

**QUALITY OF LIFE OF SCHOOL-AGED CHILDREN WITH AUTISM
SPECTRUM DISORDER: FACTORS THAT PREDICT
PARENTS' PERSPECTIVE**

by

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ABSTRACT

Quality of life among children is a multidimensional construct that encompasses social, emotional, school, and physical well-being, and is influenced by both individual and contextual factors (Kuhlthau et al., 2013; WHO, 1995). The current study evaluated the quality of life of school-aged children with autism spectrum disorder (ASD) as perceived by their parent. To address limitations of previous work, global and domain-specific quality of life, variation across domains, and variation in ratings by the child's age and gender were explored. Consistent with a bioecological framework, both individual (i.e., ASD symptom severity, maladaptive behaviours, adaptive skills, and grit) and contextual (i.e., parent mental health, sibling type, school type, reciprocal friendship, and leisure) factors were assessed in predicting quality of life. In addition to direct relationships, potential indirect relationships between specific individual and contextual factors and higher quality of life were examined. Data were collected online, internationally, from 152 parents of children ages 8 to 11 years old with ASD. Global and domain-specific quality of life were found to be lower compared to published normative data. Physical quality of life was higher than social, school, and emotional quality of life and school quality of life was higher than social quality of life. Neither the child's age nor gender was significantly associated with quality of life. Symptoms of ASD, maladaptive behaviours, and adaptive skills predicted social quality of life; maladaptive behaviours and adaptive skills predicted emotional quality of life; maladaptive behaviours, adaptive skills, and grit predicted school quality of life; and maladaptive behaviours and adaptive skills predicted physical quality of life. No

support was found for indirect relationships. Implications for understanding and improving quality of life among school-aged children with ASD are discussed.

DEDICATION

For my mentor in perseverance and passion in pursuing meaningful goals: my mom.

For my coach and supporter whose consistent effort inspires all of my work: my dad.

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CHAPTER ONE

Introduction

Overview

Quality of life is a broad, multidimensional concept that incorporates physical, psychological, and social well-being, and is influenced by personal and environmental/contextual factors (Ikeda, Hinckson, & Krageloh, 2014; Kuhlthau et al., 2013). Originating in somatic medicine (Grip, Almqvisy, Axberg, & Brogerg, 2014), the concept of quality of life was based first on assessing physical health and limitations to functioning (Gilson, Reddihough, Graham, & Waters, 2014), and was considered to be equivalent to “standard of living” (Karasimopoulou, Derri, & Zervoudaki, 2012). Current conceptualizations recognize that quality of life is not equivalent to functioning, as individuals can experience a good quality of life even when they are experiencing significant limitations in functioning (Gilson et al., 2014). Importantly, quality of life is a concept intended to capture an individual’s subjective perception of satisfaction and holistic well-being (Billstedt, Gillberg, & Gillberg, 2011; Gilson et al., 2014; Ikeda et al., 2014; Singh & Junnarkar, 2015). The most commonly used definition of quality of life was proposed by the World Health Organization (WHO). According to the WHO, quality of life is how individuals perceive:

their position in life in the context of the culture and value system and in relation to their goals, expectations, standards, and concerns. It incorporates in a complex way the individual’s physical health, psychological state, level of independence, social relationships, personal beliefs, and their relationship to salient features of the environment. (WHO, 1995, p. 1)

Generally, quality of life is considered to be an umbrella term that is interchangeable with well-being (e.g., Grip et al., 2014; Lanier, Kohl, Raghavan, & Auslander, 2015), and it is often measured by a global life satisfaction question (Land, Lamb, & Zheng, 2011), generic quality-of-life measure (e.g., the WHO Quality-of-Life measure), or population-specific measure (e.g., the quality of life of individuals with cerebral palsy). Given the subjective nature of quality of life, it is generally recommended that the construct be assessed using self-report measures (Gilson et al., 2014; Hsieh et al., 2013; Jonsson et al., 2017). However, when examining the quality of life of children, especially children with disabilities, parent reports are often utilized, particularly in situations where the children have limitations with cognition and insight and/or when there are communication problems (Cramm & Nieboer, 2012; Hsieh et al., 2013; Stokes, Korienko, Scheeren, Koot, & Begeer, 2017; Sylvester, Donnell, Gray, Higgins, & Stalker, 2014; Van Gameren-Oosterom, Fekkes, Buitendijk, Mohangoo, & Bruil, 2011).

Research on quality of life covers a wide range of areas, including evaluations of changes in quality of life across age, comparisons among groups, and predictors of quality of life. For example, studies have examined the quality of life of individuals ranging in age from the preschool years (e.g., Hsieh et al., 2013) to older adulthood (e.g., Fraser, Bungay, & Munn-Giddings, 2014). Other studies have assessed differences in quality of life at different ages and found a lower quality of life in adolescents than in children (e.g., Karasimopoulou et al., 2012; Sylvester et al., 2014). In addition, research has examined the quality of life of typically developing

individuals (e.g., Fraser et al., 2014; Hsieh et al., 2013; Singh & Junnarkar, 2015) as well as individuals who have various disabilities, health problems, or who have been exposed to negative life events (e.g., Kuhlthau et al., 2010; Sylvester et al., 2014).

Research on the quality of life of children, specifically, has examined a variety of populations, including those with physical disabilities, physical health conditions, neurodevelopmental disabilities, and learning disabilities. Much of this research has found low quality of life (Sylvester et al., 2014). This work indicates that children's quality of life is negatively affected (i.e., lower) by the presence of adverse or challenging physical, mental, and/or psychosocial factors, such as obesity (e.g., Buttitta, Iliescu, Rousseau, & Guerrien, 2014); maltreatment (e.g., Lanier et al., 2015); or specific disabilities, such as cerebral palsy (e.g., Badia, Longo, Orgaz, & Gomez-Vela, 2013) or developmental coordination disorder (e.g., Zwicker, Harris, & Klassen, 2012). However, research also has found that not all domains of children's quality of life are always negatively affected by adverse life circumstances (e.g., Ginieri-Coccosis et al., 2011; Sylvester et al., 2014). For example, Sylvester and colleagues (2014) found that children with a variety of disabilities/conditions reported high well-being in the areas of school, physical health, and relationships with family, but low well-being in relation to social pursuits with peers. Similarly, some research suggests that not all individuals in adverse circumstances report experiencing low quality of life. For example, although Grip and colleagues (2014) found that children exposed to intimate partner violence involving their parents had a lower level of quality of life than children who had visited the dentist, they found that half of the sample of children

exposed to intimate partner violence involving their parents reported a moderate quality of life.

Multiple studies have considered the quality of life of children with autism spectrum disorder (ASD), a lifelong neurodevelopmental disorder that affects social-communication and interaction, and involves restricted and repetitive behaviours and narrow interests (American Psychological Association, 2013). Characteristics that emerge directly and indirectly from the core features of ASD, such as behaviour problems, difficulties making and maintaining social relations, and reduced leisure pursuits, significantly affect the functioning and the quality of life of children with ASD (e.g., Chuang, Tseng, Lu, Shieh, & Cermak, 2014; Dahan-Oliel, Shikako-Thomas, & Majnemer, 2012; Gardiner & Iarocci, 2015; Van Steensel, Bögels, & Dirksen, 2012). Given the pervasive nature of the core and associated features of ASD, it is not surprising that, based on their parents' report, children with ASD have a low quality of life, lower than either their typically developing peers (e.g., De Vries & Geurts, 2015; Kose et al., 2013; Kuhlthau et al., 2010; Limbers, Heffer, & Varni, 2009; Öztürk et al., 2016; Potvin, Snider, Prelock, Wood-Dauphinee, & Kehayia, 2015) or children with other disorders, chronic conditions, or disabilities (e.g., Cottenceau, Roux, Blanc, Lenoir, Bonnet-Brilhault, & Barthelemy, 2012; Hoefman et al., 2014; Lee, Harrington, Louie, & Newschaffer, 2008; Russa, Matthews, & Owen-DeSchtyver, 2015; Sikora, Vora, Coury, & Rosenberg, 2012).

Research to date consistently indicates that parents of children with ASD perceive their children as having a low overall quality of life. However, quality of life is a complex construct, so it merits examination in more detail to determine how

quality of life can be promoted in children with ASD. A number of limitations of the research that has been conducted on quality of life in this population also require attention. For example, although research on the quality of life of children with ASD has established that these children experience a lower *global* quality of life than other children, research on specific *domains* of quality of life has produced inconsistencies across studies. Moreover, research has rarely examined variations across domains (e.g., home, school, peers) within this population. Further, this body of literature does not consistently examine variations in children's quality of life by their gender or their age, despite important differences in the rate and presentation of ASD across age and gender (e.g., Werling & Geschund, 2013) and age-related differences in quality of life noted in typically developing children and children with ASD (e.g., Begeer et al., 2017; Kuhlthau et al., 2010). In addition, research on quality of life of children with ASD has not been guided by a framework to select predictors. This is problematic because it is not clear why factors were chosen for examination in specific studies, and it is difficult to compare results across studies as the predictors are inconsistent.

Research on the quality of life of children with ASD also is limited in that it has focused thus far on individual characteristics rather than *contextual* factors (e.g., characteristics of their family or school context). Given that children's quality of life is affected by both individual factors as well as the contexts in which children are embedded, examination of both individual and contextual factors is a worthwhile endeavour. Research on this topic also has focused primarily on factors related to a lower quality of life. Studies of factors related to a higher quality of life also are needed, especially because identification of these factors has the potential to provide

avenues for promoting children's quality of life. Finally, previous studies on the quality of life of children with ASD have been largely descriptive—indirect relationships between variables are not usually considered. Given that quality of life is a multifaceted construct, multiple effects should be examined to understand this phenomenon more fully.

The current study addressed these gaps in the ASD literature by examining parents' perceptions of their school-aged child's quality of life, with attention to the level of global quality of life as well as the level of quality of life across specific domains (e.g., social functioning) and variation across these domains. Using an ecological framework to guide the selection of factors, multiple individual and contextual factors were examined as predictors of quality of life. In particular, the contribution of individual factors and contextual factors over and above the effect of individual factors alone were examined in association with parent-perceived quality of life of school-aged children with ASD. In addition, indirect effects of specific predictor variables (e.g., the presence of a reciprocal friendship) on the associations between individual factors (i.e., ASD symptom severity and maladaptive behaviours) and parents' rating of their child's quality of life were considered.

The next three sections of this chapter review information on ASD in general, what is known about the quality of life of individuals with ASD, and literature examining predictors of parents' perceptions of their child's quality of life. A discussion of specific limitations of these literatures is presented next, followed by a description of Bronfenbrenner's (1994) bioecological model, and then a section that

introduces the predictors for the current study. Finally, research questions and hypotheses that guided the current study are presented.

Autism Spectrum Disorder

Autism spectrum disorder (ASD) is currently conceptualized as a neurodevelopmental disorder involving deficits in social interaction and social communication as well as the presence of restricted and repetitive patterns of behaviour (American Psychological Association, 2013). The conceptualization of autism has evolved over time. Kanner (1971) first described symptoms of aloofness, speech difficulties, repeated play activities and interests, and challenges with developing relationships as “autism,” a term coined in 1911 by Bleuer (Hall & Graff, 2011; Tsai, 2014). Autism was first introduced as a defined mental health disorder in the third edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-III) and the ninth edition of the World Health Organization’s International Classification of Diseases (ICD-9-CM; American Psychiatric Association, 1980; WHO, 1987). It was described as a disorder involving difficulties in cognition, communication, and social skills. Although the conceptualization of “autism” has changed across revisions of the DSM, its core symptoms—difficulties with social communication and perseveration on interests and behaviours—have remained consistent. DSM-IV (APA, 1994) and DSM-IV-TR (APA, 2000) conceptualized autism as a triad of impairments present throughout the life course: difficulties with communication, impairments in social interaction, and engagement in restricted and repetitive behaviours (Fombonne, 2009).

The most recent revision of DSM, DSM-5, conceptualizes autism and related disorders—previously referred to as Autistic Disorder, Asperger’s Disorder, Pervasive

Developmental Disorder Not Otherwise Specified (PDD-NOS), and Childhood Disintegrative Disorder—as part of a single spectrum named autism spectrum disorder (ASD; APA, 2013). Rett’s disorder, which was also subsumed under the same category as autism and related disorders, was removed from DSM-5 because it has a different genetic etiology (Kurita, 2011). Understanding the components of the autism spectrum as involving a triad of impairments has been replaced with a definition involving a dyad of impairments: (a) deficits in social interaction and social communication and participation and (b) the presence of restricted, repetitive patterns of behaviour and interests (APA, 2013).

DSM-5 specifies that to be diagnosed with ASD individuals need impairments in social-emotional reciprocity, challenges with using and understanding nonverbal communication, and limitations in forming and maintaining relationships, as well as symptoms of restricted and repetitive behaviours and interests that may include repetitive or stereotyped motor movements, inflexibility of ideas or insistence on sameness, restricted interests, and interest in or hyper- or hypo-reactivity to sensory input. Symptoms of ASD also must not be better explained by other factors, must cause clinically significant impairment, and must be present during the early developmental period. Severity ratings are based on the level of support that the individual requires to function and are rated separately for social communication and restricted and repetitive behaviours (APA, 2013). DSM-5 also has introduced specifiers for ASD: comorbid intellectual disability; language impairment; medical, genetic, or environmental associated factors; and catatonia.

The prevalence of ASD has been estimated at 1 in 66 (Public Health Agency of Canada, 2018). There is a significant gender discrepancy with a reported 4:1 male to female ratio (Fombonne, 2009). Research indicates that the age of diagnosis of ASD is decreasing, with diagnosis possible by age two (e.g., Davis, Clifton, & Papadopoulos, 2015) and reliable diagnosis by age three (Charman & Baird, 2002; Jo et al., 2015). Aside from the functionally impairing diagnostic criteria, a variety of cascading effects can affect children with ASD (Hall & Graff, 2011). For example, children with ASD can have a comorbid intellectual disability and often have an uneven profile of development, making it difficult for them to achieve their full potential (APA, 2013; Marcus, Kuncze, & Schopler, 2005). Children with ASD also often have greater deficits in verbal than nonverbal abilities and deficits in their ability to use language functionally, which impairs everyday communication and social functioning (Weismer, Lord, & Esler, 2010). Limited participation in pretend play is also common and interferes with their ability to develop cognitive, communication, and social skills (Hobson, Hobson, Malik, Bargiota, & Caló, 2013). Often children with ASD have lower than expected adaptive functioning given their cognitive ability, which results in a mismatch between a child's actual capabilities and others' expectations of them (Howlin, 2000; Renty & Roeyers, 2007). Daily functioning is often compromised by frequent sleep problems (Cohen, Conduit, Lockley, Rajaratnam, & Cornish, 2014) and feeding (e.g., food selectivity) problems (Vissoker, Latzer, & Gal, 2015). Further, children with ASD may have tantrums and self-injurious and aggressive behaviours (Scahill, Koenig, Carroll, & Pachler, 2007). All of these associated characteristics contribute to difficulties in individual and interpersonal functioning.

Quality of Life of Individuals with ASD

Examination of quality of life provides a way to evaluate how the core and associated features of ASD affect children with ASD and their caregivers. Initially, research focused on the quality of life of parents with children with ASD. This work revealed that having a child with ASD has a more significant negative result on parents' quality of life than does parenting children with other disorders, chronic conditions, or disabilities (Cottenceau et al., 2012; Hoefman et al., 2014; Russa et al., 2015). Specifically, parents of children with ASD have reported lower marital satisfaction (e.g., Lee, 2009) as well as lower psychological, social, and physical well-being than other parents (Hoefman et al., 2014; Konstantareas, Homatidis, & Plowright, 1992; Lee, 2009; Pozo, Sarria, & Brioso, 2014). In addition, parents must cope with the increased financial burden, with the stress of accessing and implementing services and intervention, and with learning modified parenting practices to care for a child with ASD (Lickenbrock, Ekas, & Whitman, 2011). In summary, research consistently demonstrates that caring for a child with ASD is associated with a lower quality of life for parents of children with ASD than parents of other children (Kuhlthau et al., 2014; Rizk, Pizur-Barnekow, & Darragh, 2011; Tavernor, Barron, Rodgers, & McConachie, 2012; Tung et al., 2014).

In comparison, fewer studies are available on the quality of life of children with ASD. Although there are often differences between self-report and parent-report for children with ASD, self-report requires that the children have a high enough level of functioning to complete the measures which excludes children with ASD who have more impaired functioning or comorbid intellectual disability (e.g., Potvin et al., 2015).

Parent report is generally utilized given that most of these children have limited insight into their social deficits and have difficulties with comprehension (e.g., Potvin et al., 2015; Tilford et al., 2012). Studies that have examined *global* quality of life in school-aged children with ASD have found that these children are consistently rated as having a lower quality of life than their typically developing peers (Begeer et al., 2017; De Vries & Geurts, 2015; Kuhlthau et al., 2013; Limbers et al., 2009; Potvin et al., 2015; Tavernor et al., 2012). For example, De Vries and Geurts (2015) examined parent-reported quality of life using a sample of 120 children 8 to 12 years old (108 boys, 12 girls) with a diagnosis consistent with ASD and 76 typically developing children 8 to 12 years old (43 boys, 33 girls) and found that children in the ASD group were viewed as having a lower global quality of life than children in the typically developing group. Similarly, Kuhlthau and colleagues (2013) examined the quality of life of 71 children 6 to 11 years old (62 boys, 9 girls) with a diagnosis of autism, Asperger's, or PDD-NOS as reported by parents and found that global quality of life was lower relative to published normed samples of typically developing children. Limbers and colleagues (2009) also found that parent-reported quality of life in 22 children with Asperger's (6 to 12 years old; 20 boys, 2 girls) was significantly lower than the reported quality of life in a general community sample (384 boys, 43 girls).

The same pattern emerges whereby school-aged children with ASD are viewed as having lower quality of life than their typically developing peers regardless of the rater: the child or the parent. For example, Potvin and colleagues (2015) explored quality of life of children with high-functioning autism (7 to 13 years old; 26 boys, 4 girls), defined as those diagnosed with autistic disorder, PDD-NOS, or Asperger's and

with an IQ greater than 80. They found that children with ‘high functioning’ ASD rated their global quality of life lower than did their typically developing peers. The same pattern was found for parent-proxy scores (i.e., parents rating their children according to how they thought their child would respond). Similarly, Tavernor and colleagues (2012) found that parent-report and self-report of 10 boys aged 8 to 12 years with a diagnosis of ASD indicated lower quality of life compared to normative data from the quality-of-life measure standardization sample. Gender differences in global quality of life were examined in only one study. Specifically, De Vries and Geurts (2015) found that gender was not related to children’s quality of life as reported by their parents; the group by gender interaction also was not significant.

Many of these studies also examined *specific domains* of quality of life. Two studies found that all domains of quality of life assessed were lower in children with ASD. Specifically, De Vries and Geurts (2015) reported that children with ASD had a lower quality of life on physical, emotional, social, and school domains of functioning. Potvin and colleagues (2015) also found a lower quality of life for the ASD group on the physical domain and the psychosocial domain (items on the emotional, social, and school scales combined) than for their typically developing peers.

Other studies examining school-aged children with ASD have found that only some domains of quality of life are lower than their peers. For example, Kuhlthau and colleagues (2013) found that the ASD group had lower scores than the typically developing comparison group on the resilience, risk avoidance, satisfaction, and achievement domains, but that the groups did not differ significantly on the comfort domain. Research has also found that parent-proxy reports indicated lower physical,

emotional, social, and school functioning in a group with Asperger's, but not lower scores on a missed school index (Limbers et al., 2009). Further, Tavernor and colleagues (2012) found that self-reported quality of life of children with ASD was lower than that reported by the normative sample across the physical, psychological, social support, and peer domains. However, the two groups did not differ on the autonomy and parents' domain, which includes autonomy, parent relations and home life, and financial resources.

Eight studies have examined young people's quality of life using samples that included both children and adolescents (Arias, Gomez, Moran, Alcedo, Monsalve, & Fontanil, 2018; Begeer et al., 2017; Egilson, Olafsdottir, Leosdottir, Saemundsen, 2017; Kose et al., 2013; Kuhlthau et al., 2010; Lee et al., 2008; Öztürk et al., 2016; Sikora et al., 2012). Consistent with research on school-aged children with ASD, these studies found a lower global quality of life for youth with ASD than for their typically developing peers. This work also has found that youth with ASD have a lower parent-reported global quality of life compared to youth with chronic conditions (Kuhlthau et al., 2010) and peers with ADHD (Lee et al., 2008). Further, youth with a combination of ASD and symptoms of ADHD were rated lower on parent-report on global quality of life than youth with ASD without threshold symptoms of ADHD (Sikora et al., 2012).

