

**AN EXPLORATORY ANALYSIS OF PARENTAL FACTORS RELATED TO
PHYSICAL ACTIVITY IN CHILDREN LIVING WITH AUTISM**

by

Erin Marie McFee

BSN, Okanagan University College, 1999

A THESIS SUBMITTED IN PARTIAL FULFILLMENT OF
THE REQUIREMENTS FOR THE DEGREE OF
MASTER OF SCIENCE IN NURSING

in

THE COLLEGE OF GRADUATE STUDIES

THE UNIVERSITY OF BRITISH COLUMBIA

(Okanagan)

June 2019

© Erin Marie McFee, 2019

The following individuals certify that they have read, and recommend to the College of Graduate Studies for acceptance, a thesis/dissertation entitled:

**An Exploratory Analysis of Parental Factors Related to Physical Activity in Children
Living with Autism**

submitted by Erin Marie McFee in partial fulfillment of the requirements

of the degree of Master of Science in Nursing.

Dr. Lise Olsen, UBC Okanagan, Faculty of Health and Social Development

Supervisor

Dr. Alison McManus, UBC Okanagan, Faculty of Health and Social Development

Supervisory Committee Member

Dr. Grace Iarocci, SFU, Department of Psychology

Supervisory Committee Member

Dr. Kathy Rush, UBC Okanagan, Faculty of Health and Social Development

Neutral Chair

Dr. Shelly Ben-David, UBC Okanagan, Faculty of Health and Social Development

University Examiner

Abstract

Children with Autism Spectrum Disorder (ASD) experience unique developmental and social challenges that place them at increased risk for injury, which can present barriers to participation in physical activities that are normally a routine part of childhood. These barriers leave children with ASD at risk of obesity, and increased amounts of sedentary activities; as well as decreased levels of physical activity and community recreation participation. For parents raising children living with ASD, finding safe and developmentally appropriate activities for their children to engage in, can be a significant source of stress. This thesis presents a quantitative exploratory analysis of data collected from parents (N=69) through the Autism and Developmental Disorders Lab (ADDL) at Simon Fraser University in 2017. Using statistical methods, this research increases understanding of factors related to parents' decisions in providing opportunities for physical activity whilst balancing risk and safety by investigating the differences/similarities that exist between parents raising a child living with ASD, and those parents who are raising a child without ASD. Specifically this analysis explored how a child's ASD diagnosis, and/or ASD symptoms impacts parent perceived barriers to activity, child sedentary behavior/screen time, child physical activity (outside play and activity type), parents' perceptions of protection from injury and risk; as well as the impact on parent self-efficacy in balancing their child's protection from injury and risk. Results indicated that parents raising a child living with ASD did not differ significantly in their perceptions of protection from injury and risk, or in their self-efficacy from parents raising a child without ASD. However, parents report that their child living with ASD was exceeding recommended daily amounts of sedentary behavior/screen time. In addition, parents raising a child living with ASD were found to experience significantly more barriers to

activity participation; and were limited in the types of recreational activities that were available for their children to participate in.

Lay Summary

The primary goal of this research was to compare parents raising a child living with Autism to those who are not raising a child with Autism; and explore the impact the presence of an Autism diagnosis or Autism symptoms has on parents' confidence and ability to support their child to participate in safe physical activity, and protect them from injury. This analysis demonstrated the similarities and differences in parent perspectives on safety and injury prevention, as well as highlighting the barriers families living with Autism encounter when trying to provide safe physical activities for their children. The results emphasize the need for diverse inclusive programming for all children in our communities.

Preface

The data presented in this thesis research was obtained with permission from Dr. Grace Iarocci and the research team at the Autism and Developmental Disorders Lab (ADDL) at Simon Fraser University (SFU). It was collected by Dr. Iarocci and her team during a Family Camp held onsite at SFU in 2017. The quantitative exploratory analysis was conducted by Ms. Erin McFee under the supervision of Dr. Lise Olsen at UBC Okanagan. Dr. Alison McManus, and Dr. Grace Iarocci comprise Ms. McFee's thesis committee and provided guidance and feedback on the research proposal as well as throughout the research analysis. Dr. Olsen, Dr. McManus and Dr. Iarocci have reviewed this completed thesis in its entirety. Preliminary findings were presented in a poster presentation by Erin McFee at The Health and Wellbeing in Children, Youth, and Adults with Developmental Disabilities Conference in Richmond BC, in November 2018 (cited below). Ethics approval for this research was obtained through the UBC Okanagan Behavioral Research Ethics Board, and was deemed Minimal Risk. Dr. Lise Olsen was listed as the Principal Investigator. The certificate number is H17-03484.

