-item Fathering Self-Efficacy Scale (Sevigny, 2013). It was modified to be gender neutralized to make it applicable to both mothers and fathers. Reliability for this measure was good within this sample, (Cronbach's alpha = .90), which was consistent with prior research (Sevigny, in press). The scale also demonstrates good concurrent validity ($r = .26, p < .001$) in that it corresponds with a measure of parental responsibility (Sevigny, 2013). The Fathering Self-Efficacy Scale was used as it is the only scale that measures this construct that has been developed for fathers and validated with a male sample. As

many of the questions used to create this measure were similar to ones on existing scales (e.g., measures of play, safety, and discipline) that are used for mothers, this scale may still be appropriate for mothers. As it was based on existing measures that were designed for mothers, but designed to measure parenting self-efficacy for fathers, it was chosen as the most appropriate measure that could be used for both groups.

Each item on the Fathering Self-Efficacy Scale is scored on a 9-point Likert scale, with anchors allowing the respondent to indicate that they "Completely Disagree" with a statement (1), "Moderately Agree" (5), "Completely Agree" (9), or any whole number in between. The questions refer to a range of efficacy domains (e.g., "I am able to help my child cope with his or her feelings", "I am able to tend to most aspects of my child's daily care such as feeding, bathing, sleep routines", and "I know how to encourage my child's interest in the world"). Responses to the items were summed and averaged, resulting in possible scores ranging from 1-9.

2.6.4 Parenting Satisfaction. Parenting satisfaction was measured with the Satisfaction subscale of the Parenting Sense of Competence Scale (PSOC; Johnston and Mash, 1989). The satisfaction subscale of the PSOC is a nine item self-report measure in which parents answer questions about their perceptions about themselves as a parent (e.g., "If being a mother/father of a child were only more interesting, I would be motivated to do a better job as a parent"). The items on this measure are responded to using a 6-point Likert scale ranging from 1 ("Strongly Disagree" to 6 ("Strongly Agree"). All items on the Satisfaction subscale of the PSOC are reverse scored and summed together, resulting in a possible range of scores of 9-54, in which higher scores are indicative of higher levels of parenting satisfaction. Reliability for this measure was good

within this sample (Cronbach's alpha = .79), which is consistent with previous research (Johnston and Mash, 1989).

2.6.5 Sleep Quality. Sleep quality was measured with the Pittsburgh Sleep Quality Index (Buysse et al., 1989), a 19-item self-report measure of sleep quality and sleep disturbance. Reliability for this measure was acceptable within this sample (Cronbach's alpha = .66), which was lower than previous research has found (Cronbach's alpha = .83; Buysse et al., 1989). Previous research has found that it has good construct validity in that the Pittsburgh Sleep Quality Index is correlated with other measures of sleep quality and problems ($r \geq .69$) (Carpenter & Andrykowski, 1998). Furthermore, it demonstrates discriminant validity in that it correlates poorly with unrelated constructs (i.e., nausea; $r \leq .37$).

The Pittsburgh Sleep Quality Index is composed of 19 self-report questions. For the purposes of this study, the 14 self-report questions were employed, omitting the items that would typically be answered by the participant's partner. The questionnaire consists of a variety of questions asking about the respondent's sleep within the last month. Some questions are asked to quantify sleep amounts and habits (e.g., "During the past month, when have you usually gotten up in the morning?"). There are also questions asking about frequency of specific behaviours or events (e.g., "During the past month, how often have you had trouble sleeping because you had bad dreams"). These questions are scored on a 4-point Likert scale, with options of "not during past month" (0), "less than once a week" (1), "once or twice a week" (2), and "three or more times a week" (3). The self-rated items form 7 component scores which are totaled together to produce a global

score. Global scores range from 0 (“indicating no difficulty”) and 21 (“indicating severe difficulties in all areas”).

2.6.6 Health. A single-item health scale was used. Consistent with prior research (Bowling, 2005), participants were asked “In general my health is…”. They were asked to indicate their responses on a 5-point Likert scale, with response options of 1 (poor), 2 (fair), 3, (good), 4 (very good), and 5 (excellent). A single-item health scale has been found to be associated with many other measures of health, such as specific health concerns, recovery from illness, fluctuating functional status, and service usage (Bowling, 2005).

2.6.7 Psychological Functioning. Psychological functioning was measured using the Depression Anxiety Stress Scale 21 (DASS-21; Lovibond & Lovibond, 1995b), a 21-item self-report measure of depression, anxiety, and stress. Reliability for this measure was excellent within this sample (Cronbach’s alpha = .95), which is consistent with previous research. The DASS-21 has also been shown to be able to differentiate between various clinical populations (Antony, Bieling, Cox, Enns, & Swinson, 1998). The Depression Anxiety Stress Scale 21 has also been shown be able to successfully differentiate between depression, anxiety, and stress in non-clinical individuals (Lovibond & Lovibond, 1995a).

Each question is scored on a 4-point Likert scale, where the respondent can indicate that the statement “did not apply to me at all” (0), “applied to me to some degree, or some of the time” (1), “applied to me to a considerable degree, or a good part of time” (2), or “applied to me very much, or most of the time” (3). The questions refer to a range

of symptoms (e.g., “I was aware of dryness of my mouth”, “I was worried about situations in which I might panic and make a fool of myself”, and “I found it difficult to work up the initiative to do things”). The scores of these questions can be summed in three subscales (Depression, anxiety, and stress), and totaled together to form a measure of psychological distress that can range from 0 - 63. In a study looking at the general adult, nonclinical population, a total score of 7 was found to be indicative of psychological distress at the 51st percentile, 13 was found to be indicative of the 76th percentile, and 21 was found to be indicative of the 90th percentile (Henry & Crawford, 2005).

2.6.8 Caregiver Burden. Caregiver burden was measured using the Caregiver Strain Questionnaire-Short Form 7, an abbreviated version of the Caregiver Strain Questionnaire (Brannan et al., 1997), which assesses caregiver burden issues. This version consists of seven items. It is a useful tool for measuring both objective and subjective caregiver strain. Reliability for this measure was good within this sample (Cronbach’s alpha = .84), which was consistent with previous research (Brannan, Athay, & de Andrade, 2012).

The questions are scored using a 5-point Likert scale, in which the respondent can choose their level of agreement with the statement from the options 1 (not at all), 2 (a little), 3 (somewhat), 4 (quite a bit), or 5 (very much). The questions are prefaced with “In the past month, how much of a problem were the following”, and then ended with 4 questions that form the objective strain subscale (e.g., “Disruption or upset of relationships within the family due to this youth’s problems”) and 3 questions that form the subjective internalized strain subscale (e.g., “How sad or unhappy did you feel as a

result of this youth's problems"). The subscales are summed together to form a total score, which could range from 7 – 35.

2.6.9 Social Support. The Inventory of Socially Supportive Behaviors (ISSB) Short-Form (Barrera & Baca, 1990) is a self-report measure of social support. Reliability for this measure was good within this sample, (Cronbach's alpha = .87). This measure has also demonstrated high test-retest reliability in terms of the total score (Pearson's r = .88, $p < .001$) as well as construct validity in that it is correlated with social support network and perceived family support. (Barrera et al., 1981). It is composed of 19 items which all use a 5-point Likert scale, with answers of 1 (Not at all), 2 (Once or twice), 3 (About once a week), 4 (Several times a week), and 5 (About every day). The questionnaire is prefaced with "During the past four weeks, how often did other people do these activities for you, to you, or with you", and followed by questions referring to specific socially supportive behaviours (e.g., "Pitched in to help you do something that needed to get done"). It is scored by averaging the responses of all questions by summing the responses and dividing the total by 19, resulting in a score between 0 and 5.

2.6.10 Marital Satisfaction. A single-item marital satisfaction scale was used for participants who identified as married or in a common-law relationship. Consistent with prior research (Bailey, Kerley, & Kibelstis, 2012), participants were asked "On a scale of 1 to 10, rate your over-all satisfaction with your marriage with 1 being very unsatisfied and 10 being extremely satisfied". This question has been shown to correlate well with the larger and widely used Dyadic Adjustment Scale, which is used to identify marital dissatisfaction (Bailey, Kerley, & Kibelstis, 2012).

2.6.11 Child Sleep Quality. Child sleep quality was measured using the Children's Sleep Habits Questionnaire (Owens et al., 2000), a report completed by parents to rate their child's sleep. Reliability for this measure was good within this sample (Cronbach's alpha = .82). It has also been found to have acceptable test-retest reliability (ranging from .62 - .79) and to successfully differentiate between a community group and a sleep-disordered group of children aged 4-10 years (Owens et al., 2000). It has also been found to be useful in identifying sleep-disordered children aged 2 – 5.5 years and for children with developmental disorders, such as ASDs (Goodlin-Jones, Sitnick, Tang, Liu, & Anders, 2008).

It is composed of 33 items, although 2 of the items are part of two subscales. Within this study, due to human error, only 32 items were included. The existing items were summed as usual, resulting in a more conservative measure of child sleep quality than the one intended by the developers. The questions are scored using a 3-point Likert scale, in which the respondent can choose 1 (rarely), 2 (sometimes), or 3 (usually). Some questions are reverse scored to ensure that respondents are paying attention. Subscales included in this questionnaire are Bedtime (8 items; e.g., "Child falls asleep within 20 minutes after going to bed", Sleep Behavior (15 items; e.g., "Child is restless and moves a lot during sleep"), Waking During the Night (2 items; e.g., "Child awakes more than once during the night"), Morning Waking (5 items; e.g., "Child has difficulty getting out of bed in the morning"), and Daytime Sleepiness (3 item; e.g., "Child seems tired"). The subscales are summed together to form a total score, which could range from 0 – 99. The developers of this questionnaire suggest a cut off of 41 points to indicate clinically

problematic sleep. This clinical cut off was used despite a question being omitted, resulting in a more conservative interpretation of the measure.

2.6.12 Problem Behaviours. The Brief Developmental Behaviour Checklist-P24 (Taffe et al., 2007) was used to measure problem behaviours that the child is exhibiting. It is a 24-item checklist that has been validated for use with children with ASDs. Reliability for this measure was good within this sample, (Cronbach's alpha = .71). The scale is measured using 3-point Likert scales of 0 (not true as far as the informant knows), 1 (somewhat or sometimes true), and 2 (very true or often true). The scores for each item are then totalled together, creating a total score. As there are 24 items, this means that the total score will range from 0 – 48. The questions target a broad range of behaviours, including questions that are and are not conceptually related to ASDs (e.g., "Repeats the same word or phrase over and over", "Doesn't show affection", "Upset or distressed over small changes in routine or environment", and "Grinds teeth").

3.0 Results

3.1 Data Analyses

In order to determine the adequate number of participants needed for this study, a power analysis was conducted. A large effect size was anticipated as it fits the findings of similar studies of parental fatigue (e.g., Giallo et. al, 2011). If a large effect size is to be found with 80% power (a = .05), then 49 participants are needed in each group. This study meets the criteria for detecting a large effect size in the analyses used for the mothers within the sample, but not the fathers (Cohen, 1992). As such, it is possible that variables that are associated with paternal fatigue were not identified.