Regarding domains of quality of life, youth with ASD were reported to have lower quality of life in some areas but not others. For example, Kuhlthau and colleagues (2010) found that youth with ASD had lower psychosocial functioning, social functioning, and emotional functioning, but not lower school functioning or physical functioning than peers with chronic conditions. In addition, Öztürk and

colleagues (2016) found lower physical health, social functioning, and school functioning but not emotional functioning than healthy controls as reported by parents. Egilson and colleagues (2017) used self- and proxy-report and found a lower quality of life for youth with ASD on the physical well-being, psychological well-being, autonomy and parent relationships, social support and peers, and school environment domains. Arias and colleagues (2018) found lower quality of life as reported by external observers in youth with ASD and intellectual disability in the domains of interpersonal relationships, social inclusion, and physical well-being and higher quality of life for material well-being when controlling for gender, intellectual disability severity, and support needs. This study found that gender was significant in the social inclusion domain, with girls scoring lower than boys. No gender differences were found on parent-report by Kose et al. (2013), Kuhlthau et al. (2010), or Begeer et al. (2017). Regarding age, Kuhlthau et al. (2010) reported that older children had lower global scores and lower domain scores on quality of life than did younger children. Begeer and colleagues (2017) found that there was no main effect of age on subjective well-being, but that subjective well-being decreased for typically developing children as they aged and increased for children with ASD as they aged.

Three studies have examined the quality of life of adolescents with ASD. Clark and colleagues (2015) found that youth with autism, Asperger syndrome, or PDD-NOS (13 to 18 years old; 29 boys, 3 girls) had self-reported and parent-reported quality of life scores that were lower than the mean for the normative sample across domains. Cottenceau and colleagues (2012) found that youth with Asperger's or high-functioning autism (10 to 20 years old; 24 boys, 2 girls) reported a lower quality of life in leisure,

friendships, and affective and sexual relationships than did their typically developing peers and peers with diabetes. However, they reported higher scores than did their typically developing peers on self-image and higher scores than did the other two groups on relationships with parents and teachers. Psychological and physical well-being were not significantly different between the groups. Kamp-Becker and colleagues (2011) found a lower self-reported and parent-proxy-reported quality of life in the ASD sample with Asperger's, high-functioning autism, and atypical autism (12 to 15 years old; 39 boys, 3 girls) than in the typically developing sample and a higher quality of life than in the psychiatric sample. There was not a significant relationship between quality of life and age.

In summary, relatively few studies have evaluated the quality of life of school-aged children with ASD. Available studies have found consistently that parent-reported *global* quality of life is lower for children with ASD than for their typically developing peers. However, there are inconsistencies across studies when *domains* of quality of life are examined, such that some studies have found that all domains are lower for children with ASD than their typically developing peers (e.g., De Vries & Geurts, 2015) whereas other studies have found that some domains are lower and other domains are similar across groups (e.g., Kuhlthau et al., 2013). In addition, there is a paucity of research on variation in the quality of life of school-aged children with ASD across domains or as a function of age or gender, with one notable exception for gender (De Vries & Geurts, 2015). It appears that a better understanding of the level of quality of life of school-aged children with ASD requires further examination of specific domains

of quality of life and variation in quality of life across domains as well as assessment of age and gender differences in the level of children's quality of life.

Predictors of Quality of Life of Children with ASD

According to Verdugo, Schalock, Keith, and Stancliffe (2005), after it has been established that a population has a lower quality of life, as appears to be the case for school-aged children with ASD, researchers should turn their attention to examining predictors of quality of life. A variety of predictors, most of which can be described as individual characteristics of the children with ASD and a small number of contextual factors, have been examined in relation to the quality of life of school-aged children with ASD.

The relationship between *ASD symptom severity*, which refers to the level of ASD symptoms conceptualized in the DSM (APA, 2013; Fombonne, 2009), and parent-perceived quality of life of children with ASD has been examined in several studies (e.g., De Vries & Geurts, 2015; Kose et al., 2013; Kuhlthau et al., 2010).

Overall, researchers have found discrepant results between ASD symptom severity and the global quality of life among children with ASD. Although some studies have found that ASD symptom severity is related to a lower quality of life (see a review by Chiang & Wineman, 2014; De Vries & Geurts, 2015; Kose et al., 2013; Kuhlthau et al., 2010), other studies have not found this link (Kamp-Becker et al., 2011; a meta-analysis by Van Heijst & Geurts, 2015).

Regarding quality-of-life domains, research has found that ASD symptom severity is related to some domains of children's quality of life and not others. For example, research has found that ASD symptom severity is associated with less

satisfaction and lower achievement, but not with resilience, comfort, or risk avoidance domains (Kuhlthau et al., 2013). In addition, higher ASD symptom severity has been related to lower psychosocial quality of life (Markowitz et al., 2016). De Vries and Geurts (2015) found that problems in social communication and low motivation were associated with a lower physical quality of life; lower social motivation was associated with a lower emotional quality of life; and lower social communication, lower tendency to imitate behaviour, and higher social cognition were associated with a lower social quality of life (De Vries & Geurts, 2015). More repetitive behaviours have been negatively correlated with all domains of quality of life except school functioning (Kuhlthau et al., 2010).

Children with ASD exhibit many *maladaptive behaviours* (Chuang et al., 2014; Scahill et al., 2007), which are related to a lower quality of life (e.g., Kuhlthau et al., 2010). Within the literature, maladaptive behaviours have generally been examined as the broad categories of internalizing problems (e.g., depression, anxiety) and externalizing problems (e.g., conduct, hyperactivity; Boonen, Maljaars, Lambrechts, Zink, Van Leeuwen, & Noens, 2014). Regarding internalizing problems, over half of children with ASD have anxiety disorders, and they have more total anxiety, specific phobias, and social anxiety than clinically anxious children without ASD (Chuang et al., 2014; Horiuchi et al., 2014; Van Steensel et al., 2012). Regarding externalizing problems, approximately 40–50% of children with ASD have problems with hyperactivity, difficulty with peers, limited prosocial behaviours, and attention difficulties (Chuang et al., 2014; Horiuchi et al., 2014), and there is symptom overlap between ASD and ADHD (Tan, Pooley, & Spelman, 2016). These maladaptive

behaviours negatively affect children and their families. They are associated with social isolation and limited opportunities for successful interactions with typically developing peers (Horner, Carr, Strain, Todd, & Reed, 2002). They can be disruptive to family functioning, activities, and learning environments, which contributes to reduced family participation in community social activities (Manning, Wainwright, & Bennett, 2011; Norton & Drew, 1994).

Research has consistently found that the presence of maladaptive behaviours is related to a lower quality of life for children with ASD (Kuhlthau et al., 2010). For example, internalizing and externalizing symptoms have been associated with poorer physical functioning, emotional adjustment, social functioning, and school functioning (Bastiaansen Koot, Varni, & Verhulst, 2004) and with lower comfort and satisfaction scores (Kuhlthau et al., 2013), indicating that the symptoms of maladaptive behaviours have a negative influence on the functioning and adjustment of the child. There also is expected to be some, but not complete, overlap between maladaptive symptoms and functioning and the nature of the relationships is important to consider. Specifically, higher levels of anxiety have been related to a lower quality of life in children with ASD (Van Steensel et al., 2012), externalizing problems have been negatively related to risk avoidance (Kuhlthau et al., 2013), and higher irritability has been negatively associated with satisfaction, achievement, comfort, and risk avoidance but not with resilience (Kuhlthau et al., 2013).

Studies also have evaluated the relationship between *adaptive skills* and quality of life but only among adolescents with ASD (e.g., Clark et al., 2015) and young children (2 to 8 years old) with ASD (Farmer, Swineford, Swedo, & Thurm, 2018;

Markowitz et al., 2016). Adaptive skills include activities of daily living used to sustain personal sufficiency, such as the ability to independently execute skills related to communication, daily living, motor skills, and social skills (Gardiner & Iarocci, 2015; Sparrow, Cicchetti, & Balla, 2005). Children with ASD often have significant delays across adaptive skills, and their adaptive skills are often delayed relative to their cognitive capacity, which may lead to unrealistic expectations of their adaptive capabilities (Gardiner & Iarocci, 2015; Howlin, 2000; Renty & Roeyers, 2007; Smith, Greenberg, & Mailick, 2014). In addition, challenges with adaptive skills in children with ASD tend to persist or worsen throughout the lifespan (Farmer et al., 2018; Gardiner & Iarocci, 2015).

Research on youth's adaptive skills and their global quality of life has revealed inconsistent results. Some research has shown that adaptive skills are related to a higher quality of life (e.g., Tilford et al., 2012), while one study found nonsignificant correlations between both parent-reported and self-reported adaptive skills and quality of life (Clark et al., 2015), and another study found no relationship between youth's adaptive skills and their quality of life (Kamp-Becker et al., 2011). Sikora and colleagues (2012) found that youth with ASD and ADHD symptoms were not only lower on adaptive skills than the ASD-only group, but also were lower on quality of life. Regarding domains of quality of life, one study showed that adaptive skills predicted social functioning in young people with ASD, but not global quality of life or physical, emotional, or school functioning (Kuhlthau et al., 2010). It is not known whether adaptive behaviour relates to quality of life or if results would be more consistent in studies of school-aged children with ASD.

Multiple studies have examined the relationship between cognition and related factors and children's quality of life. Most research has not found a relationship between intelligence and global quality of life among individuals with ASD (De Vries & Geurts, 2015; Kamp-Becker et al., 2011; Van Heijst & Geurts, 2015). However, some studies have found that intelligence is related to certain quality of life domains. Specifically, higher intelligence has been related to higher self-reported school functioning (Bastiaansen et al., 2004), and lower cognition has been related to lower emotional functioning (Kuhlthau et al., 2010). Researchers suggest that a child's quality of life is related to his/her ability to interact with the environment and that intelligence is a less important factor (e.g., Kuhlthau et al., 2010). Other cognitive abilities, such as executive functioning, also have been examined. One study of executive functioning revealed that poor working memory, planning, and organization were associated with lower school quality of life, whereas lower inhibition and lower cognitive flexibility were associated with lower social quality of life, and poor cognitive flexibility and poor emotional control were associated with lower emotional quality of life (De Vries & Geurts, 2015).

Turning to contextual factors, very few studies have considered whether features of a child's family, school, or social contexts contribute to the quality of life of children with ASD as perceived by their parent. In the *family context*, only parent stress and parent mental health have been examined in a single study in relation to the quality of life of children with ASD. Chuang and colleagues (2014) reported that a higher level of parenting stress was associated with a higher social quality of life for preschool-aged children with ASD and that poorer parent mental health was associated with a higher

emotional quality of life in this same group. The authors suggested that parents who are more concerned about their child's quality of life invest significant time and energy into caretaking of that child, which increases their own stress and compromises their mental health. It is not known if the same result would emerge from studies with school-aged children with ASD.

In the *school context*, only one study has investigated the relationship between school type and quality of life among children with ASD. This work revealed that children who were enrolled in formal mainstream education had a higher global quality of life, and higher physical, social, and school functioning, but not higher emotional functioning, than did children who were enrolled in special education (Kose et al., 2013). Research on inclusion and children with ASD is limited and what is available provides mixed evidence (Lindsay, Proulx, Scott, & Thomson, 2014; Reed, Osborne, & Waddington, 2012). For example, although inclusion has been found to benefit children with ASD, particularly in the social domain (Eldar, Talmor, & Wolf-Zukerman, 2010), other research has found that placement in a specialized school is more beneficial than placement in mainstream schooling, particularly for children's behaviour and socialization (Reed et al., 2012). Further, children with ASD attending mainstream schools have been found to have higher levels of social anxiety, whereas no other differences were found in emotional or behavioural functioning (Zainal & Magiati, 2016).

Research examining parents' perceptions of inclusion also has provided mixed results. For example, 44% of parents in one study indicated they would appreciate alternatives to mainstream education systems (Waddington & Reed, 2006). However,

42% of parents in this sample also reported that inclusion improved their child's chances of a normal life, and 25% reported that inclusion helped their child's social skills. Overall, there are likely benefits as well as drawbacks of inclusion for individual children with ASD given that implementation of inclusion varies from school to school (Eldar et al., 2010; Reed et al., 2012), and that children with ASD are temporarily or permanently asked to leave the mainstream school system at a higher rate than their typically developing peers (Dillenburger, Jordan, McKerr, & Keenan, 2015). As a result, examining school type of children with ASD, particularly whether they are in mainstream school and whether this setting is related to their quality of life, are important objectives.

One study to date has examined factors including whether *sibling relationships* and community participation may relate to enhanced quality of life for children with ASD. Specifically, Pfiffer, Piller, Giazzoni-Fialko, and Chainani (2017) found that parents of children with ASD indicated that the relationship between their child with ASD and a typically developing sibling was important for the child with ASD as the sibling often engaged in caretaking duties. Parents in this study also reported that participation in *community activities* is beneficial for their child with ASD's quality of life. Finally, no studies have evaluated factors related to school-aged children with ASD's participation in most other contexts deemed important for children's well-being (e.g., relations with peers).

In summary, a variety of factors related to the quality of life of children with ASD have been examined. Regarding individual factors, ASD symptom severity and maladaptive behaviours have been related to parents' perception of the quality of life of

their child with ASD. In comparison, cognitive factors generally have not been related to the quality of life of children with ASD, with the exception of executive functioning deficits, which are negatively related. A relationship between adaptive skills and the quality of life of youth with ASD has been documented, but it is unclear if the same pattern would emerge for school-aged children with ASD. In comparison, little research has examined contextual factors related to the quality of life of children with ASD. The relationship between the family context and the quality of life of children with ASD has been limited to one study on parent mental health with preschool-aged children and one study on siblings, and the school context and community participation also have been examined in only one study each. It appears that individual child factors affect the quality of life of children with ASD. The extent to which contextual factors contribute to the quality of life of these children is largely unknown, although individual studies of the family context and the school context suggest that these factors also are important.

Limitations of the Literature on the Quality of Life of Children with ASD

The previous sections describing the literature available on the quality of life of children with ASD and predictors of their quality of life suggest that this topic is an emerging area of research. It is not surprising, then, that there are multiple gaps in this developing body of work. The current study addressed three significant gaps or limitations.

First, research on the quality of life of school-aged children with ASD consistently demonstrates a lower global quality of life for these children than for their typically developing peers (Begeer et al., 2017; De Vries & Geurts, 2015; Kuhlthau et

al., 2013; Limbers et al., 2009; Potvin et al., 2015; Tavernor et al., 2012). However, although some studies conclude that all domains of quality of life are lower for school-aged children with ASD, other studies find that only some domains are lower. Thus, it is unclear whether having ASD affects all domains of quality of life equally. Given the inconsistency across studies, and the discrepancy in specific domains examined across studies, it is important to continue to examine global and domain-specific quality of life in this group of children. Evaluation of variation in quality of life by children's age and by gender also is needed given the differences in presentation of ASD and related constructs across age and gender (e.g., Werling & Geschund, 2013) and possible age-related differences in quality of life found in previous research (e.g., Begeer, et al., 2017; Kuhlthau et al., 2010). Because these two variables have not been consistently evaluated in previous studies, it is not clear whether the quality of life of school-aged children with ASD is stable and the same for boys and girls during this developmental period. The primary goals of the current study were to examine the level of global quality of life and the levels of domain-specific quality of life in school-aged children with ASD, to assess variation across domains, and to assess variation in these levels by the children's age and gender.

Second, much of the research on the quality of life of school-aged children with ASD has focused on individual factors (e.g., ASD symptom severity, maladaptive behaviours) as predictors. Despite the importance of contextual factors as highlighted in prominent models of child development (e.g., Bronfenbrenner, 1994), only one study of school-aged children has examined a contextual factor (school type) as a correlate of quality of life (Kose et al., 2013) and another study of preschool-aged children with

ASD has investigated family factors (parent stress and parent mental health; Chuang et al., 2014) and another study examined sibling relationships and community activity participation in preschool-aged and school-aged children (Pfiffer et al. 2017).

Consistent with an ecological framework, the literature on quality of life of school-aged children with ASD will be strengthened by consideration of both individual and contextual factors.

Research on the quality of life of school-aged children with ASD has typically focused exclusively on factors associated with a lower quality of life (Weiss & Riosa, 2015; see Pfiffer et al., 2017), with few exceptions (e.g., Ritzema, Lach, Nicholas, & Sladeczek, 2017). Although results from this work have been helpful in identifying variables that have the potential to compromise the day-to-day experiences of these children, the concept of quality of life is intended to capture an individual's holistic well-being and not just the presence or absence of factors expected to reduce or compromise well-being (Billstedt et al., 2011). Therefore, it is essential that research on the quality of life of school-aged children with ASD expands its consideration of predictors to include factors (individual and contextual) that are expected to be associated with a *higher* quality of life. Thus, the second goal of the current study was to assess the unique effects of individual factors and contextual factors expected to be related to a higher quality of life of school-aged children with ASD.

Third, previous studies have been almost exclusively descriptive in nature and have examined only direct relationships between predictors and quality of life. There is a need to examine indirect relationships between specific predictor variables and the quality of life of school-aged children with ASD as perceived by their parent. In

particular, because peer relationships among school-aged children are generally so vital (APA, 2013; Hartup & Stevens, 1999; Solish, Perry, & Minnes, 2010), children's reciprocal friendships have the potential to be a key mechanism between both individual and contextual factors and their quality of life. Therefore, the third goal of the current study was to examine whether the presence of reciprocal friendships has an indirect influence on the relationship between two individual variables (i.e., ASD symptom severity and maladaptive behaviours) and school-aged children with ASD's quality of life as perceived by their parent.

Using a Bioecological Framework to Guide the Selection of Predictors of Quality of Life of School-Aged Children with ASD

Bronfenbrenner's (1994) bioecological model, founded upon two *main* propositions, highlights the complex interplay between individuals and the ecological systems in which they are embedded. One proposition is that development occurs through reciprocal interactions between evolving individuals and their immediate environments, and these proximal processes of interaction are considered the driving forces of development (Bronfenbrenner & Morris, 2006). Another proposition is that the magnitude and direction of proximal processes affecting development show systematic variation dependent on characteristics of the individual, the immediate and remote environments, and the construct being examined (Bronfenbrenner, 1999; Bronfenbrenner & Morris, 2006). Therefore, examining interactions among these factors is expected to increase understanding of the construct under consideration (Bornstein & Leventhal, 2015).

Bronfenbrenner's ecological framework was first published in 1979 and updated in 1994 and has evolved over three phases (Rosa & Tudge, 2013). Phase one (1973–1979) described the effect of the specific ecological systems (i.e., microsystem, mesosystem, exosystem, and macrosystem) on development. Phase one also described three essential characteristics of environments: interdependence; reciprocal interactions between individuals and their environment's influence development; and the developing person's actions and interactions are oriented within a phenomenological field (Rosa & Tudge, 2013). Phase two (1980–1993) placed an emphasis on the role of the individual and introduced the person-process-context model which views development as occurring over time through interactions between the person and the context. Phase three (1993–2006) introduced the bioecological model of human development which views biologically-based characteristics of an individual as important influences on developmental outcomes and proximal processes (Bronfenbrenner & Morris, 2006; Rosa & Tudge, 2013).

Multiple aspects of Bronfenbrenner's bioecological model make it a suitable choice as a framework for the current study. First, this model views biologically-based characteristics of individuals as important influences on developmental outcomes and proximal processes (Bronfenbrenner & Morris, 2006; Rosa & Tudge, 2013). Given the biological basis of ASD, this model highlights the potentially unique experiences of children with this disorder. Second, basic propositions of this model, outlined above, address current limitations in existing research on the quality of life of school-aged children with ASD. Specifically, these propositions call for consideration of contextual factors as well as individual factors in studies aimed at understanding children's

development, in this case children's quality of life. They also highlight the importance of considering how such factors contribute, relative to one another, to children's quality of life.

Third, and perhaps most important, Bronfenbrenner's bioecological model is consistent with the WHO definition of quality of life in its emphasis on the importance of both individual and environmental/contextual factors, and their interaction, for understanding children's experiences. A seminal paper on principles and guidelines for measuring quality of life also highlights the importance of examining individual and environmental/contextual factors as predictors of quality of life (Verdugo et al., 2005) and reflects a shift in the conceptualization of quality of life from a sole focus on characteristics of the individual to a broader focus that also includes an examination of individuals within their relevant contexts. Interestingly, Bronfenbrenner's model is the most commonly cited ecological model in the empirical literature on quality of life and in the empirical literature on ASD. Markowitz and colleagues (2016) used Bronfenbrenner's model to create a questionnaire of psychosocial quality of life for children aged 13 to 86 months with ASD. Although this is the most commonly cited model in the empirical literature on quality of life and in the empirical literature on ASD, researchers have typically not assessed a range of key predictors consistent with this model.