McFee, E., Olsen, L., McManus, A., & Iarocci, G. (2018, November). *An exploratory analysis of parent factors related to activity in children with Autism.* Poster session presented at the 6th Health and Wellbeing in Children, Youth and Adults with Developmental Disabilities Conference, Richmond, BC.

Table of Contents

Abstract	iii
Lay Summary	v
Preface	vi
List of Tables	ix
List of Figures	x
Acknowledgments	xi
Dedication	xii
Chapter 1.0: Introduction	1
1.1 Definition of Terms	3
1.2 Problem and Significance	4
1.3 Purpose and Objective	6
1.4 Potential Contributions	6
1.5 Overview of Thesis	7
Chapter 2.0: Review of the Literature	8
2.1 Sedentary Behavior in Children with Autism	8
2.2 Parent Perspectives of Safety and Injury in Children with Autism	14
2.3 Parent Self-efficacy: Raising Children with Autism	18
2.4 Summary of Literature Review	23
Chapter 3.0: Research Questions	26
Chapter 4.0: Methods	29
4.1 Context	29
4.2 Study Design and Participants	29
4.3 Study Procedures and Measurement Tools	30

4.4 Ethics and Data Management.....	34
4.5 Data Analysis	35
Chapter 5.0: Results	39
5.1 Demographic Characteristics	39
5.2 Research Question 1	42
5.3 Research Question 2.....	46
Chapter 6.0: Discussion	49
6.1 Links to Theory	53
6.2 Future Directions for Research.....	54
6.3 Limitations	55
Chapter 7.0: Conclusion.....	57
References.....	59
Appendices.....	68
Appendix A	68
Appendix B	73

List of Tables

Table 1. <i>HWREPS Variables</i>	36
Table 2. <i>Family Demographics</i>	41
Table 3. <i>Mann-Whitney U tests: Total barriers to activity</i>	44
Table 4. <i>Results of Chi-square: Activity participation</i>	45
Table 5. <i>Results of Chi-square: Activity participation (re-run)</i>	46
Table 6. <i>Spearman Correlation: Total AQ and total barriers to activity</i>	46
Table 7. <i>ANOVA</i>	48
Table 8. <i>ANOVA (re-run)</i>	48

List of Figures

<i>Figure 1. Sociocognitive Causal Model (Bandura, 2004).</i>	26
<i>Figure 2. Barriers to activity by diagnostic group</i>	44

Acknowledgements

The completion of this work represents the end of long journey of personal growth that would not have been possible without the support and guidance of an incredible group of individuals. I would like to begin by thanking Dr. Lise Olsen my thesis supervisor, and mentor. Her patience and understanding helped me to navigate this daunting process and kept me on task. These past several years, I have learned so much from her and am so appreciative of her wisdom, her humor, and for helping to me to expand my knowledge of Autism. I also wish to thank my committee members Dr. Alison McManus, and Dr. Grace Iarocci their approachability, expertise and words of encouragement. Thank you to Dr. Iarocci and the SFU team, for allowing me the opportunity to access to this unique data set, and to the families living who participated in the camps. A special thank you to Troy Boucher at the SFU ADDL Lab who worked very quickly to answer my many questions throughout the ethics and analysis process. I am elated to finally be completing my degree as it signifies the beginning of a new chapter in my nursing career, and hopefully a little less time in front of my computer screen.

Dedication

To my husband Doug and our four children Andrew, Gavin, Tristan and Nigel, thank you for your love, patience and understanding these past four years. I could not have made it to the end without your unwavering support.

Chapter 1.0: Introduction

Autism spectrum disorder (ASD), is a neuro-developmental disorder often diagnosed in childhood that can present social challenges. ASD presents differently in each individual, and rates of diagnosis are continuing to grow. ASD is more common in males and is not limited by ethnicity or socioeconomic factors. The Public Health Agency of Canada (PHAC) estimates that 1 in 66 in children between the ages of 5-17 years has ASD (PHAC, 2018). These statistics are comparable to those found in the United States indicating that 1 in 59 children are affected (Baio, Wiggins, Christensen, et al., 2018). ASD presentation frequently involves psychosocial and communication challenges as well as a repetitive focus on a topic or action. ASD can range from a mild effect where individuals may experience challenges navigating social situations and communication interactions, and have difficulty developing and maintaining relationships; to much more severe cases where individuals experience profound cognitive impairment and may display aggression or self-injurious behaviors. (American Psychiatric Association, 2013; Autism Canada, 2017; Autism Society of America, 2017).

With respect to their physical health, children with ASD are at significant risk of obesity, decreased participation in physical activity and increased levels of sedentary time (Feehan, O'Neil, Abdalla et al., 2012; Healy, Haegele, Grenier and Garcia, 2017). The needs of a child with ASD are complex. ASD is often accompanied by many behaviors that can result in complex cognitive, social and physical challenges that make it difficult for children to engage in otherwise typical childhood activities such as joining an organized group, or playing on a sports team without support. These factors have been shown to contribute to decreased engagement in physical activity and excess engagement in screen time and sedentary behaviors (Healy, Haegele, Grenier and Garcia, 2017; Montes, 2016).