Descriptive analyses were performed on all study variables and demographics, examining their frequencies. T-tests were performed on study variables, examining differences between groups. Correlations were performed on all study variables, examining the associations between the study variables. Multiple regressions were performed, examining the associations between the study variables when considered together. All analyses were performed using Statistical Package for the Social Sciences version 21. In order to preserve the independence of the data, participants who responded from the same family were omitted from all analyses.

Composite scores were created for data reduction purposes and to reduce multicollinearity concerns. Three composite scores were created from variables that were conceptually related and correlated: Measures of Mental Wellbeing (Psychological Functioning and Caregiver Burden), Measures of Physical Wellbeing (Health and Sleep Quality), and Measures of Child Difficulties (Child Sleep and Child Behaviour).

3.2 Descriptive Analyses

Table 3 displays the descriptive data for the primary variables of study. Several of the measures used provide interpretative cut-off scores, allowing for a better understanding of the sample. The PSQI suggests that scores of 5 or higher are to be considered as indicative of poor sleep quality; within this study, 81.4% of participants received a score of higher than 5, indicating that sleep problems were common within this sample of parents with children with ASDs. Psychological functioning scores suggest that the parents within this study are experiencing psychological distress at higher levels than would be expected in the general population (Henry & Crawford, 2005). Finally,

84.6% of mothers and 88.2% of fathers reported child sleep scores that are indicative of problematic sleep (Owens et al., 2000).

Table 3:
Means and standard deviations of study variables by gender

	Females Mean (*SD*)	Males Mean (*SD*)	*t*	sig.	Std. Error Difference
Fatigue	33.49 (9.02)	27.59 (7.56)	3.33	.001	1.77
Parenting Self-Efficacy	6.23 (1.28)	6.44 (1.22)	-.79	.432	.26
Parenting Satisfaction	35.12 (8.51)	38.68 (7.17)	-2.13	.035	1.67
Health	2.86 (.91)	3.00 (.85)	-.77	.443	.18
Parent Sleep	9.51 (3.76)	8.18 (3.49)	1.77	.080	.76
Psychological Functioning	23.92 (14.54)	18.18 (12.43)	2.01	.047	2.87
Caregiver Burden	24.72 (6.51)	22.97 (5.21)	1.38	.170	1.26
Social Support	1.773 (.608)	1.95 (.57)	-1.47	.144	.12
Marital Satisfaction	6.64 (2.06)	7.77 (1.92)	-2.51	.014	.45
Child Behaviour	20.45 (6.10)	19.32 (6.15)	.90	.373	1.26
Child Sleep	51.42 (9.58)	48.94 (7.80)	1.33	.186	1.87

A series of t-tests were conducted to allow for comparisons between mothers and fathers on the study variables. Mothers and fathers differed significantly on measures of fatigue, parenting satisfaction, marital satisfaction, and psychological functioning. In terms of fatigue, fathers reported significantly lower fatigue levels than mothers. In terms of parenting satisfaction, mothers reported significantly lower satisfaction levels, than fathers. In terms of marital satisfaction, mothers reported significantly lower satisfaction levels than fathers. Finally, in terms of psychological functioning, mothers reported higher levels of psychological distress than fathers. As fatigue tends to be studied in younger children, parents were also grouped in to parents of a young child (2-5 years old) and parents of an older child (6-12 years old) to determine if there parents of younger

children are more fatigued. Parents of older children and parents of younger children reported similar levels of fatigue, $t(110) = -.286$, $p \leq .775$, with means of 31.38 (SD = 9.82) and 31.89 (SD = 8.53), respectively.

3.3 Research Question 1: Among parents of children with ASDs aged 2 to 12 years, do mothers report higher levels of fatigue than fathers?

To test the hypothesis that women would report higher levels of fatigue than men, an independent sample t test was conducted. Mothers reported significantly higher levels of fatigue than fathers, $t(110) = 3.33$, $p \leq .001$.

3.4 Research Question 2: Are psychological, physiological, and situational variables associated with fatigue levels in parents?

It was anticipated that fatigue would be significantly correlated with the psychological, physiological and situational variables in the model. As shown in Table 4, Fatigue was found to be significantly correlated to each of the other study variables except Marital Satisfaction ($r = -.17$, $p \leq .107$).

Table 4:
Correlations between measures

	2	3	4	5	6	7	8	9	10	11
Fatigue	-.384**	-.566**	.662**	.566**	-.553**	.517**	-.170	-.225*	.398**	.332**
Parenting Self-Efficacy		.494**	-.306**	-.345**	.294*	-.276*	.160	.301**	.015	-.041
Parenting Satisfaction			-.687**	-.559**	.377**	-.320**	.267*	.200*	-.115	-.184
Psychological Functioning				.482**	-.395**	.358**	-.214*	-.116	.206*	.139
Caregiver Burden					-.349**	.374**	-.339**	-.191*	.277*	.374**
General Health						.381**	-.082	.182	-.226*	-.291*
Parent Sleep							-.103	-.151	.231*	.173
Marital Satisfaction								.159	-.191	-.197
Social Support									-.108	-.046
Child Sleep										.384**
Child Behaviour										

Note. $n = 112$, except for associations with marital satisfaction, where $n = 91$
** = $p < .001$
* = $p < .05$.

Furthermore, it was anticipated that study variables that were conceptually related would be significantly associated with each other, and that these associations would allow these constructs to be reduced into composite scores for data reduction purposes and to reduce multicollinearity concerns. This technique has been used in other studies of parenting (e.g., Wootton, Frick, Shelton, & Silverthorn, 1997). Four variable pairings were hypothesized: Measures of Psychological Wellbeing (Psychological Functioning and Caregiver Burden), measures of Physical Wellbeing (Health and Sleep Quality), measures of Situational Supports (Marital Satisfaction and Social Support), and measures of Child Difficulties (Child Sleep and Child Behaviour). Correlations between the variables were examined to determine if creating a composite score was appropriate. If so, the variables were converted into z-scores and then summed. As such, Psychological Wellbeing was created from the DASS-21 and Caregiver Burden measures ($r = .48$, $p \leq .001$), Physical Wellbeing was created from health and sleep quality measures ($r = -.38$, $p \leq .001$), and Child Difficulties was created from the child problematic behaviours and child sleep measures ($r = .38$, $p \leq .001$).

Though marital satisfaction was planned to be a part of the regression model, it was omitted from the analyses. As it did not correlate significantly with social support ($r = .16$, $p < .131$), the two variables could not be reduced into a Situational Supports Factor as planned. Furthermore, all of the variables correlated with fatigue except for marital satisfaction, suggesting that it is not, as hypothesized, a part of the model of fatigue.

Hierarchical multiple regressions were conducted in order to examine how psychological, physiological, and situational factors contributed to the reported levels of fatigue of parents. In order to control for demographic factors that were conceptually

likely to influence the model, these variables were entered in the first block. The demographic variables on this block consisted of age, highest level of education attained, employment status, income, child age, and number of children in the family with a diagnosis of ASDs (Elek et al., 2002, Giallo et al., 2011). The Psychological Wellbeing score, composed of the Psychological Functioning and the Caregiver Burden measures, was entered on the second block. The Physical Wellbeing score, composed of the general health and sleep quality measures, was entered on the third block. The social support measure was entered on the fourth block. Finally, Child Difficulties was entered on the fifth block.For parents, the overall model (see Table 5), was statistically significant, F (10, 101) = 14.32, $p < .001$, accounting for 58.6% of the variance. The first block of demographic variables significantly accounted for 23.4% of the variance, producing a significant model, F (6, 105) = 5.35, $p <.001$. Out of the six demographic variables, none of them was a significant predictor of fatigue. The second step of the regression, which included Psychological Wellbeing, was also significant, F (7, 104) = 18.51, $p <.001$ and accounted for 55.5% of the variance, meaning an increase of 22.1% of explained variance. Psychological Wellbeing was a significant predictor of fatigue in parents of children with ASDs. The third step of the regression, in which Physical Wellbeing was added, was also significant, F (8, 103) = 16.06, $p <.001$, accounting for 55.5% of the variance, meaning no increase of explained variance. However, Physical Wellbeing was not a significant predictor of fatigue. The fourth step of the regression, including social support, was also significant, F (9, 102) = 14.51, $p <.001$, and accounted for 56.1% of the variance, meaning an increase of 0.6% explained variance. Social support was not a significant predictor of fatigue in parents of children with ASDs. Finally, Child

Difficulties was included, resulting in a significant model, F (10, 101) = 14.31, p <.001, that accounted for 58.6% of the variance, meaning an increase of 2.5% explained variance. For parents within this sample, Child Difficulties was a significant predictor of fatigue. In the final model, Psychological Wellbeing and Child Difficulties were significantly associated with parents' levels of fatigue.

Table 5:
Regression model of fatigue for parents

	R^2	Adj R^2	Std. Error	β	t	sig.
Step 1	.23	.19				
Age			.10	-.04	-.57	.574
Education			.56	-.01	-.15	.883
Employment Status			.81	.10	1.41	.163
Total family income			.48	-.08	-1.04	.302
Number of children with a diagnosis of ASDs			1.67	-.05	-.74	.464
Age of child			.21	-.05	-.66	.512
Step 2	.56	.53				
Psychological Wellbeing			.41	.57	7.52	.000
Step 3	.56	.52				
Physical Wellbeing			.53	-.01	-.20	.843
Step 4	.56	.52				
Social Support			.99	-.08	-1.19	.237
Step 5	.59	.55				
Child Difficulties			.45	.19	2.47	.015

3.5 Research Question 3: Are the same psychological, physiological, and situational variables associated with fatigue in mothers and fathers of children with ASDs?

Hierarchical Multiple Regressions were conducted in order to examine how psychological, physical, and parental situational factors contributed uniquely to levels of fatigue in fathers and mothers. Variables were entered in the same order as in the previous hierarchical multiple regression analysis. The overall model was significant for both mothers (see Table 6) and fathers (see Table 7), with Psychological Wellbeing

acting as a significant predictor of fatigue for both groups. Physical Wellbeing and social support were not significant predictors for either group. However, there were differences in the model of fatigue for mothers and fathers.

For mothers, the overall model (see Table 6), was statistically significant, F (10, 67) = 10.12, $p > .001$, accounting for 60.2% of the variance. The first block of demographic variables produced a significant model, F (6, 71) = 4.65, $p < .001$, accounting for 28.2% of the variance. Out of the six demographic variables, none of them were significant predictors of fatigue. The second step of the regression included the psychological factor, was also significant, F (7, 70) = 13.22, $p < .001$, and significantly accounted for 56.9% of the variance, meaning an increase of 28.7% explained variance. Psychological Wellbeing was a significant predictor of fatigue in mothers of children with ASDs. The third step of the regression, in which Physical Wellbeing was included, was also significant, F (8, 69) = 11.49, $p < .001$, and accounted for 57.1% of the variance, meaning an increase of 0.2% of explained variance. Physical Wellbeing was not a significant predictor of fatigue. The fourth step of the regression included social support, was also significant, F (9, 68) = 10.07, $p < .001$, and accounted for 57.1% of the variance, meaning it did not explain additional variance. Social support was not a significant predictor of fatigue in mothers of children with ASDs. Finally, Child Difficulties was included, resulting in a significant model, F (10, 67) = 10.12, $p <.001$, that significantly accounted for 60.2% of the variance, meaning an increase of 3.1% explained variance. For mothers within this sample, Child Difficulties was a significant predictor of fatigue. In the final model for mothers, as in the final model for parents, Psychological Wellbeing and Child Difficulties were significantly associated with levels of fatigue.