Proposed Predictors of the Quality of Life of School-Aged Children with ASD as Perceived by Their Parent

The current study used Bronfenbrenner's (1994) bioecological model as a framework to guide the selection of predictors of parent-perceived quality of life of school-aged

children with ASD. Consistent with this framework and informed by previous research where possible, four individual factors and five factors from multiple contexts that were expected to be related to parent-perceived quality of life of school-aged children with ASD were examined (see Figure 1). Figure 1 is a graphical representation of the bioecological model with the four individual predictors on the top left and the five contextual predictors on the bottom left. Examining multiple individual and contextual factors in one study allows for an evaluation of the relative contributions of the proposed predictors within each type of factor, and whether contextual factors demonstrate importance above and beyond individual factors. An evaluation of the rationale for the selection of specific factors follows.

Individual predictors. *ASD symptom severity* and *maladaptive behaviours* are two factors which have received considerable attention in research exploring the quality of life of children with ASD. Existing literature clearly demonstrates that children with ASD are negatively affected by ASD symptom severity; they also experience maladaptive behaviours (internalizing and externalizing) at high rates (APA, 2013; Chuang et al., 2014; Scahill et al., 2007). Each of these characteristics has been negatively related to parent-perceived quality of life of school-aged children with ASD as described previously (e.g., De Vries & Geurts, 2015). Given the impairment caused by ASD symptom severity and by maladaptive behaviours, and the documented links between these factors and parent-perceived quality of life of school-aged children with ASD, I included both ASD symptom severity and maladaptive behaviours as predictors in the current study. I expected that a lower level of ASD symptom severity

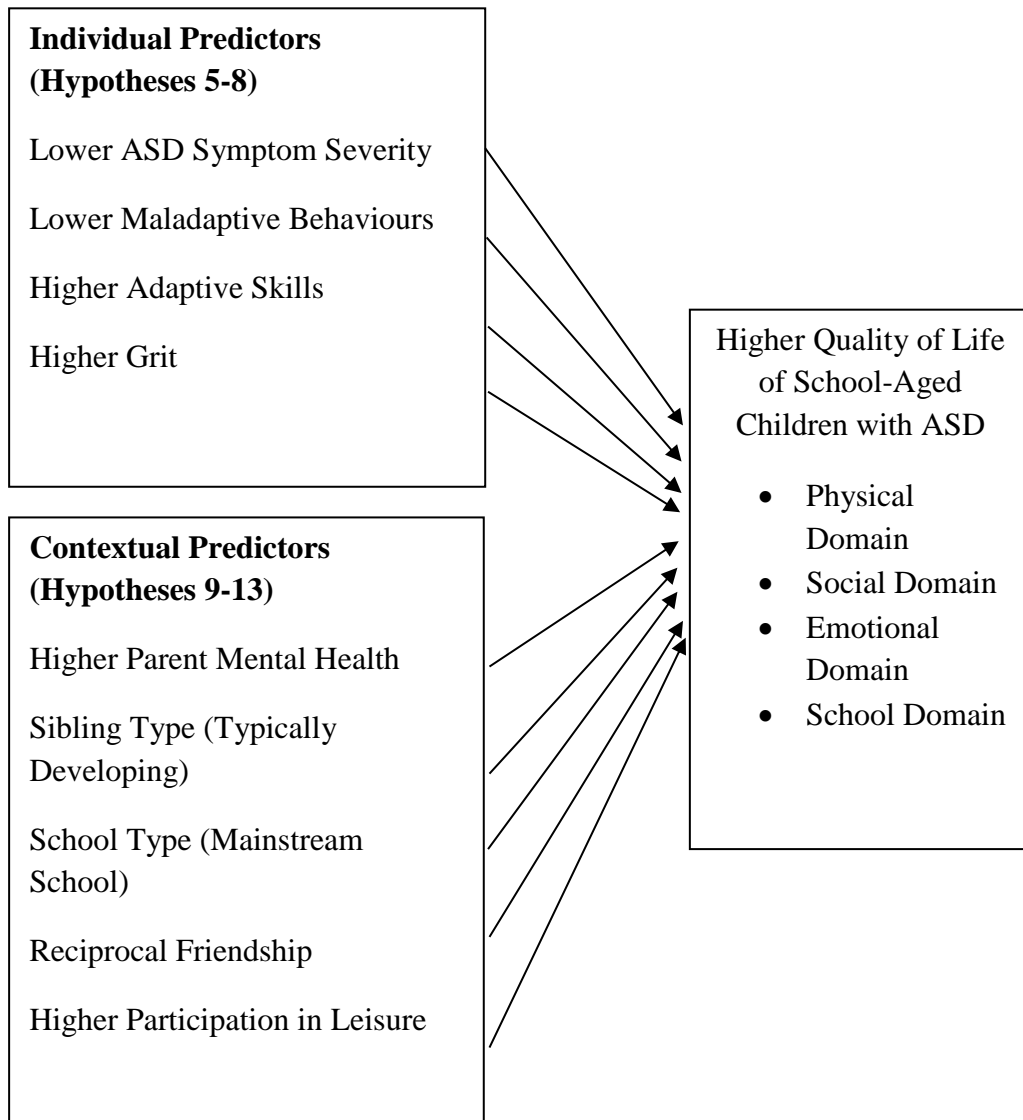


Figure 1. Proposed relationships between individual predictors and contextual predictors and parent-perceived quality of life of school-aged children with ASD.

and fewer maladaptive behaviours would each be related to higher parent-perceived quality of life of school-aged children with ASD.

Adaptive skills are a factor that has received attention in previous research on the quality of life of adolescents with ASD. Research has demonstrated that individuals with ASD have compromised adaptive skills (e.g., Gardiner & Iarocci, 2015), but the relationship between adaptive skills and quality of life in adolescence is unclear, as some studies have reported that a higher level of adaptive skills is linked to a higher quality of life (e.g., Tilford et al., 2012) and other studies have reported no relationship between these variables (e.g., Kamp-Becker et al., 2011). No studies have examined the relationship between adaptive skills and parent-perceived quality of life for school-aged children with ASD. The current study examined adaptive skills as a predictor of parent-perceived quality of life of school-aged children with ASD. Green and Carter (2014) suggested that the development of adaptive skills, with the goal of self-sufficiency, is critical to the well-being of children. Further, adaptive skills are highly valued by parents, educators, and treatment and intervention service providers (e.g., Farmer et al., 2018). Given the value placed on adaptive skills, and the importance of the development of these skills for self-sufficiency, competency in social interactions, success in school, and opportunities for participation in leisure (Dahan-Oliel et al., 2012; Green & Carter, 2014), I expected that a higher level of adaptive skills would be related to a higher quality of life of school-aged children with ASD as reported by parents.

Grit is an individual factor that was considered in the current study as a predictor of parent-perceived quality of life of school-aged children with ASD. Grit is

defined as passion and perseverance for a goal, or as having a strong emphasis on stamina in terms of a capability to put forth continued effort and interest (Duckworth, Peterson, Matthews, & Kelly, 2007; Hill, Burrow, & Bronk, 2014). Grit occurs in higher levels in older adults than in younger individuals (Duckworth et al., 2007), but children and adolescents do show evidence of grit (Duckworth & Quinn, 2009; McMahon, Haut, Schatz, Otero, & Merrill, 2015). Grit has been significantly related to conscientiousness in adults (i.e., high levels of dutifulness, self-discipline, orderliness, cautiousness, and achievement striving), and predicts passion and perseverance for long-term goals above and beyond conscientiousness (Duckworth et al., 2007). It appears to be a strong predictor of school engagement, achievement, and long-term goal attainment (Datu, Valdez, & King, 2015; Duckworth et al., 2007; Sheldon, Jose, Kashdan, & Jarden, 2015). In adolescents, grit predicts GPA and has been related to having an optimistic attribution style and being goal oriented (Duckworth & Quinn, 2009). Regarding quality of life, grit has been related to psychological well-being, satisfaction with life, and harmony in life in adult students and non-students (Vainio & Daukantaitė, 2015). In children, perseverance, a key aspect of grit, is related to quality of life in typically developing children, especially positive affect (Datu et al., 2015; Hill et al., 2014; Weber, Wagner, & Ruch, 2016).

In the only study examining grit among children with ASD, McMahon and colleagues (2015) reported that children with ASD had a lower level of grit than their typically developing peers, but, like previous studies with typically developing adolescents and adults (e.g., Duckworth & Quinn, 2009), grit was related to academic achievement in children with ASD. Because children with ASD face continuous

challenges above and beyond those faced by their typically developing peers, grit was included as an individual factor in the current study. Although no studies have specifically examined whether grit is related to the quality of life of children with ASD, I expected that children who have internal motivation to persist through significant challenges are likely to experience a higher quality of life. That is, children with ASD who have a higher level of grit may be able to stick to things that are challenging for them, such as developing adaptive skills and engaging in social and leisure pursuits, and to experience the benefit associated with these tasks as a result.

Contextual predictors. The importance of examining children within the contexts in which they are immersed to understand their experiences and development more fully is well documented (Bornstein & Leventhal, 2015; Bronfenbrenner, 1994). As a result, I believe that what is known about parent-perceived quality of life of school-aged children with ASD will be strengthened by examining contextual predictors of quality of life. Three primary contexts are particularly relevant for the study of school-aged children: family, school, and social. Markers of each of these contexts were evaluated in the current study.

Focusing first on the family context, two potential predictors of the quality of life of school-aged children with ASD were proposed: parents' mental health and sibling type. With respect to *parents' mental health*, parents are usually the most influential adults in their children's development, playing a critical role in providing needed resources, learning opportunities, skill development, and physical, social, and emotional support to their children. If parental mental health is compromised, this may reduce parents' ability to provide these resources which could conceivably reduce their

children's quality of life. Surprisingly, research examining the relationship between parents' mental health and their children's quality of life is sparse. One study found a positive relationship between parents' self-reported global well-being and their typically developing children's self-reported global well-being, though not between parents' affective well-being and the life satisfaction of their children (Clair, 2012). Two studies found that parental mental distress predicted parent-rated children's emotional well-being (Larson & Gillman, 1999; Powdthavee & Vignoles, 2008). Specifically, Larson and Gillman (1999) found that increased anxiety and anger of mothers was directly related to their adolescents' decreased ratings of affective well-being. Interestingly, positive emotions were unrelated to adolescents' well-being. Similarly, Powdthavee and Vignoles (2008) found that self-reported mental distress of parents had a negative effect on the self-reported well-being of their children aged 11 to 15 years. There was a gender difference reported by these researchers, such that parent-reported life satisfaction of boys was determined by fathers', but not mothers' distress (Powdthavee & Vignoles, 2008).

Only one study (as discussed previously) has examined the relationship between parental mental health and quality of life of children with ASD. These researchers reported that poorer parent mental health was associated with parents' report of a higher emotional quality of life for their preschoolers with ASD (Chuang et al., 2014). It is not known how parents' mental health is related to their school-aged child with ASD's quality of life. The literature on the mental health of parents of typically developing children suggests it is important to consider the extent to which parents' mental health is related to parent-reported quality of life of children with ASD. It is

plausible that higher mental health of parents would mean access to more resources (e.g., time and energy) to invest into the well-being of their children and greater ability to provide a positive family environment for their child to learn and develop within. For example, it is likely that parents who have higher mental health are able to have higher quality interactions with their children which aid in developmental processes such as the acquisition of skills related to quality of life (e.g., adaptive skills). In addition, parents with higher mental health are likely to have more resources (e.g., energy) to be better able to provide more opportunities for social interactions and participation in community activities expected to be related to higher quality of life (e.g., leisure activities). This construct was included as a predictor in the current study, and I expected that higher parent mental health would be related to their perception of a higher quality of life for their school-aged child with ASD.

Another important feature of the family context is the presence of a *sibling*. Siblings tend to spend significant time together engaged in shared interests and tend to provide companionship, nurturance, unique developmental influences, and a source of support for one another (Broody, 2004; Diener, Anderson, Wright, & Dunn, 2015). To date, the literature on siblings has focused mostly on how having a sibling with a disability affects the non-disabled sibling. For example, research has found negative effects of having a sibling with ASD on the non-affected sibling, including experiencing sibling relationship strain from aggressive and disruptive behaviours of the sibling with ASD (Diener et al., 2015; Petalas, Hastings, Nash, Lloyd, & Dowey, 2009) as well as facing negative judgements toward their sibling with ASD and participating in fewer leisure and social activities (Angell, Meadan, & Stoner, 2012;

Petalas et al., 2009), and providing care for their sibling and reduced time and attention from their parent (Pfiffer et al., 2017). In comparison, other studies have shown positive outcomes for typically developing siblings who have a sibling with ASD, including an increased level of empathy, more patience and acceptance, increased social abilities, participation in enjoyable shared activities, and special intimacy with the sibling with ASD (Angell et al., 2012; Kaminsky & Dewey, 2001; Petalas et al 2009). There are also other studies that have found no significant differences between typically developing siblings who have typically developing siblings and typically developing siblings who have siblings with ASD (e.g., Dempsey, Llorens, Brewton, Mulchandani, & Goin-Kochel, 2012).

Taken together, it appears that typically developing siblings of a child with ASD experience a range of outcomes associated with having a sibling with ASD. However, little is known about how the composition of siblings within a family with a child with ASD contributes to the development and well-being of the child with ASD. The limited available research suggests there is a direct relationship between the socialization skills of typically developing children and their sibling with ASD's socialization skills (Brewton, Nowell, Lasala, & Goin-Kochel, 2012). Interestingly, Brewton and colleagues (2012) found different relationships when examining siblings who were older versus siblings who were younger than the child with ASD. Specifically, for children with ASD who had a younger sibling, it was found that there was a significant inverse relationship between levels of internalizing behaviours of the typically developing sibling and the child with ASD's socialization (Brewton et al., 2012). For the children with ASD with an older sibling, there was a significant positive

relationship between the social communication skills of the typically developing children and their sibling with ASD's reciprocal social interaction skills (Brewton et al., 2012). Similarly, research by Ben-Itzchak and colleagues (2016) found that children with ASD who had an older typically developing sibling had less severe social affect deficits than children with ASD who did not have siblings. The presence of a sibling without ASD may provide a child with ASD with opportunities for more peer interaction, modelling of important developmental and social skills, and possible empathetic support in challenging situations (e.g., Ben-Itzchak, Zukerman, & Zachor, 2016). Overall, I expected that the presence of a typically developing sibling would be related to parent-reported higher quality of life for their child with ASD.

Focusing next on the school context, I proposed that the *type of school* that school-aged children with ASD attend is related to their quality of life as reported by their parent. School functioning is often considered a domain of quality of life, so it seems plausible that the school context predicts quality of life. School-aged children spend a significant portion of their waking hours at school, and this environment plays a pivotal role in teaching academics as well as in developing social skills, health-related behaviours, and life skills (Marks, 2000; Palmer, & Wehmeyer, 2003; Roeser, Eccles, & Sameroff, 2000). One important distinction is whether children with ASD are in a mainstream school or some other setting. Although there are significant challenges for children with ASD within mainstream schools, such as difficulty “fitting in,” vulnerability to bullying, and limited resources available to teachers to provide needed support, there are also potential opportunities, including the presence of good role models, potential friendships, support from peers and teachers, teachers building on

strengths, increased independence, increased social behaviour and interactions, and social and educational benefits that occur from being with typically developing peers (Humphrey & Lewis, 2008; McGregor & Campbell, 2001; Roeyers, 1996; Sciotto, Richwine, Mentrikoski, & Niedzwiecki, 2012; Zainal & Magiati, 2016).

One study of school type and quality of life of children with ASD found that global quality of life as well as physical, social, and school, but not emotional domains were higher for children with ASD who were attending mainstream schools than for children with ASD who were attending special education settings (Kose et al., 2013). Attendance at a mainstream school provides children with ASD with access to resources that encourage the development of skills likely to be related to a higher level of quality of life (e.g., school skills; adaptive skills). Mainstream schools also provide opportunities for social interaction with typically developing peers and access to a range of extracurricular activities likely to be related to a higher level of quality of life across domains. Given the opportunities available in mainstream schools, as well as findings from a previous study on quality of life of children in mainstream versus special schools (Kose et al., 2013), I expected that attendance at a mainstream school would predict higher quality of life.

Focusing finally on the social context, two potential predictors of the quality of life of school-aged children with ASD were proposed: reciprocal friendship and involvement in leisure activities. *Reciprocal friendships* create a sense of belonging and common interests, generate opportunities for development, and provide social support that can buffer against negative experiences (Helseth & Misvaer 2009; Moore-Dean, Renwick, & Schormans, 2016; Yucel & Yuan, 2015). They also are an important

marker of well-being for children as perceived by their parents (Hartup & Stevens, 1999; Petrina, Carter, & Stephenson, 2015). Research has shown that friendships are positively related to quality of life in typically developing children and in children with disabilities (Asbjørnslett, Engelsrud, & Helseth, 2012; Cottenceau et al., 2012; Hartup & Stevens, 1999; Helseth & Misvaer 2009). However, less is known about children with ASD. Studies have reported that children with ASD have significantly fewer friendships than their typically developing peers and their peers with an intellectual disability, and that approximately half of individuals with ASD do not have reciprocal friendships with same-aged peers (Orsmond, Krauss, & Seltzer, 2004; Solish, Minnes, & Kupferschmidt, 2003). Reciprocity is a defining feature of friendship between typically developing children and is what distinguishes peers from friends (APA, 2013; Hartup & Stevens, 1999; Solish et al., 2010). Children with ASD, however, do not always understand the concept of friendship in the same way as their typically developing peers given their deficits in social communication. Specifically, children with ASD are not always able to distinguish between a peer and a friend, and they may have limited understanding of the mutuality that is required for a peer to be considered a friend. Children with ASD often struggle to understand and contribute to the back-and-forth nature of friendships. Therefore, when examining friendships of children with ASD, it is important to examine the reciprocity of the friendship. Given the benefits of a reciprocal friendship, I expected the presence of a reciprocal friendship would be related to higher quality of life in this group.

According to the World Health Organization, *leisure* is an important part of helping children with disabilities function optimally (Dahan-Oliel et al., 2012).

Participation in leisure activities includes formal and informal activities, such as sports, arts, entertainment, religion, self-improvement, and social pursuits (Dahan-Oliel et al., 2012; Potvin, Prelock, & Snider, 2008). Leisure activities help build children's competencies, develop social skills, learn social norms, and develop skills needed to function in their school, home, and community settings (Dahan-Oliel et al., 2012; Taheri, Perry, & Minnes, 2016). Despite the potential benefits of leisure, children with ASD partake in fewer social (e.g., attending a show with a friend; having a playdate at a friend's house) and recreational (e.g., playing sports, taking lessons) leisure activities than their typically developing peers and peers with intellectual disabilities (Solish et al., 2010; Taheri et al., 2016). However, children with ASD do not differ from their typically developing peers or peers with intellectual disabilities in participation in passive leisure activities (e.g., watching television; Solish et al., 2010).

Findings show that intense and diverse participation in active physical leisure is related to physical well-being, whereas participation in leisure in general is related to emotional and social well-being in children with neurodevelopmental disabilities (Bandini et al., 2013; Dahan-Oliel et al., 2012). A recent study demonstrated the positive benefit of an exercise program on physical and psychosocial parent-perceived quality of life in children ages 6 to 12 years (Toscano, Carvalho, & Ferreira, 2018). In addition, a qualitative study conducted by Pfiffer and colleagues (2017) indicated that parents reported that community participation was an important factor in improving their children with ASD's quality of life. However, researchers have not evaluated the relationship between participation in leisure in general and quality of life for school-aged children with ASD. In light of the positive association between leisure and quality

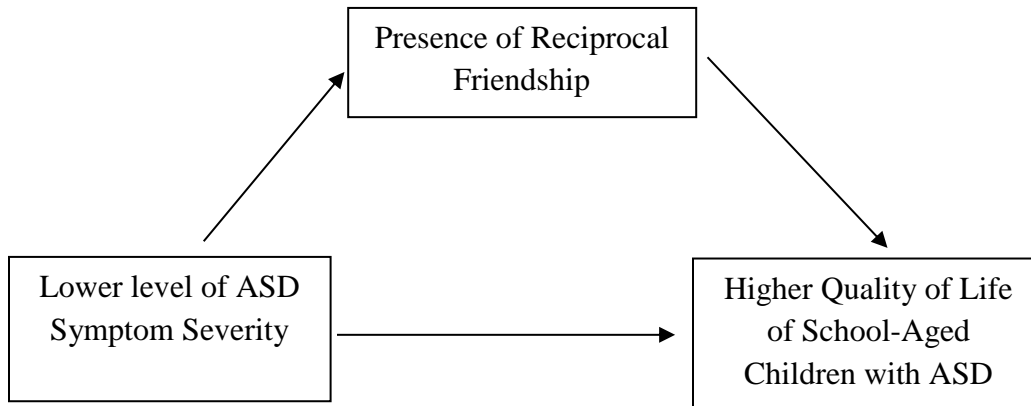
of life found for children with neurodevelopmental disabilities (e.g., Dahan- Oliel et al., 2012; Taheri et al., 2016), it is likely that children with ASD specifically would similarly benefit from leisure participation in terms of their physical, emotional, and social well-being. I expected that participation in leisure would be positively associated with higher parent-perceived quality of life of school-aged children with ASD.