Parents often assume the role of ‘navigator’ to help anticipate, guide and support their child in their growth and development (Elder, Kreider, Brasher, & Ansell, 2017). However, due to the variation in ASD presentation, and individual child needs, parents are often left to navigate this journey through trial and error; inevitably encountering many challenges and barriers along the way. In addition to the constant need to negotiate and manage their child’s complex social and developmental needs, parents are responsible for accessing health care providers and community services, ensuring children receive developmentally appropriate education, as well as securing funding for all of these services. Even organizing safe recreation activities for their child can be a daunting task, as children with ASD have been found to be at an increased risk of injury requiring medical attention (Kalb, Vasa, Ballard, et al., 2016; McDermott, Zhou and Mann, 2008). This heightened risk can increase parent concerns related to keeping their child safe and protecting them from injury (Feehan, O’Neil, Abdalla et al., 2012; Cavalari and Romanczyk, 2012; Jain, Spencer, Yang et al., 2014).

The psychosocial and physical challenges that accompany an ASD diagnosis have the potential to place children living with ASD at risk of social isolation, increased sedentary behaviors and decreased participation in physical activities. Thus, understanding the parent perspective, and exploring the impact parent experiences and actions may have on achieving a health goal of providing safe physical activity for their child is important. This focus is also a necessary component in the development of future research aimed towards providing improved services, and support for families living with ASD.

1.1 Definition of Terms

- (1) Autism Spectrum Disorder (ASD) is defined as having significant challenges with social communications and social interaction, and repetitive behaviors or restricted interests. ASD is often diagnosed in early childhood, and severity is determined by level of communication impairment and the restrictiveness of repetitive behaviors (American Psychiatric Association, 2013).
- (2) Sedentary behavior includes sitting, lying or reclining in one place for extended periods of time and engaging in recreational screen based activity time. According to the Canadian Society for Exercise Physiology (CSEP), sedentary time for children aged 5-17 years should be limited, defined as no more than 2 hours of screen time each day (CSEP, 2016).
- (3) Physical activity includes movement of the body that results in increased respiratory and heart rate, and an increased expenditure of energy. According to the CSEP, Children aged 5-17 years should participate in a minimum of 60 minutes of moderate to vigorous physical activity each day (CSEP, 2016).
- (4) The term 'parent' will refer to mothers or fathers, will be interchangeable with 'caregiver' and will be inclusive of any primary caregiver for a child.
- (5) Self-efficacy is defined as the confidence an individual has to perform a task and obtain a certain outcome (Bandura, 1977; 2004).
- (6) Parent self-efficacy (PSE) is a parent or caregivers' perception of their own competency in their role as a parent (Kuhn and Carter, 2006).
- (7) Safe physical activity or recreation will refer to participation in physical activity or recreation without incurring physical or emotional pain, or injury.

(8) Injury prevention within this study will be defined as the intent to stop or reduce the chance of unintentional injury to the child (Branche, C., Hyder, A. A., Ozanne-Smith, J., Oyebite, K., Bartolomeos, K., & Rivara, F., 2008).

(9) Risk in the context of this analysis is the parent's perception of an uncertain or undesirable outcome for the child (Niehues, A. N., Bundy, A., Broom, A., & Tranter, P., 2016).

1.2 Problem and Significance

Children with ASD encounter unique developmental and social challenges throughout their childhood. They are at a significant risk for obesity, decreased participation in physical activity and increased levels of sedentary time (Dreyer, Gillette et al., 2015; Feehan et al, 2012; Healy, Haegele, Grenier and Garcia, 2017). Research has identified several factors that contribute to this phenomenon within the ASD population including: decreased engagement in physical activity that is the result of social, cognitive and physical participation barriers; excess screen time (Healy, Haegele, Grenier and Garcia, 2017; Montes, 2016); and caregiver concerns related to safety and injury prevention (Cavalari and Romanczyk, 2012; Feehan et al, 2012; Jain et. al, 2014). Although there is agreement that children with ASD are at risk for obesity, and engage in excess screen time, there is a lack of clarity surrounding how children with ASD compare to their non-ASD more typically developing (TD) peers, and if this population of children is actually at a higher risk for obesity than children who do not have ASD (Cavalari & Romanczyk, 2012; Feehan et al, 2012; Montes, 2016). Children with ASD are also at significantly higher risk of injury requiring medical attention (Kalb, Vasa, Ballard, Woods, Goldstein and Wilcox, 2016; McDermott and Zhou, 2007), and are as much as three times more likely to suffer death from accidental injury when compared with their more typically developed

peers (Guan and Li, 2017a). To date, ASD research incorporating parent perspectives has traditionally been focused on mothers as the primary caregiver (Braunstein, Peniston, Perelman, & Cassano, 2013), and is limited on perspectives of risk and physical activity. Understanding the similarities and differences between children with ASD and those without, along with the corresponding perspective of their parents should be an important component of ASD research.