Table 6:
Regression model of fatigue for mothers

	R^2	Adj R^2	Std. Error	β	t	sig.
Step 1	.28	.22				
Age			.13	-.03	-.37	.711
Education			.70	-.11	-1.27	.208
Employment Status			.93	.08	.85	.401
Total family income			.59	-.04	-.46	.651
Number of children with a diagnosis of ASDs			2.07	-.09	-1.11	.269
Age of child			.27	-.05	-.64	.524
Step 2	.57	.53				
Psychological Wellbeing			.50	.57	5.82	.000
Step 3	.57	.52				
Physical Wellbeing			.64	-.03	-.40	.688
Step 4	.57	.51				
Social Support			1.19	.00	-.02	.987
Step 5	.60	.54				
Child Difficulties			.55	.22	2.26	.027

For fathers, the overall model (see Table 7), was statistically significant, F (10, 23) = 4.07, $p \leq .003$, with 63.9% of the variance being accounted for. The first block of demographic variables significantly accounted for the 12.5% of the variance, and did not produce a significant model, F (6, 27) = 0.64, $p \leq .696$. Out of the six demographic variables, only employment status was a significant predictor of fatigue, with unemployment being associated with the highest levels of fatigue. The second step of the regression included Psychological Wellbeing, was significant, F (7, 26) = 4.75, $p \leq .002$, and significantly accounted for 56.1% of the variance, meaning an additional 43.6% of explained variance. Psychological Wellbeing was a significant predictor of fatigue in fathers of children with ASDs. The third step of the regression, in which Physical Wellbeing was included, was also significant, F (8, 25) = 4.03, $p \leq .003$, and significantly accounted for 56.3% of the variance, meaning an additional 0.2% of explained variance.

Physical Wellbeing was not a significant predictor of fatigue. The fourth step of the regression included social support, was significant, F (9, 24) = 4.16, $p \leq .002$, and significantly accounted for 61.0% of the variance, meaning an increase of 3.7% of explained variance. Social support was not a significant predictor of fatigue although it was approaching significance. Finally, Child Difficulties was included, resulting in a significant model, F (10, 23) = 4.07, $p \leq .003$, that significantly accounted for 63.9% of the variance, meaning an additional 2.9% of explained variance. Child Difficulties was not a significant predictor of fatigue for fathers. In the final model for fathers, as in the final model for parents, Psychological Wellbeing was significantly associated with fatigue; however, unlike the parental fatigue model, the paternal fatigue model included employment status as significantly associated with levels of fatigue.

Table 7:
Regression model of fatigue for fathers

	R^2	Adj R^2	Std. Error	β	t	sig.
Step 1	.13	-.07				
Age			.20	-.07	-.49	.631
Education			1.17	-.07	-.44	.667
Employment Status			2.71	.44	2.46	.022
Total family income			1.19	.28	1.38	.182
Number of children with a diagnosis of ASDs			2.91	.01	.09	.929
Age of child			.37	-.19	-1.26	.221
Step 2	.56	.44				
Psychological Wellbeing			.90	.79	5.16	.000
Step 3	.56	.42				
Physical Wellbeing			1.07	-.15	-1.02	.318
Step 4	.61	.46				
Social Support			2.01	-.29	-1.93	.067
Step 5	.64	.48				
Child Difficulties			.86	.21	1.36	.187

3.6 Research Question 4: Are higher fatigue levels associated with lower Parenting Self-Efficacy and Parenting Satisfaction for mothers and fathers?

In order to test the hypothesis that fatigue levels would be negatively correlated with Parental Self-Efficacy, correlations were calculated for mothers and fathers. Within this sample of parents with children with ASDs, fatigue levels were significantly negatively correlated with parental self-efficacy for both mothers ($r = -.36$, $p \leq .001$) and fathers ($r = -.44$, $p \leq .009$).

It was also hypothesized that fatigue levels would be negatively correlated with Parental Satisfaction. To test this hypothesis, correlations were calculated for both mothers and fathers. Fatigue levels were negatively correlated with parental satisfaction for both mothers ($r = -.49$, $p \leq .001$) and fathers ($r = -.70$, $p \leq .001$) within this sample.

4.0 Discussion

This study contributes to our understanding of fatigue in parents of children with ASDs in a number of important ways. Through the success at recruiting a larger proportion of male participants than many other parenting studies, this study was able to examine how parental fatigue is similar and different for mothers and fathers. This study found evidence that fatigue is being experienced by both mothers and fathers of children with ASDs of a wide range of ages. Exploring parental fatigue using the TOUS model allowed this study to identify and examine correlates of fatigue, and found that while there are some similarities between variables associated with fatigue for mothers and fathers, there are also differences that have implications for our understanding of parental fatigue.

4.1 Mothers and fathers of children with ASDs are experiencing fatigue

These findings indicate that mothers and fathers who participated in this study are experiencing fatigue levels higher than those in the general population (De Vries, Michielsen, & Van Heck, 2003). It is difficult to compare the fatigue levels of the parents in this study with other groups of parents, due to the lack of a specific parental fatigue measure. Currently, researchers are studying parental fatigue using measures that have been developed for the assessment of fatigue in medical populations. These measures have been applied to the study of parental fatigue in a variety of ways making comparisons between different studies and their samples difficult. Moreover, although fatigue may be particularly relevant to parents of children with developmental disorders in general, no published studies were found examining parental fatigue in these groups. As hypothesized, mothers in this study reported significantly higher levels of fatigue than fathers. This finding is consistent with the majority of the parenting literature on fatigue for parents of typically developing children (e.g., Cooklin et al., 2012; Loutzenhiser, McAuslan, & Sharpe, 2015). Researchers have suggested that mothers may be more exposed to and impacted by family demands than fathers (Giallo et al., 2013). As women tend to do more of the daily child care activities within a couple, the additional demands of raising a child with a developmental disorder may be especially problematic for mothers. As the vast majority of fathers, but not mothers, in this study were employed full-time, it is likely that the mothers are performing more of the childcare tasks. However, it is necessary to assess the specific tasks that individual parents are performing in order to determine if these differences in fatigue are due to differences in the demands on mothers and fathers.

4.2 Fatigue is a persistent experience that is not limited to parents of young children

By expanding our study of parental fatigue to include children beyond the age of 6, this study found that fatigue is an ongoing, persistent experience for parents of children with ASDs. For both mothers and fathers, child age was not associated with their levels of fatigue. Fatigue has been generally examined in parents of young children, given the additional demands associated with caring for infants and toddlers and the assumptions that these demands lessen as children age. While this may be true for parents of typically developing children, this is clearly not the case for the parents in this study. The question remains if the ongoing, persistent nature of fatigue in parents of children with ASDs is a mark of this population, emblematic of parents of children with developmental disorders, or endemic in parents in general. More research is needed to examine fatigue in parents of older children, both typically developing and children with developmental disorders.

4.3 There are similarities and differences in the correlates associated with fatigue for mothers and fathers

The TOUS model (Lenz et al., 1997) allowed this study to identify and examine important correlates of fatigue. In contrast to prior research, parent age, education level and income were not associated with fatigue (Kocalevent et al, 2011; Schwarz, Krauss, & Hinz, 2003; Watt et al., 2000). This may be due to characteristics of this sample, as there was little variation amongst participants on these variables. While previous studies have found a relationship between employment status and fatigue levels in the general population (Loge, Ekeberg & Kaasa, 1998), full-time employment was associated with lower levels of fatigue for fathers only in this study. This finding is to be considered as suggestive of a pattern, as the vast majority of fathers in this study were employed full-time. This may reflect the division of child-care tasks discussed earlier, or it might reflect

the fact that the majority of the fathers in this study were working full-time. Examining the role of employment in larger, more diverse samples, as well as division of childcare tasks could shed more light on this relationship.

Consistent with expectations, the mothers in this study reported experiencing significant levels of psychological distress. However, by including fathers in this study, it was revealed that fathers of children with ASDs are also reporting significant levels of psychological distress. On this measure of depression, anxiety, and stress, fathers reported levels of psychological distress that exceeded what would be expected in three quarters of the general population. Despite these high levels, mothers in this study reported significantly higher levels of psychological distress than the fathers. This finding is consistent with previous research which found higher levels of depression and anxiety in mothers of children with ASDs than in fathers of the same children, and suggested that it is due to the mother being more involved with the child (Foody et. al, 2015). These findings highlight that psychological distress is a prevalent issue among parents of children with ASDs.

Given the additional challenges associated with raising a child with a diagnosis of ASDs, this study included a measure of caregiver burden to assess parents' perceptions of the level of difficulty and disruption they experience while caring for their child with a diagnosis of ASDs. Caregiver burden is understudied in fathers in general, and to the researcher's knowledge, this was the first study to compare caregiver burden in mothers and fathers of children with ASDs. As such, it provides a useful exploration of this construct in parents and a point of reference for future researchers. Mothers and fathers reported experiencing similar levels of difficult and disruptive situations associated with

caregiving for their children. It may be that while caregiver burden tends to be thought of as associated with childcare activities, there is also burden associated with the role of financial provider. It may be that though mothers tend to be impacted by the pressures of childcare and child-rearing, fathers experience a comparable pressure to provide for the family. However, the role of financial provider is often ignored in parenting research. Future research could examine the degree to which parents feel they are responsible for different domains of raising their child, including more traditionally male roles. These differences in how gender impacts the psychological factors associated with fatigue highlight the complex nature of gender and wellbeing.

Consistent with expectations, psychological factors predicted fatigue levels in both mothers and fathers. This finding lends support for the TOUS model, as it highlights the need to go beyond physical symptoms when studying fatigue. The negative association between psychological factors and fatigue has implications for clinicians. As both of the psychological factors, namely psychological functioning and caregiver burden, were significantly positively correlated with fatigue levels, these may be effective prevention and intervention focuses in combating parental fatigue. While causal directions between the relationship of psychological factors and fatigue remain to be explored by future studies and cannot be ascertained from this data, it may serve clinicians and their clients well to consider this relationship and focus their efforts on strengthening a parent's abilities to cope with and alleviate depression, anxiety, stress, and caregiver burdens.