Indirect Influence of Reciprocal Friendship

The bioecological framework supports both direct and indirect relationships between individual and contextual factors and individuals' development. Therefore, an examination of more indirect relationships should provide a better understanding of parent-reported quality of life of school-aged children with ASD. I examined whether the presence of a reciprocal friendship indirectly influences two relationships: (1) the relationship between ASD symptom severity and the quality of life of school-aged children with ASD, and (2) the relationship between maladaptive behaviours and the quality of life of school-aged children with ASD. An indirect effect results from an intervening variable that is located causally between two directly related variables and that is a mechanism through which the first variable influences the second variable (Hayes, 2013).

The current study examined whether the presence of a reciprocal friendship indirectly influenced the relationship between ASD symptom severity and the quality of life of school-aged children with ASD, as perceived by their parent (see Figure 2a). One study found that children with more ASD symptoms were less likely to have reciprocal friendships (Mazurek & Kanne, 2010). These authors suggested that symptoms associated with ASD, such as deficits in perspective taking and self-

(a)



(b)

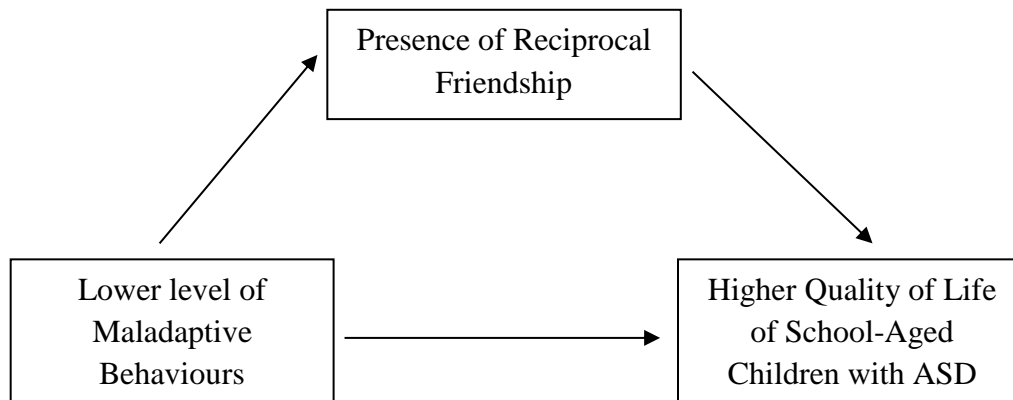


Figure 2. Indirect effects of reciprocal friendship on (a) the relationship between ASD symptom severity and parent-perceived quality of life of school-aged children with ASD and (b) the relationship between maladaptive behaviours and parent-perceived quality of life of school-aged children with ASD.

awareness, contribute to the difficulties these children have with engaging in friendships (Mazurek & Kanne, 2010). In contrast, they suggested that when children have lower levels of ASD symptoms (i.e., exhibit fewer socially inappropriate behaviours and fewer deficits in social communicative behaviours), they may be able to engage in behaviours necessary to create and maintain a reciprocal friendship. If these children are able to be successful in having a reciprocal friendship, it is expected they will experience a higher level of quality of life in ways that are similar to findings from studies of typically developing children (Helseth & Misvaer, 2009). In line with this reasoning, I expected that a lower level of ASD symptom severity would be positively related to the presence of a reciprocal friendship which, in turn, would be positively related to a higher quality of life for school-aged children with ASD as perceived by their parent.

The current study also examined whether the presence of a reciprocal friendship indirectly influenced the relationship between maladaptive behaviours and the quality of life of school-aged children with ASD as perceived by their parent (see Figure 2b). Research has found that children who have a higher level of maladaptive behaviours have difficulties with peers. For example, children with ADHD have significant difficulties making and maintaining friendships and frequently experience peer rejection, particularly if they have comorbid oppositional symptoms or conduct problems (e.g., a review by Nijmeijer et al., 2008). In addition, it has been found that children with ASD may exhibit externalizing behaviours as a consequence of social difficulties (Shae, Payne, & Russo, 2018). Therefore, it is plausible that children with ASD who have a lower level of maladaptive behaviour will be perceived as more

likeable by peers and will be able to participate in shared interests more effectively. These characteristics make a reciprocal friendship more likely, which, in turn, is related to a higher level of quality of life, as friendship serves as a protective factor from negative experiences and as a positive influence on various domains of quality of life (e.g., the social domain; e.g., Asbjornslett et al., 2012). Thus, I expected that a higher level of maladaptive behaviour would be negatively associated with the presence of a reciprocal friendship which in turn would be associated with higher parent-reported quality of life of school-aged children with ASD.

The Current Study

Quality of life is a multifaceted concept that serves as an important indicator of child development (Ikeda et al., 2014; Kuhlthau et al., 2013). It is well established that children with ASD experience a lower level of quality of life than do their typically developing peers (e.g., De Vries & Geurts, 2015; Kose et al., 2013; Kuhlthau et al., 2010). As discussed above, research on factors that predict quality of life of school-aged children with ASD is emerging. However, significant gaps within the literature remain. For example, because research has tended to focus on global quality of life, less is known about domain-specific quality of life in this group. When predictors have been evaluated, there has been a focus primarily on understanding a lower quality of life. In addition, individual factors have received attention, but contextual factors have been largely neglected. Finally, studies have not considered more indirect effects between specific predictors expected to be related to parent-reported quality of life for children with ASD.

The current study addressed these limitations and was guided by three goals: (1) to examine parent-reported global and domain-specific quality of life of school-aged children with ASD to determine whether there is variation across domains of quality of life and whether there is variation in that quality of life by children's age and gender; (2) to select and examine the direct and the relative contributions of specific individual and specific contextual factors to domains of a higher quality of life of school-aged children with ASD; and (3) to examine the indirect relationships linking specific individual factors to children's quality of life through a contextual factor. Six research questions, each with relevant hypotheses, were formulated.

Research Question 1: What are the levels of global and domain-specific quality of life of school-aged children with ASD as perceived by their parent?

Hypothesis 1: It was expected that parents would rate their children with ASD's global quality of life lower than that of their typically developing peers, as reported in published studies.

Hypothesis 2: It was expected that parents would rate their children with ASD's domain-specific quality of life lower than that of their typically developing peers, based on data from published studies for the social, emotional, and school domains.

Research Question 2: Is there variation across domains of quality of life for school-aged children with ASD as perceived by their parent?

Hypothesis 3: It was expected that there would be variation in the level of quality of life across domains reported by parents for their children with ASD, such that the level of quality of life of school-aged children with ASD would be

perceived as being higher in the physical and school domains than in the social and emotional domains.

Research Question 3: Is there variation in parents' perception of the levels of domain-specific quality of life by their children's gender or age?

Hypothesis 4: Given the paucity of research examining quality of life and children's gender or children's age, no hypothesis was made about whether there will be variation in parents' perceptions of the level of their children's quality of life by gender or age.

Research Question 4: Do individual characteristics of school-aged children with ASD, specifically the levels of their ASD symptom severity, maladaptive behaviours, adaptive skills, and grit, predict higher quality of life as perceived by their parent?

Hypothesis 5: It was expected that lower ASD symptom severity would be related to a higher quality of life on the social, physical, and school domains.

Hypothesis 6: It was expected that fewer maladaptive behaviours would be related to a higher quality of life on the social, emotional, and physical domains.

Hypothesis 7: It was expected that a higher level of adaptive skills would be related to a higher quality of life on the social and school domains.

Hypothesis 8: It was expected that a higher level of grit would be related to a higher quality of life on the social and school domains.

Research Question 5: Do factors associated with the contexts within which school-aged children with ASD develop, specifically their parents' mental health, type of sibling, type of school, reciprocal friendship, and participation in leisure activities,

predict higher quality of life as perceived by their parent after accounting for their individual characteristics (i.e., ASD symptom severity, maladaptive behaviours, adaptive skills, and grit)?

Hypothesis 9: It was expected that a higher level of parents' mental health would be related to a higher quality of life on the social and emotional domains.

Hypothesis 10: It was expected that the presence of a typically developing sibling(s) would be related to a higher quality of life on the social and emotional domains.

Hypothesis 11: It was expected that attendance at a mainstream school would be related to a higher quality of life on the social and school domains.

Hypothesis 12: It was expected that the presence of a reciprocal friendship would be related to a higher quality of life on the social and emotional domains.

Hypothesis 13: It was expected that participation in leisure activity would be related to a higher quality of life on the social, emotional, and physical domains.

Research Question 6: Does the presence of a reciprocal friendship have an indirect effect on the relationships between specific individual factors (i.e., ASD symptom severity and maladaptive behaviours) and school-aged children with ASD's quality of life?

Hypothesis 14: It was expected that having a reciprocal friendship would have an indirect effect on the relationship between ASD symptom severity and the social, physical, and school domains of quality of life.

Hypothesis 15: It was expected that having a reciprocal friendship would have an indirect effect on the relationship between maladaptive behaviours and the social, emotional, and physical domains of quality of life.

CHAPTER TWO

Method

Participants

Participants were 152 parents ($Mage = 37.03$, $SD = 6.20$), each of whom had a school-aged child with ASD (ages 8 to 11 years). The study was completed by biological mothers (66%); biological fathers (23%); and adoptive, foster, or step-parents (11%). Primary caregivers reported the following education: 2% no high school diploma; 9% high school diploma; 25% some trade, business, or community college; 18% diploma or certificate from trade, business, or community college; 32% bachelor or undergraduate degree; 11% master's or doctoral degree; and 3% of parents did not respond to this question. The participants were from urban (63%) and rural (36%) areas in Canada (26%), the USA (66%), and other countries internationally (5%). One percent of parents did not report whether they resided in an urban or rural area and 3% of parents did not report which country they resided in. Household income for participants in Canada was 11% < \$20,000; 21% < \$50,000; 26% < \$80,000; 28% < \$120,000; 8% < \$150,000; and 5% > \$150,000, and 1% of participants from Canada did not report their income. Participants from the USA had household incomes of 5% < \$20,000; 31% < \$50,000; 42% < 80,000; 16% < \$120,000; 2% < \$150,000; and 3% > \$150,000. One percent of participants from the USA did not report their income. Participants from other countries internationally had household incomes of 12% < \$20,000; 50% < \$50,000; 13% < \$120,000; and 25% < \$150,000. The children with ASD reported on in the current study were 121 males, 29 females, and two with unreported gender, and an average age of 9.26 years ($SD = 1.1$). Seventy-eight % of the

children had one or more comorbid conditions. A power analysis conducted with G-Power software (Buchner, Erdfelder, & Faul, 1997) for a multiple regression with 11 predictors, a medium effect size, and an alpha of .05 indicated that a sample size of 173 was needed to provide adequate power to detect the relationships proposed in this study.

Procedure

Approval to conduct the study was obtained from the Psychology Department Ethics Review Committee and the University of New Brunswick Research Ethics Board. An introductory flier (see Appendix A) then was (1) posted on online forums for parents with children with ASD (e.g., Kijiji; social media), (2) provided electronically to public and private agencies, clinics, and support groups that provide services and resources for parents with children with ASD and to researchers and groups who study children with ASD in North America, and (3) posted on Amazon's Mechanical Turk (MTurk), an online marketplace, to aid in recruiting a larger sample size. Parents were directed to a website that contained a consent form (see Appendix B). Once an electronic signature was obtained, participants were directed to an online survey. If the parent had multiple children with ASD who fell within the age range for this study (8 to 11 years), they were asked to complete the survey with reference to the child whose birthday was closest to the date that they began the survey. Parent report was selected for this study because children with ASD often have limited insight into their difficulties as well as known associated difficulties with reading and comprehension (Potvin et al., 2015; Tilford et al., 2012). The survey was administered

online to increase the geographical range of data collection in an effort to recruit as many participants as possible (Chen et al., 2009).

With respect to the online survey, a series of demographic questions was presented first, followed by a measure of the child's quality of life, and then the measures of the predictor variables. After participants had submitted their responses, each participant was redirected to a separate debriefing page at the end of the survey, that included a detailed description of the study and provided resources to parents (see Appendix C). On this page, participants were given the opportunity to leave their email address to enter into a draw for one of five \$20.00 USD Visa gift cards. Email addresses were kept in a separate, password-protected file and were destroyed upon completion of the study. Email addresses were kept separate from the data to ensure that the data remained anonymous.

A total of 277 participants completed the survey. One hundred and twenty five participants were excluded from the analyses because the child was not within the age range ($n = 20$), completion time was less than five minutes ($n = 10$), the participant had a non-parental relationship to the child ($n = 6$), the parent's age was less than 26 to include only participants who were at least 18 when the child was born ($n = 10$), data were missing on the dependent variable ($n = 16$), the child did not meet research criteria for ASD (i.e., score on the AQ-10 Child less than 6; $n = 34$), responses on the AQ-10 Child were out of range due to participants selecting multiple responses on questions ($n = 22$), repeat IP addresses ($n = 2$), or the participant failed the validity questions ($n = 5$). All surveys were completed in English.

Measures

Demographic information. Parents reported on their relationship to the child, their gender, age, country of residence, whether they resided in an urban or rural area, education level, family income, and the child's gender, age, ASD diagnosis, and comorbid conditions (see Appendix D).

Validity of responses questions. To check the validity of the responses on the online survey, six questions were embedded throughout to ensure that participants were attending to questions and had a child with ASD. Research has found that inattentiveness adds error to survey data (Silber, Danner, & Rammstedt, 2018). Questions to test attention included items such as “please mark the response ‘almost always true’ for your answer” and “I am paid monthly with potato chips.” To help ensure that participants were answering about a child with ASD, open-ended questions were asked, including “What were your first concerns about your child's development that led you to seek professional services (i.e., assessment and diagnosis)?” and “Does your child have any restricted and repetitive behaviours (i.e., “stim behaviours”)? If so, please describe them briefly (past or present).” Participants with invalid responses were excluded ($n = 5$).

Child quality of life. To measure parent-perceived quality of life of their child with ASD, the parent completed the Pediatric Quality of Life Inventory (PedsQL) parent report (Varni, Seid, & Kurtin, 2001; see Appendix E). The PedsQL is the most commonly used measure of children's quality of life for children with ASD and is an appropriate measure of quality of life in this population (Ikeda et al., 2014; Viecili & Weiss, 2015). The PedsQL parent report is a measure of quality of life of children aged 8 to 12 years that assesses physical (8 items), emotional (5 items), social (5 items), and

school (5 items) functioning. In addition, there is a global scale score that is a sum of all the subscales. Parents were asked to complete the 23 items on a 5-point Likert scale from *never a problem* to *almost always a problem* across the past month. All items were reverse-scored and tallied. Higher scores on the PedsQL indicate a higher level of quality of life.

The PedsQL has good psychometric properties. For example, the authors reported a good internal consistency (global scale $\alpha = .90$; Varni et al., 2001) and Bastiaansen and colleagues (2004) found acceptable internal consistencies (global score $\alpha = .87$; physical functioning $\alpha = .81$; psychosocial functioning $\alpha = .83$; emotional functioning $\alpha = .73$; social functioning $\alpha = .85$; school functioning $\alpha = .69$). In terms of concurrent validity, the PedsQL distinguishes between healthy populations and populations with health conditions, and was significantly related to indicators of morbidity and illness burden (Varni et al., 2001). In terms of discriminant validity, parent reports on the PedsQL showed only small correlations with the Child Behavior Checklist (CBCL) and small-to-medium correlations with the Youth Self-Report and were not significantly correlated with intelligence (Bastiaansen et al., 2004). In the current study, the internal consistency was $\alpha = .85$ for global quality of life, $\alpha = .79$ for physical quality of life, $\alpha = .68$ for emotional quality of life, $\alpha = .79$ for social quality of life, and $\alpha = .73$ for school quality of life.

Individual Factors

ASD symptom severity. To measure the symptom severity of ASD, parents completed the Autism Spectrum Quotient-10 item Children's Version (AQ-10 Child; Allison, Auyeung, & Baron-Cohen, 2012; Auyeung, Baron-Cohen, Wheelwright, &

Allison, 2008; see Appendix F). The AQ-10 Child is a 10-item parent-report questionnaire that examines autism symptomatology in children ages 4 to 11 years. This measure was adapted by the authors of the adult and adolescent versions of the questionnaire (Baron-Cohen, Hoekstra, Knickmeyer, & Wheelwright, 2006; Baron-Cohen, Wheelwright, Skinner, Martin, & Clubley, 2001) and the long version of the AQ-Child. On the AQ-10 Child, parents are asked to rate the extent to which they agree with each item using a 4-point Likert scale from 0 (*definitely agree*) to 3 (*definitely disagree*). Each item is then scored reflecting whether a specified trait is absent (0) or present (1). Higher summed scores indicate a higher level of traits consistent with ASD. The range of scores is from 0, indicating no autistic traits, to 10, representing full endorsement of autistic traits.

Auyeung and colleagues (2008) reported strong psychometric properties for the long version of the AQ-Child. Specifically, the internal consistency for the total scale was high ($\alpha = .97$). The test-retest reliability from a sample of 242 parents with a mean time interval between administrations of 12.3 weeks ($SD = 2.01$) was good ($r = .85, p < .001$). The AQ-Child distinguished between children with autism spectrum conditions and the general population with high sensitivity (95%) and specificity (95%) using a cut-off score of 76. Four of the five subscales were supported by factor analysis (communication, attention to detail, social skills, and imagination). The short version of the scale has high sensitivity (.95) and specificity (.97) and a positive predictive value of .94 (Allison et al., 2012). For the current study, the total scale was a sum of the 10 items, with a higher score indicating a higher level of symptoms consistent with ASD. The current study used a cut-off score of 6 out of 10 on the AQ-10 Child to be included

in the sample given the finding of Allison and colleagues (2012) that this cut-off score yielded specificity of .97. The internal consistency in the current study was $\alpha = .70$.

Maladaptive behaviours. To assess maladaptive behaviours, parents completed the Problem Behavior Scale from the Nisonger Child Behavior Rating Form (NCBRF; Aman, Tassé, Rojahn, & Hammer, 1996; see Appendix G). The NCBRF is a measure of behaviour problems for children age 3 to 16 years that was developed for use with children with developmental disabilities, including those with intellectual disability and/or ASD (Aman et al., 1996; Tassé, Aman, Hammer, & Rojahn, 1996) and was created by adapting the Child Behaviour Rating Form (Edelbrock, 1985). The Problem Behaviour scale has 66 items distributed across six subscales: conduct problems (16 items, e.g., acting out); insecure/anxious (15 items, e.g., self-conscious), hyperactive (9 items, e.g., difficulty concentrating); self-injury/stereotypic (7 items, e.g., body rocking); self-isolated/ritualistic (8 items, e.g., shyness); overly sensitive (5 items, e.g., clinging to adults); and 6 additional maladaptive behaviour items. Parents are asked to rate their child's behaviour over the past month on a 4-point Likert scale from 0 = *if the behaviour did not occur or was not a problem* to 3 = *if the behaviour occurred a lot or was a severe problem*. Item scores are summed, with a higher total score indicating a higher level of problem behaviour.

The NCBRF has good psychometric properties. Aman and colleagues (1996) reported good internal consistencies for the Problem Behaviour scale with a median alpha of .85. In terms of validity, support has been found for the convergent validity of the Problem Behaviour Scale through correlations in the expected direction with the Aberrant Behaviour Checklist (Aman et al., 1996) and the Developmental Behaviour

Checklist (Norris & Lecavalier, 2011). Support for the convergent and discriminant validity of the Problem Behaviour Scale also was found through comparison with the Problem Behaviour Inventory (Rojahn et al., 2010). In the current study, the internal consistency was $\alpha = .94$.

Adaptive skills. To assess level of adaptive skills, parents completed the GO4KIDDS Brief Adaptive Behaviour Scale (Perry, Taheri, Ting, & Weiss, 2015; see Appendix H). The GO4KIDDS Brief Adaptive Behaviour Scale is an 8-item parent-report measure of adaptive skills developed for research purposes for children aged 3 to 20 years with an intellectual disability and/or ASD. The scale evaluates four domains of adaptive skills: support needs, communication, socialization, and self-help. Each item is rated on a 5-point Likert scale, with the exception of one question that is rated on a 4-point Likert scale. The response ranges are specific to each item. Scores are summed to create an overall adaptive behaviour score ranging from 0–39, with a higher score indicating a higher level of skill development as well as a higher level of independence in skills. The total score was used in the current study, with a higher score indicating a higher level of adaptive behaviour. Perry and colleagues (2015) reported good psychometric properties including a good internal consistency ($\alpha = .87$). In terms of validity, the GO4KIDDS Brief Adaptive Scale was compared to the Scales of Independent Behaviour-Revised short form and was found to be highly related as expected ($r = .81, p < .001$). In the current study, the internal consistency was $\alpha = .85$.