Given that most studies on parental fatigue have focused on physical health issues associated with birth and delivery for mothers, this study extends the understanding of the

role of physical health in fatigue by focusing on general health and sleep quality in both mothers and fathers. Overall, the mothers and fathers in this study reported similar levels of good health and poor sleep quality. In terms of health, parents reporting poorer health also reported higher levels of fatigue. This is consistent with previous research on parents with children with ASDs, suggesting that measuring general levels of health is important in the study of parental fatigue (Giallo et al., 2011). While this current study used a one-item measure, it may be worthwhile examining which specific aspects of health are associated with fatigue among mothers and fathers, such as diet, exercise, or medical concerns. The mechanism through which fatigue is associated with general health is not clear. It may be that it prevents one from engaging in positive general health behaviours, such as exercising or eating well, or because physical inactivity and a poor diet results in fatigue.

Consistent with previous research on parents of children with ASDs, both mothers and fathers in this study reported poor levels of sleep quality (Giallo et al., 2011; Benderix, Nordström, & Sivberg, 2006). This growing body of literature points to the necessity of addressing sleep quality in these parents. Physicians and clinicians could screen parents of children with ASDs for problematic sleep, and consider providing them with skills to improve their sleep, or encourage them to seek other supports, such as respite, that may help them get the rest that they require. Consistent with expectations, lower levels of sleep quality were associated with higher levels of fatigue within this sample (Giallo et al., 2013). Future research may also benefit from less subjective measures of sleep quality, and instead seek to measure sleep quality in a more objective manner. Tools that measure sleep duration and sleep cycles, such as sleep journals, as

well as clinical observations and screenings may provide a more objective perspective on sleep within this population and its connection to fatigue. By better understanding the kinds of sleep challenges that parents are experiencing, researchers may be able to focus on the mechanisms by which fatigue and sleep quality are related.

The TOUS model suggests that situational factors will be associated with fatigue. This study focused not only on parent-based situational factors, but extended the model to examine the role of child-based characteristics in parental fatigue. In terms of parent-based factors, mothers and fathers reported similar levels of social support. As previous research has suggested that parents of children with ASDs have difficulties accessing enough social support (Benderix et al., 2006), this study used a measure of social support that focused on the frequency and quantity of social support. The findings of this study suggest that while parents are able to access social support, the frequency of this access may be limited.

As this measure of social support focused on the frequency with which a variety of supportive activities occur, it is unclear whether or not mothers or fathers feel that the support they receive is adequate. Within this sample, social support was negatively correlated with fatigue, which is consistent with the literature (Giallo et al., 2011). Social support is likely to help mitigate fatigue, as other people are able to help with demands in practical and supportive ways. It may also be the case that parents are less likely to seek out social support if they are feeling high levels of fatigue, due to mental and physical exhaustion. However, social support did not explain additional variance in fatigue levels beyond psychological factors. As one of the psychological factors, caregiving burden,

examined the perceived impact of raising their child, this may be because the social challenges associated with ASDs were already captured.

As parents of children with ASDs have a higher divorce rate than parents in the general population, this study identified marital satisfaction as a possible parent-based situational factor in the TOUS model of fatigue. In this study, parents reported their marriages as fairly satisfying, although mothers reported lower levels of marital satisfaction than fathers. This may be the reason why, contrary to expectations, marital satisfaction was not associated with parental fatigue; it may simply not have been a problem within this sample. It is also possible the mechanism by which divorce and separation are associated with higher levels of fatigue is through disrupted social patterns and socioeconomic difficulties, rather than the satisfaction with the relationship.

This study was the first to include child-based situational factors as correlates of parental fatigue in parents of older children with ASDs. The two child-based factors this study examined were child sleep quality and child problematic behaviours. Consistent with previous research on children with ASDs (Humphreys et al., 2014), parents reported that their children were experiencing poor sleep. As hypothesized, poor child sleep quality was associated with higher levels of fatigue for both mothers and fathers. This was anticipated as parents have reported that child sleep quality is a challenge for them, however, no other studies have directly linked child sleep quality of this range of children to parental fatigue. This finding that the children within this population tend to have poor sleep and that this poor sleep quality is associated with higher levels of fatigue in their parents suggests that improving the sleep quality of children with ASDs may be an important direction of research and clinical practice. Physicians could be screening for

sleep problems in children with ASDs, and providing their parents with information that may improve the quality of the child's sleep, such as good sleep hygiene habits and referrals to sleep clinics. Although causal inferences cannot be made with this data, this is evidence that services focused on improving the child's sleep quality may benefit not only the child, but the parent as well. Another option that may be useful to parents is respite, providing them an opportunity to rest while having their child cared for. Given the findings that both parents and children within this population tend to have poor sleep quality, services and information to alleviate this problem are needed for this tired group. Further research is needed to examine the impact of these and other sleep interventions on the fatigue levels of parents.

This study also found support for the hypothesis that child problematic behaviours were positively associated with fatigue. This was consistent with previous research which suggested that child behaviour challenges be considered as a factor of fatigue in parents of children with ASDs (Seymour et al., 2012). Mothers and fathers within this sample were similar in the reported level of problematic behaviour that their child engages in, with the most frequent problematic behaviours reported being that the child is impatient, overexcited, preoccupied by few interests, or upset or distressed by small changes to the environment or routines. This finding that child problematic behaviours are positively associated with fatigue is evidence that child-based variables are an important component of fatigue for researchers to consider. Furthermore, as there is evidence that fatigue impacts parenting styles and behaviours, it follows that the child's behaviours may be impacted by parental fatigue. Parents who are mentally and physically exhausted may be less likely to consistently behave in ways that extinguish problematic behaviours, and

may be more likely to find themselves and their child in stressful, tired situations which exasperate problematic behaviours. At the same time, problematic behaviour from their child is likely mentally and physically exhausting for parents. Although this study is unable to draw causal conclusions about whether fatigue impacts child behavioural problems or vice versa, it is likely that the two maintain each other once established.

Further research is needed to explore the feasibility of reducing child problematic behaviours as a means of reducing fatigue levels in parents. Parent training has been shown to affect behavioural changes in children (Lundahl, Risser, & Lovejoy, 2006), and this may be an effective means of intervention for fatigue. Research could focus on the mechanisms that help some parents manage their child's behaviours while other parents find the same behaviours more challenging. Furthermore, studies involving behavioural interventions that also measure parental wellbeing outcomes, such as fatigue, may provide useful information for those who work with children with ASDs and their parents. If reducing child problematic behaviours reduces parental fatigue, it may be an especially useful means of intervention in that it would be beneficial to both parent and child; the parent may benefit from increased wellbeing and lower fatigue, and the child may benefit in a wide range of ways, depending on the behavioural problem, from increased safety, to additional social/community opportunities, to improved abilities to communicate wants and needs.

Child-based situational variables were hypothesized to predict parental fatigue over and above psychological factors, physiological factors, and parental situational factors. Although higher levels of child-based situational factors were predictive of higher levels of fatigue in parents in general as well as mothers, they were not predictive

of higher levels of fatigue in fathers. This difference in fatigue predictors may be due to differences in the roles and expectations of mothers and fathers. It may be that mothers are perceived as or in practice are more responsible for managing child behaviours and sleep difficulties than fathers. As such, they may be more impacted by child-based situational factors. Just as fathers may be influenced by traditional gender roles when employment status impacts their fatigue levels, maternal fatigue may be influenced by the traditionally female role as the child's caregiver.

4.4 Fatigue is associated with parenting outcomes for both mothers and fathers

The TOUS model suggests that outcome variables are associated with fatigue, and as such parenting satisfaction and parenting self-efficacy were identified and examined. In terms of parenting satisfaction, parents within this sample reported similar levels to mothers of typically developing children (Dunning & Giallo, 2012), and consistent with studies of parents of typically developing children, fathers reported significantly higher levels of parenting satisfaction than mothers (Rogers & Matthews, 2004). This may be due to differences in how mothers and fathers perceive their role as parents. More realistic and attainable expectations of parenting may be the mechanism that impacts parenting satisfaction, however this suggestion requires further research examining parenting beliefs associated with parenting satisfaction.

In contrast to previous research, no difference was found between parenting self-efficacy levels in mothers and fathers. Unlike previous research, this study used a measure of parenting self-efficacy that is thought to be less biased by gender. As discussed, there is evidence that previous measures have tended to be biased towards recognizing parenting self-efficacy in mothers, but not in fathers (Sevigny, 2013). The

different levels of parenting self-efficacy in mothers and fathers that have been reported in the literature may be artefacts of measures that do not adequately measure parenting self-efficacy in fathers. Further research into the efficacy of this scale with mothers is required, however, the suggestion that measures of parenting may be more accurate if they take fathers into consideration rather than just mothers warrants consideration for future studies. Practitioners working with parents would also be prudent to consider whether the tools they use or the services they provide are based on measures that are likely to have gender biases.

As expected, both parenting self-efficacy and parenting satisfaction were significantly negatively correlated with fatigue for mothers and fathers. This provides evidence that not only is fatigue negatively associated with parental wellbeing, but it is also associated with cognitions about parenting, and enjoying one's role as a parent. In terms of the negative association between fatigue and parenting self-efficacy, it may be that fatigue reduces the parent's ability to respond to demands in ways that they would want to (e.g., reduced patience, lack of energy). It may also be that feelings of low self-efficacy are fatiguing. It is likely that fatigue and lower parenting self-efficacy maintain each other. In terms of the negative association between fatigue and parenting satisfaction, the mental component of fatigue, the cognitive exhaustion, would likely be mitigated by a sense of satisfaction in the parental role. Conversely, higher fatigue levels may behave as obstacles in mothers and fathers achieving a sense of satisfaction in the parenting role. As lower levels of fatigue within this sample were associated with more positive parenting outcomes, namely parenting satisfaction and parenting self-efficacy in both mothers and fathers, this finding highlights the importance of parental fatigue

research in supporting parents, and the impact that fatigue can have on cognitions regarding parenting.

4.5 Limitations and Future Research

There are several limitations to the current study. First, this study had limitations due to the demographics of its participants. Although extra effort was made to specifically target fathers for participation, there were still not enough fathers in this study to have adequate power to run the paternal TOUS model. As such there is a better than average chance that variables that are in reality significant were not calculated as significant, such as social support. Moreover, as only 3 fathers reported that they were not employed full-time, conclusions drawn about the impact of employment status on fatigue in fathers must be speculative. Future research must continue to target fathers and recruit them in larger numbers if their parenting experience is to be better examined by researchers. Furthermore, studies of parental fatigue would benefit from a more diverse group of participants. This sample tended to be Caucasian, married, post-secondary educated, employed full-time, and in opposite-gender relationships. How the findings of this study relate to other groups of parents remains to be explored.

Second, longitudinal studies of parental fatigue would be useful, as they may allow researchers to draw causal links between fatigue and its associated variables. Examining how fatigue varies over time in relation to other variables may lead to a better understanding of the mechanisms that impact fatigue levels. Furthermore, longitudinal studies would provide information about the relationship between fatigue and its outcomes, parenting satisfaction and parenting self-efficacy.

Third, further research is needed to examine if the factors identified in this study are associated with fatigue for parents of other groups of children with developmental disorders, such as Down's syndrome. Although there are differences in the demands and experiences of different groups of parents of children with developmental disorders, there are also similarities such as additional demands, adjusting to a diagnosis, modifying an understanding of what the child needs, and coping with a chronic disease in a dependent. Further exploration of the similarities and differences of the predictors of fatigue in these groups may provide useful information about these parents and families.