Grit. Parents completed a modified version of the Short Grit Scale (Grit-S; Duckworth, & Quinn, 2009; see Appendix I). Specifically, the scale was modified from a self-report to a parent-report measure by changing first-person language to informant-

report language while keeping the question content intact. It was modified in this way previously with a sample of parents of children with ASD (McMahon et al., 2015). Research has validated an informant report of the measure with adults by changing first-person to third-person pronouns (Duckworth & Quinn, 2009). The Grit-S is comprised of eight items that assess the consistency of interest and perseverance of effort. Each item is rated on a 5-point Likert scale, from 1 = *very much like my child* to 5 = *not like my child at all*. Half of the items are reverse-scored. The scale score reflects a mean of the items, and higher scores reflect greater presence of the grit characteristic.

In terms of psychometric properties, the Grit-S demonstrated a good internal consistency (.80) in a sample of children in a spelling bee (Duckworth & Quinn, 2009). Test-retest reliability was examined in a sample of adolescents and scores were found to be consistent across a one-year span ($r = .68, p < .001$; Duckworth & Quinn, 2009). The Grit-S has been positively related to academic achievement (McMahon et al., 2015). In the current study, the internal consistency was .64.

Contextual Factors

Parent mental health. Parent mental health was assessed using the Depression Anxiety and Stress Scale (DASS-21; Lovibond & Lovibond, 1995). The DASS-21 is a 21-item self-report measure that is a short form of the DASS-42. The DASS-21 has three subscales: depression (7 items measuring dysthymic mood, including feelings of sadness and feelings of worthlessness), anxiety (7 items measuring physical arousal symptoms, panic, and fear, such as feeling faint or trembling of the hands), and stress (7 items measuring tension, such as a high level of irritability and hyper-reactivity to

stressful situations). Parents were asked to rate how they felt over the past week using a 4-point Likert scale ranging from 0 = *did not apply to me at all* to 3 = *applied to me very much, or most of the time*. Scores on the DASS-21 are summed and multiplied by two for comparability with the DASS-42. A higher overall score indicates a higher level of symptoms consistent with depression, anxiety, and stress. The current study examined the total score, with a lower score indicating better mental health.

The DASS-21 has good psychometric properties. Regarding reliability, Antony and colleagues (1998) found a Cronbach's alpha of .94 for the depression subscale, .87 for the anxiety subscale, and .91 for the stress subscale, and Henry and Crawford (2005) found a Cronbach's alpha of .80 for depression, .82 for anxiety, .90 for stress, and .93 for the total scale. The DASS-21 was found to provide a valid measure of depression, anxiety, and stress using confirmatory factor analysis (Henry & Crawford, 2005). Importantly, these researchers found that the subscales also tap into a fourth dimension: general psychological distress. The DASS-21 subscales correlated with other measures expected to be related, including the Beck Depression Inventory, the Beck Anxiety Inventory, and the State-Trait Anxiety Inventory (Antony, Bieling, Cox, Enns, & Swinson, 1998). In addition, Henry and Crawford (2005) found that the DASS-21 was positively correlated with the negative affect scale of the Positive and Negative Affect Schedule (PANAS; .69) and negatively correlated with the positive aspect scale of this measure (-.40). Overall, the DASS-21 has good convergent and discriminant validity (Henry & Crawford, 2005). The internal consistency in the current study was .93.

Sibling type. Parents were asked to provide information about the siblings of the child with ASD (see Appendix K). The first question asked whether the child with ASD had any siblings (yes/no). If participants indicated *yes*, they were asked whether each sibling was typically developing, had ASD, or had another diagnosis. The current study used information about the presence of a typically developing sibling as a predictor of quality of life. The variable was coded as 1 = *the presence of a typically developing sibling(s)* or 0 = *no siblings or the presence of only non-neurotypical sibling(s)*.

School type. Parents were asked to indicate whether their child was attending some type of school environment (yes/no; see Appendix L). Then, for participants whose child was attending an educational setting, participants were asked whether that setting was mainstream schooling, a specialized education school, or other. The current study coded whether the child attended a mainstream school with 1 = *yes* or 0 = *no*.

Reciprocal friendship. Parents completed the friendship section of the Activities Questionnaire to assess the friendships of the child with ASD (Solish et al., 2010; see Appendix M). Parents were asked to indicate how many “mutual friends” their child with ASD had at the time. A mutual friend was defined as “child(ren) their child wants to play with and who want(s) to play with their child/friends their child plays with outside of school.” The current study examined the presence of a reciprocal friendship, defined as any response equal to or greater than 1 on the item assessing the presence of mutual friends (0 = *no reciprocal friendships*; 1 = *one or more reciprocal friendship*). No research has examined the psychometric properties of this section of The Activities Questionnaire.

Leisure. To assess their children's involvement in leisure activities, parents completed the brief version of the Activities Questionnaire (Taheri, 2015; see Appendix N). This survey was developed based on the Activities Questionnaire (Solish et al., 2010). Parents were asked to indicate whether their children participated in seven types of activities: unstructured play (e.g., having a friend over), social outings (e.g., going to a movie), special occasions (e.g., attending birthday parties), sports teams (e.g., playing soccer), lessons (e.g., skating), community activities (e.g., Cubs/Brownies), and participation in special needs programs (e.g., special camps). For the current study, participation in each of the seven activities was summed, so scores ranged from 0 to 7, with 0 indicating that the child did not partake in any leisure activities assessed and 7 indicating that the child participated in all seven types of activities.

CHAPTER THREE

RESULTS

Data Conditioning

Data conditioning involved initial screening for data entry errors and univariate and multivariate outliers, and testing assumptions important to consider for multiple regression, as outlined by Tabachnick and Fidell (2013). Univariate nonnormality is defined as Z-scores greater than 3.29 (Tabachnick & Fidell, 2013). Histograms and frequency distributions were used to identify possible univariate outliers on all predictor and criterion variables. No univariate outliers were found. Multivariate outliers were examined through Mahalanobis distances (Kline, 2011; Tabachnick & Fidell, 2013); no multivariate outliers were found.

Multiple regression analysis also requires that the predictor variables meet the assumptions of normality, linearity, homoscedasticity, and the absence of multicollinearity. Histograms of the independent and dependent variables were used to assess linearity and normality, residual plots were used to assess homoscedasticity, and correlation matrices were used to assess multicollinearity (Cohen, Cohen, West, & Aiken, 2003; Tabachnick & Fidell, 2013). The data met these assumptions, and no transformations were necessary. No participant or variable was missing more than 5% of data on the predictor variables. Little's Missing Completely at Random test indicated the data were missing at random. Cases with missing values were excluded from relevant analyses as indicated in the results of each analysis.

Descriptive Statistics and Pearson Correlations

Descriptive statistics, including means (or percentages) and standard deviations were generated for the dependent variables (i.e., global and domain quality of life) and predictor variables (individual and contextual; see Table 1). The mean for global quality of life fell below the midpoint, indicating that, on average, children with ASD were rated by their parent as “having problems” with the areas assessed at least “sometimes”. Regarding the domains of quality of life, the mean for physical quality of life fell just above the midpoint while the means for emotional, social, and school quality of life fell below the midpoint. Taken together, these data indicate that children in this sample had problems at least “sometimes” or “often” across global and domain-specific quality of life.

Turning to the individual predictor variables, the mean for ASD symptoms fell near the upper end of the scale, indicating that children in this sample were rated, on average, as having many symptoms consistent with ASD. The mean for maladaptive behaviours was near the midpoint, indicating the children in this study were rated, on average, as having a moderate level of behavioural concerns on a scale designed for children with developmental disabilities. That is, the children were rated, on average, as engaging in behaviours “occasionally” or “quite often” that parents perceived to be a “mild” or “moderate” problem. The mean for adaptive skills was slightly above the midpoint, indicating that the children in this sample were rated, on average, as having some level of independence with skills but as requiring support to be fully successful. The mean for grit was near the midpoint, indicating children in this study were rated, on average, as being “somewhat like” the characteristics of grit assessed. Taken together, results of the individual variables indicate that the children in this sample

Table 1

Descriptive Statistics for Dependent and Predictor Variables

Variable	Range	<i>M</i> (<i>SD</i>)/Frequency ASD	<i>M</i> (<i>SD</i>) TD (Varni et al., 2001)
Dependent variables			
Physical QOL	3–100	57.73(20.36)	89.32(16.35)
Emotional QOL	5–100	45.23 ^{ab} (18.23)	82.64(17.54)
Social QOL	0–100	40.59 ^a (20.41)	91.56(14.20)
School QOL	0–100	46.32 ^b (19.00)	85.47(17.61)
Global QOL	9.78– 88.04	48.01(14.16)	87.61(12.35)
Individual predictor variables			
ASD symptom severity	6–10	7.97	1.28
Maladaptive behaviours	9–175	75.20	30.60
Adaptive skills	8–32	23.09	5.81
Grit	1.25– 4.13	2.53	0.60
Contextual predictor variables			
Parent mental health	2–110	39.13	25.02
TD sibling	0–1	42%	
Schooling	0–1	75%	
Friendship	0–1	83%	
Leisure	0–6	3.14	1.45

Note. $N = 151-152$, except for schooling where $N = 137$. QOL = quality of life; TD = typically developing.

^aNo significant difference between emotional quality of life and social quality of life.

^bNo significant difference between emotional quality of life and school quality of life.

were rated, on average, as having symptoms consistent with ASD and behavioural concerns as well as difficulties with adaptive skill development, which is expected within this population.

Turning to contextual factors, the mean for parent mental health fell well below the midpoint, indicating that parents in the current study viewed the items related to mental health concerns, on average, as applying to them “to some degree or some of the time”. In terms of the sibling variable, just under half of the children in the sample were reported to have a typically developing sibling. With respect to the school context, most (75%) of the children in the current study were reported to attend a mainstream school setting. Parents in the current study indicated that the majority of children with ASD had a reciprocal friendship (83%). The mean for leisure activities was below the midpoint, indicating that children in the current study were reported to participate, on average, in less than half of the different activity types inquired about.

Relationships among the quality of life domains were examined using Pearson Product-Moment correlations (see Table 2). As expected, each domain was positively related to global quality of life ($r_s = .59 - .83$), and all the domains of quality of life were positively related to each other ($r_s = .24 - .44$). Pearson correlations between quality of life (global and domain) and predictor variables were examined (see Table 3). Regarding individual predictors, ASD symptom severity was negatively related to global quality of life, social quality of life, and school quality of life; maladaptive behaviours were negatively related to global quality of life as well as each domain of quality of life; adaptive skills were positively related to global quality of life as well as social, school, and physical quality of life; and grit was positively related to global

Table 2

Pearson's Correlation Coefficients between Global Quality of Life (QOL) and Quality of Life Domains

	Social QOL	Emotional QOL	School QOL	Physical QOL
Global QOL	.73***	.59**	.66***	.83***
Social QOL		.31***	.37***	.44***
Emotional QOL			.24**	.29***
School QOL				.37***

Note. $N = 152$. ** $p < .01$; *** $p < .001$.

Table 3

Pearson's Correlation Coefficients between Quality of Life and Predictor Variables

	Global	Social	Emotional	School	Physical
	QOL	QOL	QOL	QOL	QOL
<i>Individual predictors</i>					
ASD symptom severity	-.26**	-.38***	-.04	-.23**	-.13
Maladaptive behaviours	-.57***	-.38***	-.55***	-.42**	-.35***
Adaptive skills	.32***	.32***	-.01	.30***	.26**
Grit	.23**	.08	.16*	.38***	.09
<i>Contextual predictors</i>					
Parent mental health	-.28**	-.17*	-.35***	-.10	-.19*
TD sibling	.00	.09	-.03	.04	-.06
Schooling	.06	.05	-.02	.05	.06
Friendship	-.05	.09	-.17*	-.01	-.05
Leisure	-.04	-.03	-.13	-.02	.03

Note. $N = 151-152$, except for correlations for schooling where $N = 137$. QOL = quality of life; TD = typically developing.

* $p < .05$. ** $p < .01$; *** $p < .001$.

quality of life as well as emotional and school quality of life. Turning to contextual factors, parent mental health was negatively related to global quality of life as well as social, emotional, and physical quality of life. The presence of a reciprocal friendship was negatively related to emotional quality of life. The presence of a typically developing sibling, attendance at a mainstream school setting or participation in leisure activities were not significantly related to global or domain-specific quality of life.

Pearson correlations between potential covariates child gender and child age, and predictor variables were examined (see Table 4). Child gender was not significantly related to any of the predictor variables. Child age was significantly related to increased adaptive skills. Significant relationships were found between predictor variables. Specifically, lower levels of maladaptive behaviours were related to higher adaptive skills, more grit, and better parent mental health. Higher adaptive skills were related to having a typically developing sibling, attending a mainstream school, having a reciprocal friendship, and participation in leisure activities. Having a reciprocal friendship was related to participating in more leisure activities.

Research Question 1: Global and Domain-Specific Quality of Life

Research Question 1 focused on the level of global and domain-specific quality of life of children with ASD. Hypothesis 1 predicted that parents of children with ASD would perceive those children as having an overall lower global quality of life, on average, compared to their typically developing peers. Hypothesis 2 predicted that parents would report lower average quality of life scores on the social, emotional, and school domains compared to their typically developing peers. These hypotheses were

Table 4

Pearson's Correlation Coefficients Among Age, Gender, and Predictor Variables

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	1	2	3	4	5	6	7	8	9	10	11
1. Child age	--	-.02	.03	-.01	.19*	.01	-.06	-.10	-.02	.12	-.13
2. Child gender		--	-.12	-.02	.10	.10	-.03	.05	-.10	-.04	-.07
3. ASD symptom severity			--	.16	-.06	-.13	.02	.05	.08	-.08	-.05
4. Maladaptive behaviours				--	-.26**	-.40***	.35***	-.00	-.03	-.00	.01
5. Adaptive skills					--	.05	-.04	.25**	.17*	.27**	.22**
6. Grit						--	-.04	.07	.06	-.14	-.10
7. Parent mental health							--	.02	.06	-.10	.02
8. TD sibling								--	.07	-.09	.08
9. Schooling									--	.16	-.02
10. Reciprocal Friendship										--	.33***
11. Leisure											--

Note. $N = 151-152$, except for correlations for schooling where $N = 137$. TD = typically developing.

* $p < .05$. ** $p < .01$; *** $p < .001$.

tested by comparing the data to published data (Varni et al., 2001), as no published norms are available.

Five Z-tests were conducted. Hypothesis 1 was supported, as parents rated their children as having a lower global quality of life compared to typically developing peers ($Z = -3.15, p < .05$). Hypothesis 2 also was supported, as parents rated their children as having a lower domain-specific quality of life than typically developing peers for all four domains: physical ($Z = -1.93, p < .05$), social ($Z = -3.59, p < .05$), emotional ($Z = -2.29, p < .05$), and school ($Z = -2.22, p < .05$). Taken together, the results indicate that parents, on average, reported that their children with ASD had lower global quality of life, as well as lower domain-specific quality of life, than typically developing peers.

Research Question 2: Variation across Quality of Life Domains

Research Question 2 examined the variation across quality of life domains for school-aged children with ASD. Hypothesis 3 predicted variation in parents' perceptions of their child's quality of life across the quality of life domains, with higher quality of life in the physical and school domains than the social and emotional domains. Hypothesis 3 was tested with a one-way repeated-measures ANOVA with four levels (social, emotional, school, and physical domains). The data used were the raw scores from the PEDS-QL with a possible range of 0-100 given the ease of interpreting these scores and comparison across previous studies. Sphericity was not violated. There was a significant effect of quality of life across domains, $F(3, 453) = 31.97, p = .000, \eta^2_{\text{partial}} = .41$. The significant F-test was followed with the more conservative Bonferroni pairwise comparisons at the .05 level (Tabachnick & Fidell, 2013). Post hoc comparisons indicated that physical quality of life was significantly

higher than emotional, social, and school quality of life. In addition, school quality of life was significantly higher than social quality of life. Emotional quality of life did not differ from social or school quality of life. Taken together, the results provide partial support for Hypothesis 3.

Research Question 3: Quality of Life by Age and Gender

Research Question 3 asked whether there was variation in quality of life by the child's gender or the child's age. No hypotheses were made, given the paucity of research examining the effects of school-aged children's gender and children's age on their quality of life. Variation by child gender was examined using a MANOVA to control for the correlations between the dependent variables and to control for family-wise error (Tabachnick & Fidell, 2013). Child gender was entered as the independent variable; the dependent variables were the four quality of life domains (i.e., social, emotional, school, and physical). Pillai's trace was examined as it is more robust (Tabachnick & Fidell, 2013). The multivariate effect for gender was not significant, $F(4, 145)$; Pillai's Trace = 1.23, $p = .30$. Therefore, univariate comparisons did not require examination.

Child age was examined as a continuous variable to retain variability. Pearson correlations were examined to determine whether child age was significantly correlated with parent-perceived quality of life of children with ASD. Child age was not significantly related to global quality of life ($r = .01$, $p > .05$), and also not related to quality of life in any of the domains: physical ($r = .02$, $p > .05$), emotional ($r = -.01$, $p > .05$), social ($r = -.04$, $p > .05$), and school ($r = .06$, $p > .05$). Given that neither child gender nor child age was significantly related to parents' perception of their child's

quality of life, child gender and child age were not entered as covariates in subsequent analyses.

Research Questions 4 and 5: Individual and Contextual Predictors of Parent-Reported Quality of Life

Research Question 4 and Hypotheses 5–8 stated that individual factors (i.e., ASD symptom severity, maladaptive behaviours, adaptive skills, and grit) would predict specified domains of quality of life of school-aged children with ASD as perceived by their parent. Research Question 5 and Hypotheses 9–13 stated that contextual predictors (i.e., parent mental health, sibling type, school type, reciprocal friendship, and participation in leisure) would predict specified domains of quality of life over and above the contribution of individual predictors.

These hypotheses were tested using four hierarchical multiple regression analyses, one for each quality of life domain (i.e., social, emotional, school, and physical). In each hierarchical multiple regression, the individual factors (i.e., ASD symptom severity, maladaptive behaviours, adaptive skills, and grit) were entered on Step 1, and the contextual factors (i.e., parent mental health, sibling type, school type, presence of a reciprocal friendship, and participation in leisure) were entered on Step 2. See Table 5 for details on social quality of life, Table 6 for details on emotional quality of life, Table 7 for details on school quality of life, and Table 8 for details on physical quality of life.

The first regression analysis (Table 5) examined the predictive ability of individual and contextual factors with respect to parent-reported social quality of life. The four individual factors (i.e., ASD symptom severity, maladaptive behaviours,

Table 5

Hierarchical Regression Analysis Predicting Social Quality of Life

	B	SE B	β	ΔR^2	F
Predictors					
Step 1. Individual Factors				.35***	17.41***
ASD symptoms	-6.12***	1.16***	-.34***		
Maladaptive behaviours	-0.22***	0.06***	-.31***		
Adaptive skills	0.94**	0.27**	.26**		
Grit	-4.24	2.65	-.12		
Step 2. Individual and Contextual Factors				.02	0.70
ASD symptoms	-6.38***	1.19***	-.39***		
Maladaptive behaviours	-0.22***	0.06***	-.32***		
Adaptive skills	0.92**	0.30**	.25**		
Grit	-4.54	2.73	-.13		
Parent mental health	-0.02	0.06	-.03		
TD sibling	2.26	3.17	.05		
Mainstream school	1.22	3.53	.03		
Reciprocal friend	2.46	4.47	.04		
Leisure	-1.79	1.12	-.12		

Note. $N = 137$. * $p < .05$. ** $p < .01$. *** $p < .001$. TD = typically developing.

Table 6

Hierarchical Regression Analysis Predicting Emotional Quality of Life

	B	SE B	β	ΔR^2	F
Predictors					
Step 1. Individual Factors				.34***	16.85***
ASD symptoms	0.03	1.04	.00		
Maladaptive behaviours	-0.39**	0.05***	-.63***		
Adaptive skills	-0.59*	0.24*	-.18*		
Grit	-2.65	2.38	-.09		
Step 2. Individual and Contextual Factors				.05	2.03
ASD symptoms	-0.17	1.04	-.01		
Maladaptive behaviours	-0.35***	0.05***	-.57***		
Adaptive skills	-0.36	0.26	-.11		
Grit	-3.08	2.39	-.10		
Parent mental health	-0.11	0.06	-.15		
TD sibling	-1.14	2.78	-.03		
Mainstream school	1.03	3.09	.02		
Reciprocal friend	-7.60	3.91	-.15		
Leisure	-1.20	0.98	-.09		

Note. $N = 137$. * $p < .05$. ** $p < .01$. *** $p < .001$. TD = typically developing.