Finally, further research is needed to assess the feasibility and efficacy of interventions for treating and preventing fatigue in parents. Though the evidence from this study suggests that psychological factors may be a target of intervention for both mothers and fathers, different interventions may be more or less effective for parents in each group. Furthermore, as employment status was a significant predictor of fatigue for fathers, it warrants examining if employment supports and skills training would reduce fatigue levels. For mothers, as child-based situational factors were a significant predictor of fatigue, parenting training that targets problematic child behaviours and sleep may prove to be useful in treating and preventing fatigue. Exploring interventions for fatigue that recognize the nuanced role of gender may be able to not only reduce fatigue levels, but also improve parenting self-efficacy and parenting satisfaction.

4.2 Conclusion

The different predictors of fatigue that emerged when mothers and fathers were considered as separate groups demonstrate that nuances can be lost when they are considered a single homogenous group. Much research examines parenting by either

examining mothers only and extrapolating to fathers, or including mothers and fathers in the same analyses. However, either of these approaches is problematic as mothers and fathers have shown that they experience some elements of parenting differently. It is important that research acknowledge that it is problematic to assume that mothers and fathers can be combined into one group without losing information about the nuanced role that their gender may play. It is also important that practitioners critically assess whether or not a study examining parenting or parenting experiences has adequately addressed men when using it to guide work with fathers.

In sum, this study expanded the understanding of fatigue in parents in that it examined it in both mothers and fathers of a wider age range of children with ASDs using a theoretical framework, specifically the TOUS model. Fatigue appears to be an ongoing experience for both mothers and fathers, though mothers reported higher levels of fatigue than fathers. The TOUS model was a useful way of identifying and exploring variables that were associated with fatigue, including child-based situational variables. There are both similarities between the predictors of fatigue for mothers and fathers (e.g., psychological factors are predictive of fatigue, and fatigue is predictive of higher levels of both parenting satisfaction and parenting self-efficacy) and differences in the predictors of fatigue for mothers and fathers (i.e., employment status is predictive of fatigue in fathers and child-based situational factors are predictive of fatigue in mothers). Finally, higher levels of fatigue were associated with positive parenting outcomes, namely lower levels of parenting satisfaction and parenting self-efficacy. By using a theoretical model that included child-based situational variables and studying mothers

and fathers separately, this study provides a better understanding of fatigue in parents of children with ASDs.

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Appendix A: Recruitment Poster

exhausted???

Are you a **parent of a child with Autism between the ages of 2 and 12 years of age?**

If so, we are interested in

your experiences with fatigue

You will be asked to complete an anonymous online questionnaire that will take approximately 40 minutes

This study has been approved by the University of Regina and RQHR.

For more information please contact:

Child and Family Research Group
ivens20s@uregina.ca
http://uregina.ca/~loutzlyn
306-585-4800

Appendix B: Consent Form

University of Regina

Fatigue in parents of children with Autism Spectrum Disorder:
The role of parental and child factors

You are being asked to take part in a research project. This project is being conducted by Sarah Elizabeth Ivens, B.A. (Hons.), and is being supervised by Dr. Lynn Loutzenhiser, Associate Professor, Department of Psychology, University of Regina. All research projects carried out by the Department of Psychology are covered by the rules of the Research Ethics Board at the University of Regina.

Below is an explanation of the research study. Please read through it carefully and if you agree to participate, please check the YES box at the end of this form.

It is recommended that you print a copy of the consent form for your own records before proceeding to the questionnaire.

Purpose of the Study: We are interested in learning more about your experiences as a parent of a child with autism aged 2-12 years old. You will be asked about your experiences with fatigue, parenting, health, marital satisfaction, social support, and your child's behaviours.

Procedure: You will be asked to complete a questionnaire that will take approximately 20-30 minutes of your time. Please feel free to ask questions regarding the procedures and goals of the study or your role.

Potential Risks and Benefits: There are no known or anticipated risks to you by participating in this research. While there are no clear benefits to you participating in this research, your participation is appreciated and it is hoped that the information you provide will help develop a better understanding of fatigue in parents of children with autism. As some of the following questions are of a personal nature, it is possible that the

questions will result in feelings of discomfort or anxiety. Resources will be available at the end of the study in the event that you are experiencing anxiety or distress.

Compensation: To compensate you for your time, you can enter a draw to win a $50 gift card. There will be an option to submit your email address at the end of the study to be entered in this draw. Your email address will be kept separately from your responses.

Confidentiality: Your responses will be kept confidential. While the results of the study will likely be shared and may be published in scientific reports, the fact that you participated in the study will be kept confidential.

All information collected as part of this study will be kept in the strictest confidence. While the data collection is done online, it will be protected using security protocols (the same as used by banking institutions). The data, while being compiled on-line, are only accessible through a user name and password. Your files will be electronically deleted after 10 years upon completion of the study. Access to this information will be limited to the primary researchers.

Right to Withdraw: Your participation is voluntary. You may withdraw from the study without explanation or penalty of any sort. Data that is submitted will be assumed to be provided voluntarily.

Follow up: Results from the study will be available on our research lab's website (http://uregina.ca/~loutzlyn/ResearchFindings.html).

Questions or Concerns: Contact the researcher using the information at the bottom of the page. This project has been approved on ethical grounds by the University of Regina and Regina Qu'Appelle Health Region Research Ethics Boards. Any questions regarding your rights as a participant may be addressed to the committee at (585-4775 or research.ethics@uregina.ca). Out of town participants may call collect.

Researcher: Sarah Elizabeth Ivens, B.A. (Hons.), Department of Psychology, University of Regina, 306-351-2996, ivens20s@uregina.ca

Supervisor: Lynn Loutzenhiser, Ph.D., Department of Psychology, University of Regina, 306-585-4078, lynn.loutzenhiser@uregina.ca

Consent: I understand the above conditions, and consent to participate in this study.
❍ YES (1)

Appendix C: Battery of Questionnaires

How old are you?

What gender do you identify as?
- ❍ Female (1)
- ❍ Male (2)
- ❍ Other (3)

Which province / territory do you live in?
- ❍ Alberta (1)
- ❍ British Columbia (2)
- ❍ Manitoba (3)
- ❍ New Brunswick (4)
- ❍ Newfoundland and Labrador (5)
- ❍ Northwest Territories (6)
- ❍ Nova Scotia (7)
- ❍ Nunavut (8)
- ❍ Ontario (9)
- ❍ Prince Edward Island (10)
- ❍ Quebec (11)
- ❍ Saskatchewan (12)
- ❍ Yukon (13)

What are the last three letters/numbers of your postal code?

What is your ethnicity?
- ❑ Aboriginal (1)
- ❑ African (2)
- ❑ Asian (3)
- ❑ Caucasian (4)
- ❑ Hispanic (5)
- ❑ Middle Eastern (6)
- ❑ Other (7)

What is your employment status?
- ❑ Part-time work (1)
- ❑ Full-time work (2)
- ❑ Unemployed (3)
- ❑ Student (4)

What is the highest level of education you have obtained?
- ❍ Less than high school (1)
- ❍ High school (2)
- ❍ Bachelor's Degree (3)
- ❍ Technical school certificate / diploma (4)
- ❍ Master's Degree (5)
- ❍ Doctoral Degree or Post-Doctoral Degree (6)

What is your marital status
- ❑ Married (1)
- ❑ Common-law (2)
- ❑ Divorced (3)
- ❑ Single (4)

Answer If What is your marital status Married Is Selected Or What is your marital status Common-law Is Selected

What is your partner's gender?
- ❍ Female (1)
- ❍ Male (2)
- ❍ Other (3)

What is your total family income?
- ❍ Less than $20,000 (1)
- ❍ $20,000-$40,000 (2)
- ❍ $40,000-$60,000 (3)
- ❍ $60,000-$80,000 (4)
- ❍ >$80,000 (5)

How many children do you have?

How many of your children have received a diagnosis of an Autism Spectrum Disorder? If you have more than one child with ASD, please pick one child to consider when answering the remaining questions.
- ❍ 1 (1)
- ❍ 2 (2)
- ❍ 3 (3)
- ❍ 4 (4)
- ❍ 5 (5)

How many years old was your child when diagnosed with ASD?
- ❍ 1 (1)
- ❍ 2 (2)
- ❍ 3 (3)
- ❍ 4 (4)
- ❍ 5 (5)
- ❍ 6 (6)
- ❍ 7 (7)
- ❍ 8 (8)
- ❍ 9 (9)
- ❍ 10 (10)
- ❍ 11 (11)
- ❍ 12 (12)

How many years old is your child who has been diagnosed with ASD?
- ❍ 2 (1)
- ❍ 3 (2)
- ❍ 4 (3)
- ❍ 5 (4)
- ❍ 6 (5)
- ❍ 7 (6)
- ❍ 8 (7)
- ❍ 9 (8)
- ❍ 10 (9)
- ❍ 11 (10)
- ❍ 12 (11)
- ❍ 13 or older (12)

If 13 or older Is Selected, Then Skip To End of Survey

Is your child's communication
- ❍ Predominantly nonverbal (1)
- ❍ Somewhat verbal, but only understood by those familiar with my child (2)
- ❍ Somewhat verbal, and understood by those people who have just met my child (3)
- ❍ Predominantly verbal (4)

Has your child received any additional medical diagnoses?
- ❍ Yes (1)
- ❍ No (2)

Answer If Has your child received any additional medical diagnoses? Yes Is Selected
What additional medical diagnoses has your child with ASD received?

The next set of questions are designed to help us understand children's behaviours that some parents find problematic. Please consider your child with ASD's behaviours over the past six months when answering these questions.

For each item that describes your child, now or within the past six months, please select the 2 if the item is very true or often true. Select 1 if the item is somewhat or sometimes true of your child. If the item is not true of your child select the 0. If your child is unable to behave in the way referred to in an item, select the 0. For example, if your child has no speech, then for the item "Repeats the same word or phrase over and over" select the 0.

	not true as far as you know 0 (1)	somewhat or sometimes true 1 (2)	very true or often true2 (3)
Becomes over-excited. (1)	❍	❍	❍
Chews or mouths objects, or body parts. (2)	❍	❍	❍
Confuses the use of pronouns e.g. uses "you" instead of "I". (3)	❍	❍	❍
Doesn't show affection, (4)	❍	❍	❍
Grinds teeth. (5)	❍	❍	❍
Has nightmares, night terrors or walks in sleep. (6)	❍	❍	❍
Impatient. (7)	❍	❍	❍
Inappropriate sexual activity with another. (8)	❍	❍	❍
Jealous. (9)	❍	❍	❍
Kicks, hits others. (10)	❍	❍	❍
Laughs or giggles for no obvious reason. (11)	❍	❍	❍
Preoccupied with only one or two particular interests. (12)	❍	❍	❍
Refuses to go to school, activity centre or workplace. (13)	❍	❍	❍
Repeats the same word or phrase over and over. (14)	❍	❍	❍
Smells, tastes, or licks	❍	❍	❍

objects. (15)			
Switches lights on and off, pours water over and over; or similar repetitive activity. (16)	❍	❍	❍
Stubborn, disobedient or unco-operative. (17)	❍	❍	❍
Says he/she can do things that he/she is not capable of. (18)	❍	❍	❍
Sees, hears, something which isn't there. Hallucinations. (19)	❍	❍	❍
Tells lies. (20)	❍	❍	❍
Tense, anxious, worried. (21)	❍	❍	❍
Underreacts to pain. (22)	❍	❍	❍
Upset and distressed over small changes in routine or environment. (23)	❍	❍	❍
Wanders aimlessly. (24)	❍	❍	❍

Do you have anything else you would like to tell us about your child's behaviour?