Table 7

Hierarchical Regression Analysis Predicting School Quality of Life

	B	SE B	β	ΔR^2	F
Predictors					
Step 1. Individual Factors				.29***	13.42***
ASD symptoms	-1.79	1.12	-.12		
Maladaptive behaviours	-0.15**	0.05**	-.23**		
Adaptive skills	0.08**	0.26**	.24**		
Grit	8.41**	2.54**	.26**		
Step 2. Individual and Contextual Factors				.01	.29
ASD symptoms	-1.87	1.15	-.12		
Maladaptive behaviours	-0.14*	0.06*	-.22*		
Adaptive skills	0.92**	0.29**	.27**		
Grit	8.06**	2.65**	.25**		
Parent mental health	-0.01	0.06	-.02		
TD sibling	-1.40	3.07	-.04		
Mainstream school	0.35	3.42	.01		
Reciprocal friend	-4.06	4.33	-.08		
Leisure	0.42	1.08	.03		

Note. $N = 137$. * $p < .05$. ** $p < .01$. *** $p < .001$. TD = typically developing.

Table 8

Hierarchical Regression Analysis Predicting Physical Quality of Life

	B	SE B	β	ΔR^2	F
Predictors					
Step 1. Individual Factors				.17***	6.63***
ASD symptoms	-1.57	1.31	-.10		
Maladaptive behaviours	-0.22***	0.06***	-.31***		
Adaptive skills	0.67*	0.30*	.19*		
Grit	-1.85	2.98	-.05		
Step 2. Individual and Contextual Factors				.05	1.58
ASD symptoms	-1.52	1.31	-.09		
Maladaptive behaviours	-0.17*	0.07*	-.25*		
Adaptive skills	0.99**	0.33**	.27**		
Grit	-1.83	3.02	-.05		
Parent mental health	-0.10	0.07	-.12		
TD sibling	-7.25*	3.51*	-.17*		
Mainstream school	3.24	3.91	.07		
Reciprocal friend	-9.25*	4.95*	-.17*		
Leisure	0.37	1.23	.03		

Note. $N = 137$. * $p < .05$. ** $p < .01$. *** $p < .001$. TD = typically developing.

adaptive skills, and grit) were entered on Step 1. This block of factors was significant, accounting for 34.5% of the variance in social quality of life. Unexpectedly, the contextual variables (i.e., parent mental health, sibling type, school type, presence of a reciprocal friendship, and participation in leisure) entered on Step 2 did not add significantly to the variance accounted for in social quality of life. The three individual factors that were significant predictors of social quality of life were, as expected, fewer ASD symptoms, lower levels of maladaptive behaviour, and higher levels of adaptive skills. Unexpectedly, grit did not predict social quality of life.

The second regression analysis (Table 6) examined the predictive ability of individual and contextual factors with respect to parent-reported emotional quality of life. The four individual factors (i.e., ASD symptom severity, maladaptive behaviours, adaptive skills, and grit) were entered as a block on Step 1, which was significant and accounted for 33.8% of the variance in emotional quality of life. Again, unexpectedly, the addition of the contextual factors (i.e., parent mental health, sibling type, school type, presence of a reciprocal friendship, and participation in leisure) on Step 2 did not add significantly to the variance accounted for in emotional quality of life. Regarding the significant predictors on Step 1, as expected, fewer maladaptive behaviours predicted a higher level of emotional quality of life. Unexpectedly, adaptive skills also were found to significantly predict emotional quality of life. Consistent with expectations, ASD symptoms and grit did not significantly predict emotional quality of life.

The third regression analysis (Table 7) examined the predictive ability of individual and contextual factors with respect to parent-reported school quality of life.

Individual factors (i.e., ASD symptom severity, maladaptive behaviours, adaptive skills, and grit) were entered on Step 1, which was significant, accounting for 28.9% of the variance in school quality of life. Contextual factors (i.e., parent mental health, sibling type, school type, presence of a reciprocal friendship, and participation in leisure) entered on Step 2 again did not account for significantly additional variance. As expected, higher levels of adaptive skills and increased grit predicted higher school quality of life on Step 1. Unexpectedly, fewer maladaptive behaviours also predicted higher school quality of life. The finding that lower levels of ASD symptoms did not significantly predict higher school quality of life was unexpected.

The fourth regression analysis (Table 8) examined whether the individual and contextual factors predicted physical quality of life. Individual factors (i.e., ASD symptom severity, maladaptive behaviours, adaptive skills, and grit) were entered on Step 1, which was significant and accounted for 16.7% of the variance in physical quality of life. Step 2 included contextual factors (i.e., parent mental health, sibling type, school type, presence of a reciprocal friendship, and participation in leisure) and did not add significantly to the variance accounted for. As expected, fewer maladaptive behaviours predicted higher physical quality of life and higher levels of grit did not predict higher physical quality of life. Higher adaptive skills were also found to significantly predict physical quality of life. Unexpectedly, ASD symptoms did not predict physical quality of life.

Taken together, the individual factors, as expected, generally predicted quality of life, whereas the contextual factors did not predict quality of life over and above the individual factors, which was contrary to expectations. Regarding the individual

factors, Hypothesis 5 was partially supported in that, as expected, ASD symptoms predicted social quality of life and not emotional quality of life, but, contrary to expectation did not predict school or physical quality of life. Hypothesis 6 also was partially supported, as maladaptive behaviours predicted social, emotional, and physical quality of life as expected. However, maladaptive behaviours also predicted school quality of life, which was unexpected. Hypothesis 7 also was partially supported, as adaptive skills predicted social and school quality of life. Unexpectedly, adaptive skills also predicted emotional and physical quality of life. Hypothesis 8 was partially supported, as grit predicted school quality of life and did not predict emotional or physical quality of life. However, grit did not predict social quality of life, contrary to expectation.

As for contextual factors, none of Hypotheses 9–13 were supported. That is, none of the contextual variables significantly added to the variance accounted for in any of the quality-of-life domains (i.e., social, emotional, school, or physical) over and above the individual factors.

Research Question 6: Indirect Effect of Reciprocal Friendship

Research question 6 and hypotheses 14 and 15 stated that reciprocal friendship would have an indirect effect on the relationships between ASD symptom severity and the social, physical, and school domains of quality of life and on the relationship between maladaptive behaviours and the social, emotional, and physical domains of quality of life. To test these hypotheses, causal mediation analyses were conducted in the statistical programming language R with quasi-Bayesian confidence intervals based on bootstrap samples of 1,000 (Imai, Keele, Tingley, & Yamamoto, 2017). When the

95% biased-corrected confidence interval did not contain zero, it was concluded that the effect was not supported. Unstandardized estimates are presented in Tables 9 and 10. Given that the focus of the question was on the indirect effects of reciprocal friendship, significant correlations between ASD symptom severity or maladaptive behaviours and quality of life were not required (Hayes & Rockwood, 2017). Additionally, tests of significance of the individual paths between ASD symptom severity or maladaptive behaviours and reciprocal friendship or between reciprocal friendship and quality of life domains were not required (Hayes & Rockwood, 2017).

Hypothesis 14 predicted that reciprocal friendship would have an indirect effect on the relationship between ASD symptom severity and social, school, and physical quality of life. The results indicated that there was no support for the direct relationship between ASD symptom severity and physical or emotional quality of life. There was support for the direct relationship between ASD symptom severity and social and school quality of life. None of the indirect effects of ASD symptom severity through reciprocal friendship were supported.

Hypothesis 15 predicted that reciprocal friendship would indirectly influence the relationship between maladaptive behaviours and social, emotional, and physical quality of life. The results support a significant direct relationship between maladaptive behaviours and each of the four domains of quality of life. In contrast, the indirect effects of maladaptive behaviours through reciprocal friendship were not supported. Taken together, hypotheses 14 and 15 were not supported.

Table 9

*Effects of ASD Symptom Severity on Quality of Life Through Reciprocal Friendship**(Unstandardized Estimates)*

	BC ^a 95% CI			Indirect effect	BC ^a 95% CI		Total effect	BC ^a 95% CI	
	Direct effect	Lower	Upper		Lower	Upper		Lower	Upper
AQ ¹	-1.96	-5.36	0.76	0.03	-5.17	3.82	-1.94	-8.72	2.46
AQ ²	-1.02	-3.71	2.60	-0.27	-4.69	4.47	-1.25	-5.84	5.58
AQ ³	-6.04 ^b	-8.58	-3.59	0.03	-1.90	2.07	-6.02 ^b	-9.14	-2.95
AQ ⁴	-3.56 ^b	-6.07	-1.22	-0.09	-2.73	3.09	-3.64 ^b	-7.17	-0.08

Note. N = 151. Results are based on 1,000 bootstrap samples. AQ = autism symptom severity.

^a Bias-corrected confidence intervals. ^b An effect that is supported as indicated by a confidence interval that does not include zero. ¹ Physical quality of life. ² Emotional quality of life. ³ Social quality of life. ⁴ School quality of life.

Table 10

*Effects of Maladaptive Behaviours on Quality of Life Through Reciprocal Friendship
(Unstandardized Estimates)*

	BC ^a 95% CI			Indirect effect	BC ^a 95% CI		Total effect	BC ^a 95% CI	
	Direct effect	Lower	Upper		Lower	Upper		Lower	Upper
MB ¹	-0.23 ^b	-0.34	-0.13	0.01	-1.13	1.12	-0.22	-1.34	0.92
MB ²	-0.33 ^b	-0.41	-0.24	-0.01	-1.22	1.21	-0.34	-1.55	0.90
MB ³	-0.25 ^b	-0.36	-0.15	0.02	-1.15	1.25	-0.23	-1.39	1.03
MB ⁴	-0.26 ^b	-0.36	-0.14	0.02	-1.65	1.80	-0.23	-1.88	1.54

Note. N = 151. Results are based on 1,000 bootstrap samples. MB = maladaptive behaviours.

^a Bias-corrected confidence intervals. ^b An effect that is supported as indicated by a confidence interval that does not include zero. ¹ Physical quality of life. ² Emotional quality of life. ³ Social quality of life. ⁴ School quality of life.

CHAPTER FOUR

Discussion

In the current study, an ecological framework was used to guide the selection and evaluation of whether or not specific individual factors (i.e., ASD symptom severity, maladaptive behaviours, adaptive skills, and grit) and contextual factors (i.e., parent mental health, sibling type, school type, reciprocal friendship, and participation in leisure) contributed to a higher level of parent-perceived quality of life of school-aged children with ASD. Guided by this framework, three research goals were developed. The first set of goals was to examine the level of global quality of life and the levels of domain-specific quality of life in school-aged children with ASD, to assess variation across quality of life domains, and to assess variation in quality of life by the children's age and the children's gender. The second goal was to assess the contribution of specific individual factors and specific contextual factors to the quality of life of children with ASD and whether contextual factors contribute to the quality of life of school-aged children with ASD after key individual factors have been accounted for. The third goal was to examine whether a contextual variable (i.e., the presence of a reciprocal friendship) had an indirect effect on the relationship between two individual variables (i.e., ASD symptom severity and maladaptive behaviours) and school-aged children with ASD's quality of life as perceived by their parent.

Global and Domain-Specific Quality of Life in School-Aged Children with ASD

The first goal of the current study was to explore levels of quality of life globally and by domain for children with ASD as reported by their parent, to examine

variation across four domains, and to examine variation by the children's age and gender. I hypothesized that, compared to published data for typically developing peers, children with ASD would have lower global quality of life (Hypothesis 1) and lower quality of life in the social, emotional, and school domains (Hypothesis 2).

Consistent with Hypothesis 1, children with ASD were rated as having lower global quality of life than typically developing children assessed by Varni and colleagues (2001). This study was utilized for comparison given its large sample size and comparable age range. Although direct comparisons with the previous literature are challenging because of sample differences, the finding that children with ASD in the current study have lower global quality of life than a sample of typically developing children is in line with previous research that has consistently found that children with ASD have lower global quality of life than their typically developing peers (e.g., De Vries & Geurts, 2015; Kose et al., 2013; Kuhlthau et al., 2010; Limbers et al., 2009; Öztürk et al., 2016; Potvin et al., 2015). However, it must be noted that Varni and colleagues (2001) examined quality of life of typically developing children only, and therefore, a direct comparison of the level of quality of life among another sample of children with ASD was not possible.

Turning to domain-specific quality of life, consistent with Hypothesis 2, the current study found that parent-perceived quality of life of school-aged children with ASD was lower than published data on healthy controls in the domains of social, emotional, and school quality of life. Physical quality of life also was found to be lower for children in the current study compared to published data on healthy controls. These results are consistent with previous work using the PedsQL by De Vries and Geurts

(2015) and Potvin and colleagues (2015), who also found that all domains of quality of life were lower for children with ASD than their non-affected peers. In contrast, Kuhlthau and colleagues (2013) found that children with ASD were rated, using the Child Health and Illness Profile—Child Edition, by their parents as having lower resilience, risk avoidance, satisfaction, and achievement, but not lower comfort than typically developing peers. It is possible that the inconsistent findings across studies are due to the different measures capturing differing constructs despite both attempting to measure quality of life. However, the PedsQL is the most commonly used measure of quality of life in this population (Tavernor et al., 2012) and has solid psychometric properties (Viecili & Weiss, 2015).

Another factor that may be important when examining domain-specific quality of life in children with ASD and typically developing children is the informant. Given that quality of life is a subjective construct, it is recommended that the perspective of the individual be used when possible (Stokes et al., 2017). Research has found that children with ASD rate some domains of quality of life lower, but not others (e.g., school), than their typically developing peers (Tavernor et al., 2012) and parent proxy ratings (Limbers et al., 2009). It is possible that the differences between parent- and self-report stem from children with ASD being less aware of their various difficulties (Cramm & Nieboer, 2012; Hsieh et al., 2013; Stokes et al., 2017). In general, multiple factors likely contribute to the variability found in research on children with ASD's quality of life, including the measure used and who is chosen as the informant.

Regarding variation across domains in parent reports of children with ASD's quality of life, the physical and school domains of quality of life were expected to be

rated higher than the social and emotional domains (Hypothesis 3). Consistent with expectations, physical quality of life was rated significantly higher than the other three domains of quality of life. The prediction about school quality of life was partially supported, such that school quality of life was rated higher than social quality of life, but was not rated higher than emotional quality of life. In addition, emotional and social quality of life were not significantly different from one another. I am not aware of previous studies that have examined the variation in quality of life across domains within a sample of school-aged children with ASD, despite calls to do so from a number of researchers (e.g., Telman, Van Steensel, Maric, & Bögels, 2017).

Given that ASD is a social communication disorder and not a physical disability, it seems logical that physical quality of life would be higher than the other domains of quality of life in this population. In addition, given that the features of ASD include difficulties with social-emotional reciprocity, it seems reasonable that the social and emotional domains of quality of life would be lower in this population. The results suggest that, for children with ASD, quality of life is not a uniform construct. Knowing which aspects of quality of life are higher and lower helps to highlight strengths and targets for intervention for children with ASD.

Concerning variation in quality of life by the child's gender and age, I did not make specific hypotheses because of the dearth of available literature. Consistent with De Vries and Geurts (2015), my analyses showed no difference in parents' ratings of global or domain-specific quality of life by child's gender. However, a post-hoc power analysis indicated that there was insufficient power to detect gender differences in quality of life in the current study. Although most research has not found gender

differences in quality of life domains in this population (e.g., Begeer et al., 2017; Kose et al., 2013; Kuhlthau et al., 2010), Arias and colleagues (2018) reported that girls scored lower than boys on the social inclusion domain of the Kidscreen. However, their sample included children and adolescents with intellectual disability only. It is possible that the different measure used in their study, the different diagnostic groups, or the wider age range of the sample contributed to their result. Research on gender differences in various aspects of ASD, including quality of life, is complicated by having too few girls in samples to provide adequate statistical power due to the lower prevalence of females with ASD, the later diagnosis of girls (e.g., CDC, 2012), and the different presentation of ASD in girls than boys (e.g., Begeer et al., 2013). As research yields more information about ASD in girls as compared to boys, a better understanding of whether gender plays any role in children with ASD's quality of life may emerge.

The analyses showed that children's age was not significantly related to quality of life in the current study. To the best of my knowledge, the current study is the first to examine variation by age in quality of life as perceived by parents of children with ASD in school-age specifically. Previous research on varied ages has shown inconsistent results. Begeer and colleagues (2017) found no main effect of age on quality of life for children with ASD and Kamp-Becker and colleagues (2011) found no significant difference in quality of life by age in adolescents with ASD. In contrast, Kuhlthau and colleagues (2010), who used a wider age range, found higher quality of life for younger (2 to 7 years old) than older (8 to 17 years old) children. This suggests that there could be age-related changes in quality of life for children with ASD between

preschool and adolescence, but not necessarily within the more restricted age ranges of the current study and other studies (Begeer et al., 2017; Kamp-Becker et al., 2011).

Given that the available research does not conclusively answer whether there is variation by age in quality of life in children and youth with ASD, further study of this question is warranted.

Individual and Contextual Predictors of Parent-Perceived Quality of Life

The second goal of the current study was to identify individual and contextual factors expected to predict domain-specific quality of life of school-aged children with ASD as perceived by their parents. An ecological framework alongside previous literature were used to select relevant variables. Four individual factors (i.e., ASD symptom severity, maladaptive behaviours, adaptive skills, grit) and five contextual factors (i.e., parent mental health, presence of a typically developing sibling, attendance in a mainstream school, presence of a reciprocal friendship, participation in leisure) were selected for evaluation.

Individual Variables

ASD symptom severity. It was anticipated that fewer ASD symptoms would predict higher social, physical, and school quality of life (Hypothesis 5), which was partially supported. Fewer ASD symptoms predicted higher social quality of life, but not higher physical or school quality of life. The current results are consistent with De Vries and Geurts's (2015) finding that difficulties in social communication were related to lower social quality of life and Kuhlthau and colleagues' (2010) finding that restricted and repetitive behaviours were negatively correlated with social quality of life. Given that the core deficits in ASD include difficulties with reciprocal social

communication and the presence of restricted and repetitive behaviours, it seems reasonable that higher levels of these symptoms may negatively interfere with social quality of life. Children with ASD who have fewer difficulties with reciprocal interactions may relate to peers more easily and more readily engage in social exchanges and activities than children with higher levels of social communication difficulties. Similarly, children with fewer restricted and repetitive behaviours may not be perceived as unusual compared to their peers and they also may present with higher levels of social engagement.

The result that ASD symptom severity did not predict physical quality of life is inconsistent with previous research (Kose et al., 2013). Difficulties in social communication, lower levels of motivation (De Vries & Geurts, 2015), and increased repetitive behaviours have been found to be related to lower physical quality of life (Kuhlthau et al., 2010). The current study examined the severity of ASD symptoms as a single construct encompassing social communication and restricted and repetitive behaviours (i.e., the AQ-10 Child). It is possible that this global measure of both social communication deficits and restricted and repetitive behaviours was not as sensitive as the symptom-specific measures used in previous studies.

The finding that ASD symptom severity was not a predictor of school quality of life is consistent with research that found no relationship between ASD symptoms and school quality of life (De Vries & Geurts, 2015; Kuhlthau et al., 2010) and inconsistent with research that found that ASD symptoms related to aspects of school quality of life (Kose et al., 2013; Kuhlthau et al., 2013). Variation in the instruments used to measure ASD symptom severity may have contributed to the varied results. It is also possible

that examining the components of ASD separately (i.e., social communication and restricted and repetitive behaviours) may have uncovered relationships that remained hidden in the present global approach. For example, repetitive behaviours may interfere with focus on academic tasks and learning but not overall school quality of life. Further, social communication deficits may relate to difficulties interacting during school break times, which may lead to lower social quality of life but not school quality of life.

Maladaptive behaviours. Lower levels of maladaptive behaviour were expected to predict higher social, emotional, and physical quality of life (Hypothesis 6); this hypothesis was fully supported. In addition, the current study found that lower levels of maladaptive behaviour also predicted higher school quality of life. These findings are congruent with previous research that found higher levels of maladaptive behaviour were related to lower global (Kuhlthau et al., 2010) and domain-specific (Bastiaansen et al., 2004) quality of life. The results highlight the importance of examining maladaptive behaviours when exploring quality of life, as this factor seems to have associations across all domains.

Certain domains of quality of life may be particularly influenced by specific maladaptive behaviours. For example, children with ASD and internalizing behaviours may have difficulties interpreting social cues, impairing their social inclusion and well-being (Factor, Ryan, Farley, Ollendick, & Scarpa, 2017). In contrast, children with ASD and externalizing symptoms may have difficulties with social awareness, leading to inappropriate overtures and exclusion (Factor et al., 2017). Therefore, children with

ASD with internalizing or externalizing behaviours may struggle in social interactions, though for different reasons, which may be detrimental to social quality of life.