The next set of questions are designed to help us understand children's sleep habits Please consider your child with ASD's behaviours over the past week when answering these questions.

Bedtime Select your child's bedtime:

- ❍ earlier than 6pm (1)
- ❍ 6:00pm (2)
- ❍ 6:15pm (3)
- ❍ 6:30pm (4)
- ❍ 6:45pm (5)
- ❍ 7:00pm (6)
- ❍ 7:15pm (7)
- ❍ 7:30pm (8)
- ❍ 7:45pm (9)
- ❍ 8:00pm (10)
- ❍ 8:15pm (11)
- ❍ 8:30pm (12)
- ❍ 8:45pm (13)
- ❍ 9:00pm (14)
- ❍ 9:15pm (15)
- ❍ 9:30pm (16)
- ❍ 9:45pm (17)
- ❍ 10:00pm (18)
- ❍ 10:15pm (19)
- ❍ 10:30pm (20)
- ❍ 10:45pm (21)
- ❍ 11:00pm (22)
- ❍ 11:15pm (23)
- ❍ 11:30pm (24)
- ❍ 11:45pm (25)
- ❍ 12:00am (26)
- ❍ 12:15am (27)
- ❍ 12:30am (28)
- ❍ 12:45am (29)
- ❍ 1:00am (30)
- ❍ later than 1:00am (31)

The following statements are about your child's sleep habits and possible difficulties with sleep. Think about the past week in your child's life when answering the questions. If last week was unusual for a specific reason (such as your child had an ear infection and did not sleep well or the TV set was broken), choose the most recent typical week. Answer USUALLY if something occurs 5 or more times in a week; answer SOMETIMES if it occurs 2-4 times in a week; answer RARELY if something occurs never or 1 time during a week. Also, please indicate whether or not the sleep habit is a problem by selecting "Yes", No", or "Not applicable (N/A)".

				Problem?	
	3 Usually (5-7) (1)	2 Sometimes (2-4) (2)	1 Rarely (0-1) (3)	Yes (1)	No (2)
Child goes to bed at the same time at night (1)	❍	❍	❍	❍	❍
Child falls asleep within 20 minutes after going to bed (2)	❍	❍	❍	❍	❍
Child falls asleep alone in own bed (3)	❍	❍	❍	❍	❍
Child falls asleep in parent's or sibling's bed (4)	❍	❍	❍	❍	❍
Child falls asleep with rocking or rhythmic movements (5)	❍	❍	❍	❍	❍
Child needs special object to fall asleep (doll, special blanket, etc.) (6)	❍	❍	❍	❍	❍
Child needs parent in the room to fall asleep (7)	❍	❍	❍	❍	❍
Child is ready to go to bed at bedtime (8)	❍	❍	❍	❍	❍
Child resists going to bed at bedtime (9)	❍	❍	❍	❍	❍

Child struggles at bedtime (cries, refuses to stay in bed, etc) (10)	❍	❍	❍	❍	❍
Child is afraid of sleeping in the dark (11)	❍	❍	❍	❍	❍
Child is afraid of sleeping alone (12)	❍	❍	❍	❍	❍

Sleep Behavior Child's usual amount of sleep each day: _____ hours and _____ minutes (combining nighttime sleep and naps)

Hours (1)

Minutes (2)

				Problem?	
	3 Usually (5-7) (1)	2 Sometimes (2-4) (2)	1 Rarely (0-1) (3)	Yes (1)	No (2)
Child sleeps too little (1)	❍	❍	❍	❍	❍
Child sleeps too much (2)	❍	❍	❍	❍	❍
Child sleeps the right amount (3)	❍	❍	❍	❍	❍
Child sleeps about the same amount each day (4)	❍	❍	❍	❍	❍
Child wets the bed at night (5)	❍	❍	❍	❍	❍
Child talks during sleep (6)	❍	❍	❍	❍	❍
Child is restless and moves a lot during sleep (7)	❍	❍	❍	❍	❍
Child sleepwalks during the night (8)	❍	❍	❍	❍	❍
Child moves to someone else's bed during the night (parent, brother, sister, etc) (9)	❍	❍	❍	❍	❍
Child reports body pains during sleep (10)	❍	❍	❍	❍	❍

Child grinds teeth during sleep (your dentist may have told you this) (11)	❍	❍	❍	❍	❍
Child snores loudly (12)	❍	❍	❍	❍	❍
Child seems to stop breathing during sleep (13)	❍	❍	❍	❍	❍
Child snorts and/or gasps during sleep (14)	❍	❍	❍	❍	❍
Child has trouble sleeping away from home (visiting relatives, vacation) (15)	❍	❍	❍	❍	❍
Child awakens alarmed by a frightening dream (16)	❍	❍	❍	❍	❍

The following statements are about your child's sleep habits and possible difficulties with sleep. Think about the past week in your child's life when answering the questions. If last week was unusual for a specific reason (such as your child had an ear infection and did not sleep well or the TV set was broken), choose the most recent typical week. Answer USUALLY if something occurs 5 or more times in a week; answer SOMETIMES if it occurs 2-4 times in a week; answer RARELY if something occurs never or 1 time during a week. Also, please indicate whether or not the sleep habit is a problem by selecting "Yes", No", or "Not applicable (N/A)".

Waking During the Night

				Problem?	
	3 Usually (5-7) (1)	2 Sometimes (2-4) (2)	1 Rarely (0-1) (3)	Yes (1)	No (2)
Child awakes once during the night (1)	❍	❍	❍	❍	❍
Child awakes more than once during the night (2)	❍	❍	❍	❍	❍
Child returns to sleep without help after waking (3)	❍	❍	❍	❍	❍

Write the number of minutes a night waking usually lasts:

Morning Waking Select the time of day child usually wakes in the morning: (please include AM or PM)

- ❍ before 4:00am (1)
- ❍ 4:00am (2)
- ❍ 4:15am (3)
- ❍ 4:30am (4)
- ❍ 4:45am (5)
- ❍ 5:00am (6)
- ❍ 5:15am (7)
- ❍ 5:30am (8)
- ❍ 5:45am (9)
- ❍ 6:00am (10)
- ❍ 6:15am (11)
- ❍ 6:30am (12)
- ❍ 6:45am (13)
- ❍ 7:00am (14)
- ❍ 7:15am (15)
- ❍ 7:30am (16)
- ❍ 7:45am (17)
- ❍ 8:00am (18)
- ❍ 8:15am (19)
- ❍ 8:30am (20)
- ❍ 8:45am (21)
- ❍ 9:00am (22)
- ❍ 9:15am (23)
- ❍ 9:30am (24)
- ❍ 9:45am (25)
- ❍ 10:00am (26)
- ❍ 10:15am (27)
- ❍ 10:30am (28)
- ❍ 10:45am (29)
- ❍ 11:00am (30)
- ❍ later than 11:00am (31)

				Problem?	
	3 Usually (5-7) (1)	2 Sometimes (2-4) (2)	1 Rarely (0-1) (3)	Yes (1)	No (2)
Child wakes up by him/herself (1)	❍	❍	❍	❍	❍
Child wakes up with alarm clock (2)	❍	❍	❍	❍	❍
Child wakes up in negative mood (3)	❍	❍	❍	❍	❍
Adults or siblings wake up child (4)	❍	❍	❍	❍	❍
Child has difficulty getting out of bed in the morning (5)	❍	❍	❍	❍	❍
Child takes a long time to become alert in the morning (6)	❍	❍	❍	❍	❍
Child wakes up very early in the morning (7)	❍	❍	❍	❍	❍
Child has a good appetite in the morning (8)	❍	❍	❍	❍	❍

The following statements are about your child's sleep habits and possible difficulties with sleep. Think about the past week in your child's life when answering the questions. If last week was unusual for a specific reason (such as your child had an ear infection and did not sleep well or the TV set was broken), choose the most recent typical week. Answer USUALLY if something occurs 5 or more times in a week; answer SOMETIMES if it occurs 2-4 times in a week; answer RARELY if something occurs never or 1 time during a week. Also, please indicate whether or not the sleep habit is a problem by selecting "Yes", No", or "Not applicable (N/A)".

Daytime Sleepiness

				Problem?	
	3 Usually (5-7) (1)	2 Sometimes (2-4) (2)	1 Rarely (0-1) (3)	Yes (1)	No (2)
Child naps during the day (1)	❍	❍	❍	❍	❍
Child suddenly falls asleep in the middle of active behavior (2)	❍	❍	❍	❍	❍
Child seems tired (3)	❍	❍	❍	❍	❍

During the past week, your child has appeared very sleepy or fallen asleep during the following (check all that apply):

	1 Not Sleepy (1)	2 Very Sleepy (2)	3 Falls Asleep (3)
Play alone (1)	❍	❍	❍
Watching TV (2)	❍	❍	❍
Riding in car (3)	❍	❍	❍
Eating meals (4)	❍	❍	❍

Do you have any additional comments about your child's sleep habits?

Some parents of children with ASD report that they experience challenges in their role as a caregiver. The next set of questions are designed to help us understand your experience of being a caregiver for your child with ASD. Please consider your experiences over the past month when answering these questions.

Please look back over the past month and try to remember how things have been for your family. We are trying to get a picture of how life has been in your household over that time. Please read each statement carefully, then select the option that best matches how you feel things have been for your family over the past month. IN THE PAST MONTH, HOW MUCH OF A PROBLEM WERE THE FOLLOWING:

	Not At All (1)	A Little (2)	Somewhat (3)	Quite A Bit (4)	Very Much (5)
Interruption of personal time resulting from this child's problems? (1)	❍	❍	❍	❍	❍
Your missing work or neglecting other duties because of this child's problems? (2)	❍	❍	❍	❍	❍
Financial strain for your family as a result of this child's problems? (3)	❍	❍	❍	❍	❍
Disruption or upset of relationships within the family due to this child's problems? (4)	❍	❍	❍	❍	❍
How sad or unhappy did you feel as a result of this child's problems? (5)	❍	❍	❍	❍	❍
How worried did you feel about this child's future? (6)	❍	❍	❍	❍	❍

How tired or strained did you feel as a result of this child's problems? (7)	❍	❍	❍	❍	❍

Do you have any additional comments about being a caregiver for your child with ASD?

Some parents of children with ASD report that they feel fatigued and exhausted. The next set of questions are designed to help us understand your energy and experiences of fatigue.

This set of questions are to help us understand your energy and experiences of fatigue.The following 10 statements refer to how you usually feel. For each statement you can choose one out of five answer categories, varying from never to always. 1 = never, 2 = sometimes, 3 = regularly, 4 = often, and 5 = always.

	Never (1) (1)	Sometimes (2) (2)	Regularly (3) (3)	Often (4) (4)	Always (5) (5)
I am bothered by fatigue (1)	❍	❍	❍	❍	❍
I get tired very quickly (2)	❍	❍	❍	❍	❍
I don't do much during the day (3)	❍	❍	❍	❍	❍
I have enough energy for everyday life (4)	❍	❍	❍	❍	❍
Physically, I feel exhausted (5)	❍	❍	❍	❍	❍
I have problems starting things (6)	❍	❍	❍	❍	❍
I have problems thinking clearly (7)	❍	❍	❍	❍	❍
I feel no desire to do anything (8)	❍	❍	❍	❍	❍
Mentally, I feel exhausted (9)	❍	❍	❍	❍	❍
When I am doing something, I can concentrate quite well (10)	❍	❍	❍	❍	❍

Is there anything else you would like to tell us about your energy and fatigue?

Some parents of children with ASD report that they occasionally question their ability to effectively parent their child. The next set of questions are designed to help us understand the kinds of things that are easier and more difficult for parents raising a child with ASD.

This questionnaire is designed to help us gain a better understanding of the kinds of things that are easier and more difficult for parents when it comes to raising a young child. Please indicate your opinion about each of the statements below by selecting the appropriate number.

	1 Completely Disagree (1)	2 (2)	3 (3)	4 (4)	5 Moderately Agree (5)	6 (6)	7 (7)	8 (8)	9 Completely Agree (9)
I am able to provide financially for my family in the long term (1)	❍	❍	❍	❍	❍	❍	❍	❍	❍
I am able to instil important values in my child (2)	❍	❍	❍	❍	❍	❍	❍	❍	❍
I am able to meet the immediate financial needs of my family (3)	❍	❍	❍	❍	❍	❍	❍	❍	❍
I am able to make time to spend with my child (4)	❍	❍	❍	❍	❍	❍	❍	❍	❍
I am able to tend to most aspects of my child's daily care such as feeding, bathing, sleep routines (5)	❍	❍	❍	❍	❍	❍	❍	❍	❍
I am able to explain rules to my child in a way he or she can understand (6)	❍	❍	❍	❍	❍	❍	❍	❍	❍

I do less childcare than most parents I know (7)	❍	❍	❍	❍	❍	❍	❍	❍	❍
I am able to help my child cope with his or her feelings (8)	❍	❍	❍	❍	❍	❍	❍	❍	❍
I know how to encourage my child's interest in the world (9)	❍	❍	❍	❍	❍	❍	❍	❍	❍
I am patient with my child when he or she tests the rules I put in place (10)	❍	❍	❍	❍	❍	❍	❍	❍	❍
I know how to arrange my home to minimize safety hazards (11)	❍	❍	❍	❍	❍	❍	❍	❍	❍
I know how to play with my child at his or her level (12)	❍	❍	❍	❍	❍	❍	❍	❍	❍
I am a positive role model for my child (13)	❍	❍	❍	❍	❍	❍	❍	❍	❍
I can sense when my child is starting to feel frustrated or upset (14)	❍	❍	❍	❍	❍	❍	❍	❍	❍
I know when it is time to step in to protect my child from harm (15)	❍	❍	❍	❍	❍	❍	❍	❍	❍

Even in tough times, I am able to provide financially for my family (16)	❍	❍	❍	❍	❍	❍	❍	❍	❍
I can always think of fun things to do with my child (17)	❍	❍	❍	❍	❍	❍	❍	❍	❍
I am mentally and emotionally there for my child when he or she needs me (18)	❍	❍	❍	❍	❍	❍	❍	❍	❍
I have a lot of difficulty balancing the needs of my work with the needs of my family (19)	❍	❍	❍	❍	❍	❍	❍	❍	❍
I'm usually able to do my fair share of the childcare responsibilities (20)	❍	❍	❍	❍	❍	❍	❍	❍	❍
I usually am able to put money aside for my child's future (21)	❍	❍	❍	❍	❍	❍	❍	❍	❍
I can provide the daily care my child needs (22)	❍	❍	❍	❍	❍	❍	❍	❍	❍

This questionnaire is designed to help us gain a better understanding of the kinds of things that are easier and more difficult for parents when it comes to raising a young child. Please indicate your opinion about each of the statements below by selecting the appropriate number.

	6 strongly disagree (1)	5 (2)	4 (3)	3 (4)	2 (5)	1 strongly agree (6)
Even though being a parent could be rewarding, I am frustrated now while my child is at his/her present age. (1)	❍	❍	❍	❍	❍	❍
I go to bed the same way I wake up in the morning, feeling I have not accomplished a whole lot. (2)	❍	❍	❍	❍	❍	❍
I do not know why it is, but sometimes when I'm supposed to be in control, I feel more like the one being manipulated. (3)	❍	❍	❍	❍	❍	❍
My mother/father was better prepared to be a good mother/father than I am. (4)	❍	❍	❍	❍	❍	❍

A difficult problem in being a parent is not knowing whether you're doing a good job or a bad one. (5)	❍	❍	❍	❍	❍	❍
Sometimes I feel like I'm not getting anything done. (6)	❍	❍	❍	❍	❍	❍
My talents and interests are in other areas, not in being a parent. (7)	❍	❍	❍	❍	❍	❍
If being a mother/father of a child were only more interesting, I would be motivated to do a better job as a parent. (8)	❍	❍	❍	❍	❍	❍
Being a parent makes me tense and anxious. (9)	❍	❍	❍	❍	❍	❍

Is there anything else you would like to tell us about the challenges of parenting?

Research has shown that parents of children with developmental disorders often report having difficulties with sleep. The next set of questions are designed to help us understand your sleep habits. Please consider your sleep habits over the past month when answering these questions.

This set of questions are designed to help us understand your sleep habits. The following questions relate to your usual sleep habits during the past month only. Your answers should indicate the most accurate reply for the majority of days and nights in the past month. Please answer all questions

During the past month, when have you usually gone to bed at night? USUAL BED TIME:

- ❍ earlier than 6:00pm (1)
- ❍ 6:00pm (2)
- ❍ 6:15pm (3)
- ❍ 6:30pm (4)
- ❍ 6:45pm (5)
- ❍ 7:00pm (6)
- ❍ 7:15pm (7)
- ❍ 7:30pm (8)
- ❍ 7:45pm (9)
- ❍ 8:00pm (10)
- ❍ 8:15pm (11)
- ❍ 8:30pm (12)
- ❍ 8:45pm (13)
- ❍ 9:00pm (14)
- ❍ 9:15pm (15)
- ❍ 9:30pm (16)
- ❍ 9:45pm (17)
- ❍ 10:00pm (18)
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- ❍ 12:00am (26)
- ❍ 12:15am (27)
- ❍ 12:30am (28)
- ❍ 12:45am (29)
- ❍ 1:00am (30)
- ❍ 1:15am (31)
- ❍ 1:30am (32)
- ❍ 1:45am (33)
- ❍ 2:00am (34)
- ❍ 2:15am (35)
- ❍ 2:30am (36)
- ❍ 2:45am (37)
- ❍ 3:00am (38)
- ❍ later than 3:00am (39)

During the past month, how long (in minutes) has it usually taken you to fall asleep each night? NUMBER OF MINUTES:

During the past month, when have you usually gotten up in the morning? USUAL GETTING UP TIME:

- ❍ earlier than 4:00am (1)
- ❍ 4:00am (2)
- ❍ 4:15am (3)
- ❍ 4:30am (4)
- ❍ 4:45am (5)
- ❍ 5:00am (6)
- ❍ 5:15am (7)
- ❍ 5:30am (8)
- ❍ 5:45am (9)
- ❍ 6:00am (10)
- ❍ 6:15am (11)
- ❍ 6:30am (12)
- ❍ 6:45am (13)
- ❍ 7:00am (14)
- ❍ 7:15am (15)
- ❍ 7:30am (16)
- ❍ 7:45am (17)
- ❍ 8:00am (18)
- ❍ 8:15am (19)
- ❍ 8:30am (20)
- ❍ 8:45am (21)
- ❍ 9:00am (22)
- ❍ 9:15am (23)
- ❍ 9:30am (24)
- ❍ 9:45am (25)
- ❍ 10:00am (26)
- ❍ 10:15am (27)
- ❍ 10:30am (28)
- ❍ 10:45am (29)
- ❍ 11:00am (30)
- ❍ 11:15am (31)
- ❍ 11:30am (32)
- ❍ 11:45 am (33)
- ❍ 12:00pm (34)
- ❍ later than 12:00pm (35)

During the past month, how many hours of actual sleep did you get at night? (This may be different than the number of hours you spend in bed.):

- ❍ 1 (1)
- ❍ 1.5 (2)
- ❍ 2 (3)
- ❍ 2.5 (4)
- ❍ 3 (5)
- ❍ 3.5 (6)
- ❍ 4 (7)
- ❍ 4.5 (8)
- ❍ 5 (9)
- ❍ 5.5 (10)
- ❍ 6 (11)
- ❍ 6.5 (12)
- ❍ 7 (13)
- ❍ 7.5 (14)
- ❍ 8 (15)
- ❍ 8.5 (16)
- ❍ 9 (17)
- ❍ 9.5 (18)
- ❍ 10 (19)
- ❍ 10.5 (20)
- ❍ 11 (21)
- ❍ 11.5 (22)
- ❍ 12 (23)
- ❍ more (24)

For each of the remaining questions, check the one best response. Please answer all questions. During the past month, how often have you had trouble sleeping because you...

	Not during the past month (1)	Less than once a week (2)	Once or twice a week (3)	Three or more times a week (4)
Cannot get to sleep within 30 minutes (1)	❍	❍	❍	❍
Wake up in the middle of the night or early morning (2)	❍	❍	❍	❍
Have to get up to use the bathroom (3)	❍	❍	❍	❍
Cannot breathe comfortably (4)	❍	❍	❍	❍
Cough or snore loudly (5)	❍	❍	❍	❍
Feel too cold (6)	❍	❍	❍	❍
Feel too hot (7)	❍	❍	❍	❍
Had bad dreams (8)	❍	❍	❍	❍
Have pain (9)	❍	❍	❍	❍

Other reason(s), please describe

How often during the past month have you had trouble sleeping because of this?