Adaptive skills. Higher levels of adaptive behaviours were expected to predict higher social and school quality of life (Hypothesis 7). The current study found support for this hypothesis. Additionally, higher adaptive skills also were found to predict higher physical quality of life and higher emotional quality of life. This finding highlights the importance of examining adaptive skills when exploring quality of life as adaptive skills are relevant across all domains. The findings of the current study are consistent with research that found significant or trending relationships between adaptive skills and quality of life in children and youth (Clark et al., 2015; Kuhlthau et al., 2010; Tilford et al., 2012). In contrast, Kamp-Becker and colleagues (2011) found no significant relationship between adaptive skills and global quality of life.

Regarding the social domain of quality of life, children who are more efficient and independent in self-help tasks have increased resources (e.g., time and energy) to dedicate to social pursuits. Further, children with adaptive skills that are more congruent with their chronological age may appear less distinguishable from their peers and therefore participate more in social interactions (Rotheram-Fuller, Kasari, Chamberlain, & Locke, 2010). In terms of the school domain of quality of life, it is plausible that children requiring less support for tasks of daily living may be able to dedicate more time to their academics and participation in school activities. With respect to physical quality of life, children with higher levels of independence with adaptive skills may be able to engage in physical activities more fully and complete physically demanding tasks. Regarding emotional quality of life, children who have

more independence in adaptive skills may have higher levels of self-efficacy and positive emotions.

Grit. Grit was expected to predict social and school quality of life (Hypothesis 8). Partial support for this hypothesis was found: higher levels of grit predicted higher levels of school quality of life, but not higher levels of social quality of life. The relationship between grit and school quality of life is congruent with a study that found grit to be related to higher academic achievement in children with ASD (McMahon et al., 2015). The lack of relationship between grit and social quality of life may be explained by several factors. Specifically, children with ASD may have reduced social motivation and unusual perseverative interests that may not be consistent with the interests of their typically developing peers. In addition, higher levels of grit may be related to more rigidity in terms of resistance to change, transitions, and play led by others. These factors may negatively affect social quality of life (Factor, Condy, Farley, & Scarpa, 2016). It is possible that a measure of grit for children with ASD that inquires about perseverance of effort and consistency of interest as they relate to the child's specific interests as well as their general engagement in tasks may be beneficial in parsing out differences in this population.

Contextual Variables

Parent mental health. Research has found that parents of children with ASD have poorer mental health than parents of typically developing children (e.g., Vasilopoulou & Nisbet, 2016) and children with other developmental challenges or health concerns (e.g., Abbeduto et al., 2004). Parents in the current study had similar mental health concerns as parents of children with ASD in previous research.

Compromised mental health is associated with less optimal parenting and caregiving environments (e.g., England & Sim, 2009; Huang, Abura, Theise, & Nakigudde, 2017). To my knowledge, this was the first study to examine the relationship between parent mental health and quality of life of school-aged children with ASD. It was expected that increased levels of parent mental health would predict higher social and emotional quality of life in children with ASD (Hypothesis 9). No support was found for this hypothesis.

Although parent mental health was not a predictor of quality of life, there was a significant *inverse* relationship between parent mental health and global quality of life as well as social and emotional quality of life of school-aged children with ASD. This is consistent with findings that higher parenting stress and poorer parent mental health were associated with higher social quality of life and higher emotional quality of life, respectively, in preschool-aged children with ASD (Chuang et al., 2014). The counterintuitive finding of poorer parental mental health being related to higher quality of life may partially be explained by the cost of high levels of caring and intervention by the parents of children with ASD. This investment by parents of personal resources (e.g., time and energy) into the care of their children likely positively contributes to their children's quality of life while having detrimental effects on the parent's own well-being. Importantly, although there was a relationship between parent mental health and quality of life in the current study, parent mental health did not predict quality of life.

Sibling. The presence of a typically developing sibling was expected to be associated with higher social and emotional quality of life (Hypothesis 10). This

hypothesis was not supported. The mere presence of a typically developing sibling may be insufficient to influence quality of life. It is possible that what is critical is the *quality* of the relationship. Sibling relationship quality has been shown to be related to a number of social-emotional factors, including temperament, persistence, level of problem behaviour, level of functioning, and social skills (Brewton et al., 2012; Rivers & Stoneman, 2008; Tudor, Rankin, & Lerner, 2018). Positive sibling relationships have been found to be a protective factor that may shield school-aged children and adolescents with ASD from poor emotional and behavioural functioning (Tudor et al., 2018), which also influence quality of life. The potential relationship between positive sibling relationships and increased quality of life necessitates examination of factors related to the quality of sibling relationships.

Research indicates that factors including birth order and sibling age may be important. The presence of an older sibling versus having no sibling was related to higher levels of social communication in children with ASD (Ben-Itzhak et al., 2016). Siblings relationships may be more influential prior to entry to school, given the greater proportion of time siblings spend together prior to school entry and the increased influence of peer relationships after school entry. Future research could seek to parse out differences in sibling relationship quality and influence across time and how these factors may relate to quality of life.

School type. Attendance at a mainstream school was expected to predict higher social and school quality of life (Hypothesis 11). No support was found for this hypothesis. Previous findings have been mixed with some research reporting benefits of attending mainstream schools (Eldar et al., 2012; Kose et al., 2013; Reed et al.,

2012) and some research reporting no differences or negative outcomes of attending mainstream schools (Zainal & Magiati, 2016).

The current study used an international sample to examine the potential relationship between attending a mainstream school and children with ASD's quality of life. Importantly, inclusion criteria as well as types and level of supports may differ across jurisdictions which may influence whether an individual child's needs are met (Falkmer, Anderson, Joosten, & Falkmer, 2015; Goodall, 2015; Waddington & Reed, 2017). Further, individual child characteristics may determine whether integration is beneficial (Cook, Ogden, & Winstone, 2016; Jones & Frederickson, 2010). For example, at least one study found that children with ASD with less impaired social skills were *more* at risk of rejection by peers, perhaps because typically developing peers were less willing to make accommodations for peers with subtle difficulties (Jones & Frederickson, 2010). The current study did not control factors such as inclusion criteria, type and level of support, and individual child characteristics which may have negatively impacted the ability to detect relationships.

Reciprocal friendship. The presence of a reciprocal friendship was expected to be associated with higher social and emotional quality of life (Hypothesis 12). This hypothesis was not supported. Emerging research on friendships of children with ASD has highlighted the complexities of the construct of friendship. Although the quality of friendships of children with ASD may objectively be judged to be poor (e.g., Bauminger & Kasari, 2000; Bauminger & Shulman, 2003; Calder, Hill, & Pellicano, 2013; Chamberlain, Kasari, & Rothermanfuller, 2007; Kasari, Locke, Gulsrud, & Rotheram-Fuller 2011; Mendelson, Gates, & Lerner, 2016; Petrina, Carter, Stephenson,

& Sweller, 2016; Rotheram-Fuller et al., 2010), children with ASD may be satisfied with those friendships (e.g., Bauminger, Shulman, & Agam, 2004; Calder et al., 2013; Chamberlain et al., 2007; Petrina et al., 2016). The current study did not examine friendship satisfaction, despite its potential importance for understanding the relationship between friendship and quality of life.

The *composition* of the friendship also may be important. Specifically, friendships between a child with ASD and a typically developing child have been found to have benefits including increased responsiveness and language as well as higher levels of complex play (Bauminger et al., 2008). However, the authenticity and reciprocity of these relationships is unclear given the allowances the typically developing peer is making for the child with ASD (Rotheram-Fuller et al., 2010). Friendships between a child with ASD and a child with a disability, on the other hand, had other benefits including opportunities for leadership roles for the child with ASD (Bauminger et al., 2008). Given such differences, it would be worth examining whether or not the type of friendship influences quality of life of the child with ASD.

Leisure. Participation in leisure activities was expected to predict higher social, emotional, and physical quality of life (Hypothesis 13). No support was found for this hypothesis. This unexpected finding is incongruent with previous research which has consistently demonstrated the benefits of leisure on quality of life of children with neurodevelopmental disorders (Bandini et al., 2013; Dahan-Oliel et al., 2012; Pfiffer et al., 2017; Toscano et al., 2018).

The current study examined the number of leisure activities participated in and there was insufficient power to include multiple types of leisure. Categorical data also

were collected on the frequency of each activity separately. There was no relationship between the frequency of any of the activities and quality of life. There was a relationship between less participation in social and recreational programs for children with disabilities and higher social quality of life. Further exploration of this relationship may be warranted to determine whether other factors contribute to this relationship.

It is possible that the number of leisure activities is insufficient to capture the complex relationship between leisure and quality of life. The type and satisfaction of leisure activities may relate better to quality of life. Relative to their typically developing peers, children with ASD tend to engage in more pacing and self-stimulatory and repetitive behaviours (Bandini et al., 2013), but fewer social and recreational activities (Solish et al., 2010). In addition, children with ASD tend to prefer solitary activities; they tend to not enjoy formal and physical activities as much as their typically developing peers (Brewster & Coleyshaw, 2011; Eversole et al., 2016). In brief, other dimensions of leisure—including type, satisfaction, and frequency of enjoyed activities (Eversole et al., 2016; Hilton, Crouch, & Israel, 2008; Ratcliff, Hong, & Hilton, 2018; Wigston, Falkmer, Vaz, Parsons, & Falkmer 2017), not measured in the current study—may be able to predict quality of life better than simply the number of activities in which a child participated.

Indirect Effects of Reciprocal Friendship

It was expected that the presence of a reciprocal friendship would have an indirect influence on the relationship between ASD symptom severity and the social, physical, and school domains of quality of life (Hypothesis 14). No support was found for this hypothesis. Similarly, it was expected that the presence of a reciprocal

friendship would indirectly influence the relationship between maladaptive behaviours and the social, emotional, and physical domains of quality of life (Hypothesis 15).

Support was not found for this hypothesis.

There are several plausible explanations as to why there was no indirect influence of a reciprocal friendship on the relationship between ASD symptom severity or maladaptive behaviours and quality of life. Given the importance that parents place on their children developing friendships (e.g., Petrina et al., 2015), it is possible that parents in the current study supported the development of at least one friendship regardless of the severity of ASD symptoms or the level of maladaptive behaviours of their children with ASD. It also is possible that parents were being generous in their interpretation and reporting of reciprocal friendships, given the value they place on friendship. In the current study, the majority of parents rated their child with ASD as having a reciprocal friend even for the children with the highest level of ASD symptom severity and for the children with the highest level of maladaptive behaviours. A better way to measure reciprocal friendship would be to use objective measures (e.g., sociograms, teacher ratings) or to look at the support required to develop and maintain that friendship (Anderson, Locke, Kretzmann, Kasari, & AIR-B Network, 2016; Rotheram-Fuller et al., 2010).

Implications for Quality of Life of School-Aged Children with ASD

Several implications can be drawn from the current study examining parent-perceived quality of life of school-aged children with ASD. Individual and contextual factors expected to predict quality of life for children with ASD were examined, consistent with Bronfenbrenner's (1994) model and the WHO's definition of quality of

life as being related to both individual and environmental factors as well as interactions between these factors. The assertion that individual factors are important to consider was supported by the current study: all individual predictors were related to at least one domain of quality of life, though not always with all domains of quality of life.

The findings of the regression analyses indicated that individual factors predicted different domains of quality of life. Importantly, these individual predictors are all malleable. Maladaptive behaviours predicted each domain of quality of life and therefore, interventions targeting this construct may be beneficial for increasing quality of life (Drmic, Aljunied, & Reaven, 2017; Factor et al., 2017). Adaptive skills also predicted all quality of life domains. Research has highlighted the importance of increasing adaptive skills and interventions aimed at increasing adaptive skills have shown mixed support for effectiveness (e.g., Bal, Kim, Cheong, & Lord, 2015; Blacklock, Perry, & Geier, 2014). Given that grit predicted school quality of life, it may be of interest to determine whether grit can be increased in children with ASD and, if so, whether that would result in increased school quality of life. Interestingly, ASD symptom severity was a predictor only of social quality of life. This suggests that reduction of ASD symptoms—although seemingly an obvious goal—may not be the most effective intervention target when the goal is to improve the child’s global quality of life.

Turning to contextual predictors, the importance of environmental factors highlighted in Bronfenbrenner’s (1994) model and the WHO’s definition of quality of life was not supported by the current study. Specifically, although there were relationships between some of the contextual factors and quality of life, the contextual

factors were much less salient than the individual factors, and, in the regression analyses, did not predict quality of life over and above the individual factors. It is possible that the way the contextual factors were measured in the current study limited the ability to detect significant relationships (e.g., measuring the presence rather than the quality of factors). Research on the contextual factors is relatively sparse in comparison to research on the individual factors. Indeed, the current study is the first to examine most of the contextual factors used here in relation to quality of life, and the understanding of these factors—and how to measure them—in the ASD population is still emerging. It is therefore premature to conclude that the contextual factors are unimportant or that interventions to address contextual factors would not be relevant for improving the quality of life of school-aged children with ASD.

The importance of interactions between individual and contextual variables is also highlighted in Bronfenbrenner's (1994) bioecological model and the WHO (1995) definition of quality of life. The current study examined the indirect influence of reciprocal friendship on the relationship between ASD symptoms and quality of life, and between maladaptive behaviours and quality of life. Reciprocal friendship was not found to have an indirect influence on either relationship examined. Regarding indirect effects, it is possible that the current study was not able to capture the full complexity of reciprocal friendship. If so, an indirect effect would not have been found even if it exists. With a different measure or conceptualization of the variable, it is possible that evidence for an indirect relationship may be found.

Thus, a surface-level examination of the results of the current study may lead to the conclusion that contextual factors and indirect relationships are not important for

understanding parent-perceived quality of life in school-aged children with ASD. However, careful review and integration of all available literature indicates that a more plausible explanation may be that individual factors are in fact the best understood predictors of quality life, and therefore they emerge as the most salient factors when examining quality of life.

Limitations

Several limitations of the sample of the current study should be mentioned. The current study did not confirm the diagnosis of ASD given that the data was collected online. However, to increase confidence that the sample was comprised of children with ASD only participants who scored their child a 6 or higher on the AQ-10 Child were retained as this cut-off score has been found to have high specificity (Allison et al., 2012). In addition, parents answered open-ended questions about their child's symptoms and diagnosis, and participants whose answers were incongruent with the presentation of ASD were excluded from the study. It was not possible to examine the cognitive level of the children in the current study. However, research examining the relationship between cognition and quality of life has produced mixed results and a meta-analysis by Van Heijst and Geurts (2015) did not find a relationship between intellectual ability and global quality of life. The current study did not examine the influence of comorbidity given the logistical challenges in collecting and validating this data.

Parent report was used to collect data about the child's quality of life which provides information on the parents' perspective of their child's quality of life, but does not provide an understanding of the child's subjective experience of their own quality

of life which may have yielded different results and provided increased understanding of some of the contextual factors including friendship and leisure. However, using parent reports allows for inclusion of children who would not be able to complete self-report measures and who have limited insight into their areas of difficulty (e.g., Potvin et al., 2015; Tilford et al., 2012). Due to challenges with recruitment alongside many participants being excluded from the analyses due to the reasons stated above, the study did not have enough participants to be adequately powered. Although it is possible that relationships exist that were not able to be detected due to reduced power, the regression analyses indicated that the effect of adding the contextual factors was small in magnitude across domains of quality of life. Therefore, an increase in participants would be unlikely to create a meaningful change.

Several limitations of the measures in the current study are important to mention. Specifically, measures were not available for some of the predictors selected in the current study and the available measures were not all validated for children with ASD. Measures with adequate to good psychometric properties were utilized when possible though some measures had limited range and variance which may have impacted the results found in the regression analyses, particularly the lack of finding of contextual factors predicting quality of life beyond the individual factors. Future research would benefit from development and validation of measures with wider ranges and specific to this population where possible. In addition, the emotional quality of life domain and grit had lower than ideal internal consistency. In the case of both maladaptive behaviours and adaptive skills, there is potential for overlap between these measures and the quality-of-life measure. However, although the predictors were

correlated with the dependent measure, they each accounted for some, but not most, of the variance in quality of life, indicating they are distinct concepts. Finally, in retrospect, I did not measure certain aspects of variables – such as friendship *quality* or leisure *satisfaction* which may have led to the creation of more meaningful variables that may have captured the relationships between contextual factors and quality of life among children with ASD. For example, the presence of a friendship that is perceived to be meaningful to the child with ASD or engagement in leisure activities that the child with ASD enjoys may predict a higher level of quality of life while the mere presence of a friendship or attending leisure activities did not predict higher quality of life. Variables of friendship or leisure that do not capture whether the experience is meaningful to the child with ASD may not be able to detect the potential relationships between the constructs of friendship or leisure and quality of life.

Directions for Future Research

Several directions for research on parent-perceived quality of life of school-aged children with ASD emerge from the results of the current study. The amount of variance accounted for in each domain of quality of life suggests there are additional factors contributing to quality of life that were not measured in the current study. For example, although type and severity of comorbidities were not examined in the current study, they may be important individual factors to consider when examining quality of life of children with ASD (e.g., Sikora et al., 2012). Exploration of whether comorbidities relate directly to quality of life and whether there are indirect influences of comorbidities (e.g., comorbid conditions may influence adaptive skills and in turn quality of life) would be a worthy endeavour. Examining how contextual factors such

as family sense of coherence or marital quality may relate to quality of life in children would be beneficial given research indicating that these factors relate to parent/family quality of life (e.g., Benson, & Kersh, 2011; McStay, Trembath, & Dissanayake, 2014). Children typically spend considerable time within their family environment and it seems reasonable that family dynamics that influence family quality of life might also relate to child quality of life.

Future studies could extend the findings of the current study through examining quality and satisfaction for relevant factors. Specifically, rather than examining the *presence* of a sibling or friend as in the current study, research exploring the *quality* of these relationships is needed. A more nuanced examination of sibling relationships should consider the birth order and age of the siblings to understand better how the quality of the sibling relationship (e.g., Ben-Itzhak et al., 2016; Tudor et al., 2018) may relate to quality of life for children with ASD. Regarding friendship, research could examine the relationship quality and satisfaction including whether the friend is typically developing or has a developmental disability and the level of adult support needed for the friendship to exist (e.g., Rotheram-Fuller et al., 2010). This more in-depth understanding of friendship may elucidate a relationship with quality of life. Research on the relationship between satisfaction and quality of life also would be helpful for understanding constructs such as leisure (e.g., Brewster & Coleyshaw, 2011; Eversole et al., 2016) and friendship where children with ASD have been found to have perceptions that vary from the perceptions of their parents and peers (e.g., Petrina et al., 2016; Solish et al., 2010).

Although results of the current study did not support indirect relationships through reciprocal friendship, it is possible that some of the individual and contextual predictors may influence one another, and in turn quality of life, in a meaningful way. For example, maladaptive behaviours create barriers to participation in leisure activities for children with ASD (e.g., Must, Phillips, Carol, & Bandini, 2015). Future research could examine whether the relationship between maladaptive behaviours and leisure (e.g., leisure satisfaction) influences quality of life for children with ASD. Additionally, a child's participation in leisure activities may increase their adaptive skills (e.g., Lang et al., 2010; Tomporowski, Lambourne, & Okumura, 2011). Future research could explore whether this increase in adaptive skills leads to an increase in quality of life.

Conclusion

Quality of life is a multifaceted construct comprising social, emotional, school, and physical domains. In line with existing research, the current study demonstrated that global quality of life was lower for children with ASD than their typically developing peers. Regarding domains of quality of life, the current study provided new insight that not all domains are equally impacted for school-aged children with ASD as perceived by their parents. Knowing that physical quality of life was the least impacted domain while social and emotional quality of life domains were the most impacted provides useful information for researchers and clinicians.

In line with an ecological framework, the current study examined individual and contextual predictors of higher quality of life as well as indirect influences between predictive factors of quality of life. The current study found that individual factors (i.e., maladaptive behaviours, ASD symptom severity, adaptive skills, and grit) predicted

domains of quality of life. Therefore, the effort to identify malleable factors related to positive quality of life was successful. Importantly, maladaptive behaviours and adaptive skills predicted all domains of quality of life, and thus are particularly useful targets for future research and intervention efforts.

In contrast, contextual factors (i.e., parent mental health, sibling type, school type, presence of a reciprocal friendship, and participation in leisure activities) did not predict parent-perceived quality of life of school-aged children with ASD over and above individual factors. Importantly, although the individual predictors accounted for some of the variance in each domain of quality of life, not all of the variance was accounted for. This indicates that there are predictors of quality of life that were not captured in the current study. Given that the WHO's (1995) definition of quality of life pointedly draws attention to contextual factors, future research should continue to examine different contextual variables that may relate to quality of life (e.g., family sense of coherence). In addition, research using measures that examine the quality—not the mere presence—of sibling and friend relationships alongside measures that examine the satisfaction of leisure activities would be most welcome. The indirect effects of reciprocal friendship on the relationship between ASD symptoms and quality of life and between maladaptive behaviours and quality of life were not supported in the current study.

Increasing quality of life of school-aged children with ASD is critical. The current study informs understanding of quality of life for children with ASD across domains of quality of life. In addition, directions for future research that emerged from the current study include examining how malleable factors such as sibling relationship

quality and leisure satisfaction may predict increased quality of life in children with ASD. Other directions for future research include exploring additional indirect influences between individual and contextual factors (e.g., indirect relationships between maladaptive behaviours and leisure satisfaction and quality of life).

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Appendix A

Information Letter for Recruitment of Parents of Children with ASD



Online research for parents of children with autism spectrum disorder:

Children's Quality of Life Study

If you have a child with:

- Autism, Aspergers, or PDD-NOS (Pervasive Developmental Disorder – not otherwise specified)

AND

- Your child is age 8-11 years

We are interested in hearing from you!

We are interested in factors related to quality of life of children with ASD from the view of their parents.

For more information go to [URL] or contact the investigators at t533z@unb.ca or bdentrem@unb.ca. Visiting the website does not obligate you to participate.

Participation in this study involves approximately 30-45 minutes of completing questionnaires online. After completing the questionnaires, you may choose to enter a draw for 1 of 5 \$20.00 Visa gift cards.

This study is being conducted by Mandy Fulton, Ph. D. Candidate, t533z@unb.ca, and Dr. Barbara D'Entremont, Ph.D, L.Psyc, Professor, bdentrem@unb.ca, from the University of New Brunswick. For more information, please contact either investigator.

[hard copy fliers posted on physical bulletin boards will have pull off tabs with the website URL on them]

Appendix B

Consent Form

Project Title: Online Research for Parents of Children with Autism Spectrum Disorder: Quality of Life Study

Principal Investigator: Mandy Fulton

Address: Psychology Department, University of New Brunswick, Fredericton, NB

Email: t533z@unb.ca

What is it about?

We are conducting a study examining the well-being of school-aged children with autism spectrum disorder (ASD). We invite you to participate in this study.

Who is doing it?

The study is being conducted by Mandy Fulton, a PhD Candidate in the Department of Psychology at the University of New Brunswick under the supervision of Barbara D'Entremont, PhD, a Professor in the Department of Psychology at the University of New Brunswick.

What will I have to do?

If you choose to participate, you will complete an online questionnaire. The survey takes most people approximately 30-45 minutes to complete all of the questions. You will be asked to complete demographic questions and questions about the child's autism symptoms, behaviours, functional skills, task persistence, parent's mental well-being, sibling type, school type, reciprocal friendships, and participation in activities.

What will I get for participating?

You may choose to enter into a draw for one of five \$20.00 Visa gift cards. Your answers will provide important information for helping professionals to better understand the quality of life of children with ASD.

How will my answers be kept confidential and private?

This study will not collect any personal information such as your name or address. All information will be kept strictly confidential. The data are stored on

a secure server on the University of New Brunswick website. The server is protected by a firewall. Data will be stored on password-protected computers that only the researchers have access to it.

What are my rights as a participant in this survey?

Participation is *completely voluntary*. You may choose not to answer a specific item and continue with the questionnaires. You may also choose that you do not want to continue the study for any reason at any time by closing your browser. **Your data can only be used by the researchers after you click the submit button at the end of the survey.**

Why might I not want to do it?

We do not expect that you will feel uncomfortable during the study. However, sometimes people are upset by answering questions about their child with ASD. In order to provide you with more information we have provided resources about ASD and quality of life on the debriefing page.

Who can I contact for more information?

If you have questions at any time, please contact Mandy Fulton at t533z@unb.ca, or Dr. D'Entremont at bdentrem@unb.ca.

This project is on file with the Research Ethics Board at the University of New Brunswick (REB# 2016-198). If you have questions or concerns about your rights or treatment as a participant please contact the Chair of the UNB Department of Psychology Ethics Board at voyer@unb.ca.

_____ I have read the above statements and **AGREE** to participate in this research.

SUBMIT BUTTON

Appendix C

Debriefing Form

Determining what factors predict quality of life in children with autism spectrum disorder is an important process. We know that children with autism spectrum disorder (ASD) tend to have lower quality of life than their peers. At the same time, we know that having higher levels of certain behaviours (e.g., self-help skills) is related to having higher levels of quality of life for children with ASD.

Although we know some of the factors that are related to quality of life, we do not yet know which factors are the most important and how these factors relate to one another. In this study, we are looking at a variety of factors related to quality of life in children with ASD to understand how the factors relate to one another. Your participation in this study will help us to better understand the relationships between symptoms of autism, child behaviors, self-help skills, persistence, parent mental health, sibling type, school type, reciprocal friendships, and leisure activities. We hope that information from this study will help service providers to be able to provide better supports for families and children with ASD. We hope that this research will provide new directions and ideas for helping to improve quality of life for these children and their families.

We would like to thank you for participating in this research study and for contributing to our understanding of quality of life in children with ASD.

A summary of results of this study will be posted on the following website (URL) as soon as the study is completed and the results are prepared.

If you would like to be entered into a draw for 1 of 5 \$20.00 Visa gift cards, please click the following link (URL). Your email address will not be linked to the data collected for the study.

Academic references:

Chiang, H. M., & Wineman, I. (2014). Factors associated with quality of life in individuals with autism spectrum disorders: A review of literature. *Research in Autism Spectrum Disorders*, 8, 974-986. doi:10.1016/j.rasd.2014.05.003

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A helpful list of parenting books related to autism spectrum disorder can be found here:

http://www.parentbooks.ca/Autism_Featured_Books_Families.html

Appendix D

Demographic Questions

Reporting summary information will help to understand how well findings from this research project represent the “general public”. Responses to these questions will be confidential and will not be associated with your child’s name or your name in any way. Feel free to omit questions you do not wish to answer.

If you have more than one child with ASD who falls within the age range of 8-11 years, please complete this survey for the child whose birthday falls closest to today’s date.

Relationship to the child:

	You	Partner (if married/common law)
Biological father		
Biological mother		
Adoptive father		
Adoptive mother		
Foster father		
Foster mother		
Other Please specify:- _____		

Your age:

Country of residence: _____

Select the setting you live in: urban rural

Highest level of education:

	You	Partner (if married/common law)
Grade 8 or less		
Some high school		
Completed high school		
Some trade, technical or vocational school or business college		
Some community college or CEGEP		
Some university		

Diploma or certificate from community college/university		
Diploma or certificate from trade, technical or vocational school or business college		
Bachelor or undergraduate degree (e.g., BA, BSC, BED)		
Master's degree (e.g., MA, MSC, MED)		
Degree in medicine (MD), dentistry (DDS, DMD), veterinary medicine (DVM), optometry (OD), or law (LLB)		
Earned doctorate (e.g., PhD, DSC)		
Other please specify: _____		

Household income:

Less than \$15,000		Less than \$60,000		Less than \$120,000	
Less than \$20,000		Less than \$70,000		Less than \$150,000	
Less than \$30,000		Less than \$80,000		More than \$150,000	
Less than \$40,000		Less than \$90,000		Prefer not to say	
Less than \$50,000		Less than \$100,000			

Questions about your child with ASD

Child's Age (in years and months): _____

Child gender:

Male	
Female	

Child ASD diagnosis:

Autism Spectrum Disorder	
Autistic Disorder	
Asperger's Syndrome	
Pervasive Developmental Disorder- Not Otherwise Specified	
Other/unsure (Please specify)	

Please indicate if your child with ASD has been diagnosed by a health care professional with any of the following:

ADHD	
Anxiety	

Depression	
Other mental health condition (specify)	
Cerebral Palsy	
Down Syndrome	
Cancer	
Diabetes	
Asthma	
Epilepsy	
Other physical health condition (specify)	

Appendix E¹**Child Quality of Life****Pediatric Quality of Life Inventory (Varni, Seid, & Kurtin, 2001)**

¹This measure could not be copied for publication due to copyright.

Appendix F²**ASD Symptom Severity****Autism Spectrum Quotient (Auyeung et al., 2008)**

²This measure could not be copied for publication due to copyright.

Appendix G³**Maladaptive Behaviours**

**The Nisonger Child Behavior Rating Form (Parent version) (Aman, Tassé,
Rojahn, & Hammer, 1995)**

³This measure could not be copied for publication due to copyright.

Appendix H

Adaptive Skills

The GO4KIDDS Brief Adaptive Scale (Perry et al., 2015)

1. What level of help or support is needed for your child (e.g., toileting, dressing, eating)?
 - a. Requires support for almost all aspects of life
 - b. Requires support for most, but not all, aspects of life
 - c. Requires support for some aspects of life
 - d. Requires support for only a few aspects of life
2. How much does your child understand spoken language?
 - a. Able to understand very little spoken language
 - b. Able to understand some basic language and simple instructions familiar to contexts (e.g., sit down)
 - c. Able to understand most basic instructions and questions
 - d. Able to understand most routine everyday language
 - e. Able to understand complex language about a wide range of topics
3. How much does your child use spoken language to communicate?
 - a. Able to use very little meaningful speech
 - b. Able to communicate basic needs and wants
 - c. Able to communicate needs, wants and some ideas

- d. Able to communicate about a limited range of topics in a meaningful way
 - e. Able to communicate about a wide variety of topics in a meaningful way
4. How much does your child engage in social interactions with familiar adults?
- a. Shows little or no interest in social interactions with familiar adults
 - b. Shows limited social interest but will sometimes respond to familiar adults
 - c. Shows some interest, responds to others, but does not initiate social interactions with familiar adults
 - d. Shows clear social interest, responds to others and sometimes initiates social interactions with familiar adults
 - e. Engages in a wide range of social interactions involving both responding and initiating social contact with familiar adults
5. How much does your child engage in social interactions with other children?
- a. Shows little or no interest in social interactions with other children
 - b. Shows limited social interest but will sometimes respond to other children
 - c. Shows some interest, responds to others, but does not initiate social interactions with other children
 - d. Shows clear social interest, responds to others and sometimes initiates social interactions with other children

- e. Engages in a wide range of social interactions involving both responding and initiating social contact with other children
6. Please select the most accurate description of your child's skills in eating:
- a. Needs complete assistance with eating
 - b. Eats with fingers
 - c. Can use spoon but may be messy
 - d. Uses spoon and fork
 - e. Eats completely independently with proper use of all cutlery
7. Please select the most accurate description of your child's skills in toileting:
- a. Wears diapers day and night
 - b. Wears diaper but indicates when needs changing
 - c. Indicates or asks to use toilet, but does not go independently
 - d. Toilet trained in daytime (occasional accidents); wears diaper or pull-up at night
 - e. Completely toilet trained day and night
8. Please select the most accurate description of your child's skills in dressing:
- a. Needs complete assistance dressing and undressing
 - b. Cooperates with dressing (e.g. raising arms)
 - c. Can remove or pull on/up clothes
 - d. Can dress self quite well but needs help with buttons, zippers, etc.
 - e. Can dress and undress self completely

Appendix I⁴**Grit****Short Grit Scale (Duckworth & Quinn, 2009)- Modified**

⁴This measure could not be copied for publication due to copyright.

Appendix J

Parent Mental Health

Depression Anxiety Stress Scales- Short Form (DASS-21)

Instructions: Please read each statement and press a response that indicates over the past week how much the statement has applied to you. There are no right or wrong answers. Do not spend too much time on any statement.

	Did not apply to me at all	Applied to me to some degree, or some of the time	Applied to me a considerable degree, or a good part of time	Applied to me very much, or most of the time
1. I found it hard to wind down				
2. I was aware of dryness of my mouth				
3. I couldn't seem to experience any positive feeling at all				
4. I experienced breathing difficulty (e.g., excessively rapid breathing, breathlessness in the absence of physical exertion)				
5. I found it difficult to work up the initiative to do things				
6. I tended to over-react to situations				
7. I experienced trembling (e.g., in the hands)				

8. I felt that I was using a lot of nervous energy				
9. I was worried about situations in which I might panic and make a fool of myself				
10. I felt I had nothing to look forward to				
11. I found myself getting agitated				
12. I found it difficult to relax				
13. I felt down-hearted and blue				
14. I was intolerant of anything that kept me from getting on with what I was doing				
15. I felt I was close to panic				
16. I was unable to become enthusiastic about anything				
17. I felt I wasn't worth much as a person				
18. I felt that I was rather touchy				
19. 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)				
20. I felt scared without any good reason				
21. I felt that life was meaningless				

Appendix K**Sibling type**

1. Does your child with ASD have siblings? No _____ Yes _____

If yes, then for each sibling:

2. How old is the sibling?
3. What is the gender of the sibling?
4. Is this sibling:

Typically developing	Diagnosed with ASD	Diagnosed with "other", please specify

Appendix L

School Type

1. Does your child with ASD attend a school setting during the school year?

If yes, then:

2. Please indicate the type of school setting your child attends

Mainstream School	Specialized School	Other (please specify)

If the parent indicates that the child attends mainstream school, then:

1. Please indicate all the supports your child receives at school (please check all that apply)

Full time one-to-one support from a teacher's assistant	Part time one-to-one support from a teacher's assistant	Pull out time with a resource or special education teacher	Other (please specify)

Appendix M

Reciprocal Friendship

FRIENDSHIPS (Solish et al., 2010)

For the following questions please indicate the most appropriate answer from the choices beneath each question.

- How many mutual friends does your child have (i.e., children your child wants to play with and who want to play with your child; friends your child plays with outside of school)?
0 1 2 3 4 5 6 or more
- How many hours a week does your child spend with those friends?
0 1 2 3 4 5 6 or more N/A
- Does your child have a best friend?
Yes No
- How many of your child's friends have disabilities?
0 1 2 3 4 5 6 or more N/A
- How many of your child's friends do not have disabilities?
0 1 2 3 4 5 6 or more N/A

Appendix N

Participation in Leisure

Activity Participation (Taheri, 2015)

Please tell us about your child's participation in social and recreational activities. Please indicate for each one, whether your child participates in it and how often. If it is an activity your child does participate in, please indicate with whom he/she does it. If your child does not do it, please indicate the reasons why not.

1. Does your child spend unstructured time with peers (e.g., at friends' houses, friends coming over)? (If yes, answer a-c; If no, answer d)
2.
 - a. How often? (circle one)
 - i. Less than once a month
 - ii. Once a month
 - iii. Once a week
 - iv. Twice a week
 - v. Everyday
 - b. With whom? (choose all that apply)
 - i. Peers without disabilities
 - ii. Peers with disabilities
 - c. Who helps/supports your child with participation in this activity?
 - i. Parent(s)

- ii. Other family member
 - iii. Other adult (paid or unpaid)
 - iv. Other (please specify)_____
- d. Why not? (choose all that apply)
- i. Child not able to
 - ii. Child not interested
 - iii. Activity not available
 - iv. No support (or not adequate support) available to accompany child
 - v. Child is not allowed or invited
 - vi. Logistical reasons (distance, cost, etc.)
 - vii. Other (please specify):_____
3. Does your child go on social outings (e.g., going to the mall, to the movies, out for meals)? (If yes, answer a-c; If no, answer d)
- a. How often? (circle one)
 - i. Less than once a month
 - ii. Once a month
 - iii. Once a week
 - iv. Twice a week
 - v. Everyday
 - b. With whom? (choose all that apply)
 - i. Peers without disabilities

- ii. Peers with disabilities
- c. Who helps/supports your child with participation in this activity?
 - i. Parent(s)
 - ii. Other family member
 - iii. Other adult (paid or unpaid)
 - iv. Other (please specify)_____
- d. Why not? (choose all that apply)
 - i. Child not able to
 - ii. Child not interested
 - iii. Activity not available
 - iv. No support (or not adequate support) available to accompany child
 - v. Child is not allowed or invited
 - vi. Logistical reasons (distance, cost, etc.)

Other (please specify):_____

4. Does your child go to special occasions with friends (e.g., birthday parties)?
(If yes, answer a-c; If no, answer d)
- a. How often? (circle one)
 - i. Less than once a month
 - ii. Once a month
 - iii. Once a week
 - iv. Twice a week

- v. Everyday
- b. With whom? (choose all that apply)
 - i. Peers without disabilities
 - ii. Peers with disabilities
- c. Who helps/supports your child with participation in this activity?
 - i. Parent(s)
 - ii. Other family member
 - iii. Other adult (paid or unpaid)
 - iv. Other (please specify)_____
- d. Why not? (choose all that apply)
 - i. Child not able to
 - ii. Child not interested
 - iii. Activity not available
 - iv. No support (or not adequate support) available to accompany child
 - v. Child is not allowed or invited
 - vi. Logistical reasons (distance, cost, etc.)

Other (please specify):_____

5. Does your child play on sports teams (e.g., hockey, soccer, etc.)? (If yes, answer a-c; If no, answer d)

- a. How often? (circle one)
 - i. Less than once a month

- ii. Once a month
 - iii. Once a week
 - iv. Twice a week
 - v. Everyday
- b. With whom? (choose all that apply)
- i. Peers without disabilities
 - ii. Peers with disabilities
- c. Who helps/supports your child with participation in this activity?
- i. Parent(s)
 - ii. Other family member
 - iii. Other adult (paid or unpaid)
 - iv. Other (please specify)_____
- d. Why not? (choose all that apply)
- i. Child not able to
 - ii. Child not interested
 - iii. Activity not available
 - iv. No support (or not adequate support) available to accompany child
 - v. Child is not allowed or invited
 - vi. Logistical reasons (distance, cost, etc.)

Other (please specify):_____

6. Does your child take lessons (e.g., swimming, gymnastics, skating, etc.)? (If yes, answer a-c; If no, answer d)
- a. How often? (circle one)
 - i. Less than once a month
 - ii. Once a month
 - iii. Once a week
 - iv. Twice a week
 - v. Everyday
 - b. With whom? (choose all that apply)
 - i. Peers without disabilities
 - ii. Peers with disabilities
 - c. Who helps/supports your child with participation in this activity?
 - i. Parent(s)
 - ii. Other family member
 - iii. Other adult (paid or unpaid)
 - iv. Other (please specify)_____
 - d. Why not? (choose all that apply)
 - i. Child not able to
 - ii. Child not interested
 - iii. Activity not available

- iv. No support (or not adequate support) available to accompany child
- v. Child is not allowed or invited
- vi. Logistical reasons (distance, cost, etc.)

Other (please specify): _____

7. Does your child take part in community activities (e.g., Sunday School, Cubs/Brownies, etc.)? (If yes, answer a-c; If no, answer d)

- a. How often? (circle one)
 - i. Less than once a month
 - ii. Once a month
 - iii. Once a week
 - iv. Twice a week
 - v. Everyday
- b. With whom? (choose all that apply)
 - i. Peers without disabilities
 - ii. Peers with disabilities
- c. Who helps/supports your child with participation in this activity?
 - i. Parent(s)
 - ii. Other family member
 - iii. Other adult (paid or unpaid)
 - iv. Other (please specify) _____
- d. Why not? (choose all that apply)

- i. Child not able to
- ii. Child not interested
- iii. Activity not available
- iv. No support (or not adequate support) available to accompany child
- v. Child is not allowed or invited
- vi. Logistical reasons (distance, cost, etc.)

Other (please specify): _____

8. Does your child take part in social & recreational programs for children with disabilities (e.g., Special Olympics, special camp programs)? (If yes, answer a-c; If no, answer d)
- a. How often? (circle one)
 - i. Less than once a month
 - ii. Once a month
 - iii. Once a week
 - iv. Twice a week
 - v. Everyday
 - b. With whom? (choose all that apply)
 - i. Peers without disabilities
 - ii. Peers with disabilities
 - c. Who helps/supports your child with participation in this activity?
 - i. Parent(s)

- ii. Other family member
 - iii. Other adult (paid or unpaid)
 - iv. Other (please specify)_____
- d. Why not? (choose all that apply)
- i. Child not able to
 - ii. Child not interested
 - iii. Activity not available
 - iv. No support (or not adequate support) available to accompany child
 - v. Child is not allowed or invited
 - vi. Logistical reasons (distance, cost, etc.)
 - vii. Other (please specify):_____

CURRICULUM VITAE

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2010 - 2019 PhD

Clinical Psychology (CPA Full Accreditation)

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Supervisor: Barbara D'Entremont, PhD

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PUBLICATIONS:

Fulton, M. L., & D'Entremont, B. (2013). Utility of the Psycho-Educational Profile-3 for assessing cognitive and language skills of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 43(10), 2460-2471. doi:10.1007/s10803-013-1794-y

CONFERENCE PRESENTATIONS:

Fulton, M. (2014). *Pretend play as a predictor of language skills: Contributions of functional versus symbolic play and shared versus solitary play.* Poster presented at the International Meeting for Autism Research, Atlanta, Georgia, USA.

Fulton, M. (2012). *Utility of the Psycho-Educational Profile-3 for assessing cognitive and language skills of children with autism spectrum disorders.* Poster presented at the International Meeting for Autism Research, Toronto, ON.

Fulton, M. (2009, May). *Stepping Stones: A Pathway to Meaningful Relationships Between Students and Professors*. Paper presented at the Atlantic Provinces Council on the Sciences Psychology Conference, Halifax, NS.