❍ Not during the past month (1)
❍ Less than once a week (2)
❍ Once or twice a week (3)
❍ Three or more times a week (4)

During the past month, how would you rate your sleep quality overall?
- ❍ Very good (1)
- ❍ Fairly good (2)
- ❍ Fairly bad (3)
- ❍ Very bad (4)

During the past month, how often have you taken medicine (prescribed or "over the counter") to help you sleep?
- ❍ Not during the past month (1)
- ❍ Less than once a week (2)
- ❍ Once or twice a week (3)
- ❍ Three or more times a week (4)

During the past month, how often have you had trouble staying awake while driving, eating meals, or engaging in social activity?
- ❍ Not during the past month (1)
- ❍ Less than once a week (2)
- ❍ Once or twice a week (3)
- ❍ Three or more times a week (4)

During the past month, how much of a problem has it been for you to keep up enough enthusiasm to get things done?
- ❍ No problem at all (1)
- ❍ Only a very slight problem (2)
- ❍ Somewhat of a problem (3)
- ❍ A very big problem (4)

Do you have a bed partner or roommate?
- ❍ No bed partner or roommate (1)
- ❍ Partner/roommate in other room (2)
- ❍ Partner in same room, but not same bed (3)
- ❍ Partner in same bed (4)

Is there anything else that you would like to tell us about your sleep habits?

Answer If What is your marital status Married Is Selected Or What is your marital status Common-law Is Selected

On a scale of 1 to 10, rate your over-all satisfaction with your marriage with 1 being very unsatisfied and 10 being extremely satisfied.

_____ Overall satisfaction with marriage (1)

Some parents of children with ASD have suggested that social support is especially important when raising a child with ASD. The next set of questions are designed to help us understand ways in which you feel socially supported. Please consider your experiences over the past four weeks when answering these questions.

We are interested in learning about some of the ways that you feel people have helped you or tried to make life more pleasant for you over the past four weeks. Below you will find a list of activities that other people might have done for you, to you, or with you in recent weeks. Please read each item carefully and indicate how often these activities happened to you during the past four weeks. Please read each item carefully and select the rating that you think is the most accurate. During the past four weeks, how often did other people do these activities for you, to you, or with you:

	Not at all (1)	About once a week (2)	Once or twice (3)	Several Times a Week (4)	About every day (5)
Gave you some information on how to do something. (1)	❍	❍	❍	❍	❍
Helped you understand why you didn't do something well. (2)	❍	❍	❍	❍	❍
Suggested some action you should take. (3)	❍	❍	❍	❍	❍
Gave you feedback on how you were doing without saying it was good or bad. (4)	❍	❍	❍	❍	❍
Made it clear what was expected of you. (5)	❍	❍	❍	❍	❍
Told you what he/she did in a situation that was similar to yours. (6)	❍	❍	❍	❍	❍

Told you that he/she feels close to you. (7)	❍	❍	❍	❍	❍
Let you know that he/she will always be around if you need help. (8)	❍	❍	❍	❍	❍
Told you that you are OK just the way you are. (9)	❍	❍	❍	❍	❍
Expressed interest and concern in your well-being. (10)	❍	❍	❍	❍	❍
Comforted you by showing you some physical affection. (11)	❍	❍	❍	❍	❍
Told you that he/she would keep the things you talk about private. (12)	❍	❍	❍	❍	❍
Agreed that what you wanted to do was the right thing. (13)	❍	❍	❍	❍	❍
Did some activity together to help you get your mind off things. (14)	❍	❍	❍	❍	❍
Gave or loaned you over $25. (15)	❍	❍	❍	❍	❍

Provided you with a place to stay. (16)	❍	❍	❍	❍	❍
Loaned you or gave you something (a physical object) that you needed. (17)	❍	❍	❍	❍	❍
Pitched in to help you do something that needed to get done. (18)	❍	❍	❍	❍	❍
Went with you to someone who could take action. (19)	❍	❍	❍	❍	❍

In general my health is...

- ❍ Poor (1) (1)
- ❍ Fair (2) (2)
- ❍ Good (3) (3)
- ❍ Very good (4) (4)
- ❍ Excellent (5) (5)

Some parents of children with ASD report difficulties with mood and stresses. The next set of questions are designed to help us understand your moods and emotional experiences.

The following questions are to help us understand your moods and emotional experiences.Please read each statement and circle a number 0, 1, 2 or 3 that indicates how much the statement applied to you over the past week. There are no right or wrong answers. Do not spend too much time on any statement. The rating scale is as follows: 0 Did not apply to me at all 1 Applied to me to some degree, or some of the time 2 Applied to me a considerable degree, or a good part of time 3 Applied to me very much, or most of the time

	0 (1)	1 (2)	2 (3)	3 (4)
I found it hard to wind down (1)	❍	❍	❍	❍
I was aware of dryness of my mouth (2)	❍	❍	❍	❍
I couldn't seem to experience any positive feeling at all (3)	❍	❍	❍	❍
I experienced breathing difficulty (e.g., excessively rapid breathing, breathlessness in the absence of physical exertion) (4)	❍	❍	❍	❍
I found it difficult to work up the initiative to do things (5)	❍	❍	❍	❍
I tended to over-react to situations (6)	❍	❍	❍	❍
I experienced trembling (e.g., in the hands) (7)	❍	❍	❍	❍
I felt that I was using a lot of nervous energy (8)	❍	❍	❍	❍

I was worried about situations in which I might panic and make a fool of myself (9)	❍	❍	❍	❍
I felt that I had nothing to look forward to (10)	❍	❍	❍	❍
I found myself getting agitated (11)	❍	❍	❍	❍
I found it difficult to relax (12)	❍	❍	❍	❍
I felt down-hearted and blue (13)	❍	❍	❍	❍
I was intolerant of anything that kept me from getting on with what I was doing (14)	❍	❍	❍	❍
I felt I was close to panic (15)	❍	❍	❍	❍
I was unable to become enthusiastic about anything (16)	❍	❍	❍	❍
I felt I wasn't worth much as a person (17)	❍	❍	❍	❍
I felt that I was rather touchy (18)	❍	❍	❍	❍
I was aware of the action of my heart in the absence of physical exertion (e.g., sense of heart rate increase, heart missing a beat) (19)	❍	❍	❍	❍

I felt scared without any good reason (20)	❍	❍	❍	❍
I felt that life was meaningless (21)	❍	❍	❍	❍

Is there anything else you would like to share about how parenting impacts your moods or emotional experiences?

Has another parent of your child with ASD also completed this survey?

- ❍ Yes (1)
- ❍ No (2)

We are interested in comparing responses of mothers and fathers, and would appreciate it if you could encourage your child with ASD's other parent to complete this survey as well. If you would like us to email them a link to the survey, please enter their email address.

Thank you for participating! Your answers are appreciated. In the event that the questions have caused you distress, here are some resources for you: Information and strategies for coping with stress http://www.cmha.ca/mental_health/stress/ Information about anxiety http://www2.thefsagroup.com/CMHA/pdfLib/Anxiety-MI-NTNL-brochure-2014-web.pdf Resources about depression http://depressionhurts.ca/en/default.aspx Ways to get support for mental health across Canada http://www.cmha.ca/mental-health/find-help/

If you would like to be entered in the draw for the amazon gift card, please email the researcher at ivens20s@uregina.ca and your email address will be entered into the draw.

If you have any additional comments for the researchers, please share them below:

Please click below to submit the survey

Appendix D: Recruitment Email

Subject:
Wanted: YOUR experiences with fatigue!
Body:
Are you a parent of a child with autism between 2-12 years of age?
We are interested in learning more about your experiences with fatigue!
You are invited to complete a confidential, online questionnaire about fatigue in parents of children with autism. The questionnaire will take approximately 40 minutes.
Participants will be entered into a draw for a $50 gift card to Amazon.ca.
While we are interested in the experiences of parents, we are especially interested in information about fathers, because little research has looked at parenting experiences of fathers. We are currently interested in one parent responding from each family.
To complete the survey, please visit http://uregina.ca/~loutzlyn/Research.html
This project has been approved on ethical grounds by the University of Regina and Regina Qu'Appelle Health Region Research Ethics Boards.
For more information, please feel free to contact me at ivens20s@uregina.ca
Thank you for your time,
Sarah Elizabeth Ivens
Child and Family Research Group
University of Regina
http://uregina.ca/~loutzlyn/
306-585-4800

Appendix E: Recruitment via Social Media

One of these two scripts will be used, depending on the allowed text length (e.g., twitter has a maximum number of characters that can be used)

1) Interested in participating in research about fatigue in parents of ASD children age 2-12? [url]

OR

2) Wanted: YOUR experiences with fatigue!

Are you a parent of a child with autism between 2-12 years of age?

We are interested in learning more about your experiences with fatigue!

You are invited to complete a confidential, online questionnaire about fatigue in parents of children with autism. The questionnaire will take approximately 40 minutes. Participants will be entered into a draw for a $50 gift card to Amazon.ca.

While we are interested in the experiences of parents, we are especially interested in information about fathers, because little research has looked at parenting experiences of fathers. We are currently interested in one parent responding from each family.

To complete the survey, please visit http://uregina.ca/~loutzlyn/Research.html

This project has been approved on ethical grounds by the University of Regina and Regina Qu'Appelle Health Region Research Ethics Boards.

For more information, please feel free to contact me at ivens20s@uregina.ca

Thank you for your time,

Sarah Elizabeth Ivens
Child and Family Research Group
University of Regina
http://uregina.ca/~loutzlyn/
306-585-4800

Appendix F: University of Regina Research Ethics Board Approval Form

University of Regina

Research Ethics Board
Certificate of Approval

PRINCIPAL INVESTIGATOR	DEPARTMENT	REB#
Sarah Elizabeth Ivens 2467 Elliott Street Regina, SK S4N 3H4	Psychology	2014-147

SUPERVISOR
Dr. Lynn Loutzenhiser – Psychology Department

FUNDER(S)
Internally Funded

TITLE
Fatigue in Parents of Children with Autism Spectrum Disorder. The Role of Parental and Child Factors

APPROVAL OF	APPROVED ON	RENEWAL DATE
Application for Behavioural Research Ethics Review RQHR Email invitation to participate Recruitment scripts for social media – one of two scripts will be used depending on the allowed text length Consent Form Recruitment Poster Questionnaires	December 11, 2014	December 11, 2015

Full Board Meeting ☐

Delegated Review ☒

CERTIFICATION
The University of Regina Research Ethics Board has reviewed the above-named research project. The proposal was found to be acceptable on ethical grounds. The principal investigator has the responsibility for any other administrative or regulatory approvals that may pertain to this research project, and for ensuring that the authorized research is carried out according to the conditions outlined in the original protocol submitted for ethics review. This Certificate of Approval is valid for the above time period provided there is no change in experimental protocol, consent process or documents.

Any significant changes to your proposed method, or your consent and recruitment procedures should be reported to the Chair for Research Ethics Board consideration in advance of its implementation.

ONGOING REVIEW REQUIREMENTS
In order to receive annual renewal, a status report must be submitted to the REB Chair for Board consideration within one month of the current expiry date each year the study remains open, and upon study completion.
Please refer to the following website for further instructions: *http://www.uregina.ca/research/REB/main.shtml*

Dr. Larena Hoeber, Chair
University of Regina
Research Ethics Board

Please send all correspondence to:
Office for Research, Innovation and Partnership
University of Regina
Research and Innovation Centre 109
Regina, SK S4S 0A2
Telephone: (306) 585-4775 Fax: (306) 585-4893 research.ethics@uregina.ca