Parents assume the primary responsibility for monitoring and navigating their child's health and development whilst weighing potential risks and benefits. This responsibility can be especially challenging when caring for a child with ASD; and has been shown to have a significant impact on caregivers' perceptions of their own competency or parent self-efficacy (PSE) (Boshoff, Gibbs, Phillips, Wiles and Porter, 2016; Kuhn and Carter, 2006; Weiss, Tint, Paquette-Smith and Lunskey, 2016). Research has demonstrated that feelings of PSE can be negatively impacted by multiple factors including barriers to services, immigrant status, child age, and caregiver burden (Batool and Khurshid, 2015; Weiss, Tint, Paquette-Smith and Lunskey, 2016). Alternatively, feelings of PSE can be increased through caregiver involvement in positive developmental activities with their child (Kuhn & Carter, 2006). Active participation in safe and developmentally appropriate recreation and physical activity is an important component of childhood. Understanding the impact of PSE in families of children with ASD, as it relates specifically to their child's participation in these activities is necessary to understand how best to support this population. This research will aim to further this understanding about parents' PSE in relation to physical activities for those raising children with ASD compared to those without ASD and will seek to illuminate factors that are positively and negatively associated with those perceptions.

1.3 Purpose and Objective

This research presents an exploratory analysis of data collected in 2017 through the Autism and Developmental Disorders Lab (ADDL) led by Dr. Grace Iarocci at Simon Fraser University (SFU). This was a unique opportunity to explore and understand factors related to parents' decisions in providing opportunities for physical activity whilst balancing risk and safety for their children living with ASD. We explored whether there are challenges related to supporting child participation in physical activity that are unique to parents of children with ASD; what role ASD symptoms, and the child's IQ play; how this impacts parents' ability to balance risk and safety for their children; and the role of PSE. The analysis was theoretically grounded within Social Cognitive Theory (Bandura, 2004) and considered differences and similarities between parents who have a child with ASD, and those who do not. Data for this research was collected through surveys completed by parents, as part of a two day Social Science Camp held at SFU in Burnaby, British Columbia in 2017.

1.4 Potential Contributions

Physical activity plays an important role in physical and psychological growth and development in children. In Canada, children and youth across the country (including those with ASD) are exceeding recommended daily levels of recommended sedentary behavior (assessed as screen time), whilst struggling to meet their recommended daily levels of physical activity (ParticipACTION, 2018). Children with ASD are amongst those at risk, however there is a lack of clarity surrounding how children with ASD compare to their more typically developed (TD) peers. The findings from this analysis provide a unique opportunity to consider the complex relationships between multiple factors that impact parents raising a child with ASD whilst comparing and contrasting to parents who are raising TD children. The use of Albert Bandura's

Sociocognitive Causal Framework (2004) as an underlying lens to view the findings illuminate supports, barriers and contributing factors that can influence parents' abilities to successfully manage their child's physical activity and sedentary behaviors, while still balancing risk and addressing safety needs. These possibilities for comparison between parent groups are invaluable and will aid clarification of the unique struggles of families with coping with an ASD diagnosis. This understanding can inform future services to address identified challenges that are unique to ASD families, as well as highlighting challenges shared by both ASD and TD families.

1.5 Overview of Thesis

The remainder of this thesis will be outlined in the following manner: a review of current literature; presentation of the research questions; description of the research methods; research results; a discussion of the findings, with links to other study findings and theory; and the conclusion.

Chapter 2.0: Review of the Literature

The literature review for this research addresses three main areas: (a) Sedentary behavior in children with Autism; (b) Parent perspectives of safety and injury in children with Autism; and (c) Parent self-efficacy: raising children with Autism. The structure of this review was guided by the content of the Health and Wellness Risk Engagement and Protection Survey. This tool serves as one of the primary sources of data collected for this thesis research and encompasses measures related to, injury prevention and risk engagement attitudes, parental self-efficacy, sedentary behaviors and participation in organized sport. The Health and Wellness Risk Engagement and Protection Survey (Appendix A) is an amalgamation of the Health and Wellness Index for Kelowna Youth created for the study initiated in 2017 by Dr. McManus and Dr. Lutes; and the Risk Engagement and Protection Survey (Olsen, Ishikawa, Masse, Chan and Brussoni, 2017) and will be explained in detail within the ‘data collection measures’ section of this paper. Searched years for the literature review were restricted to 2012-2018 to reflect the most current understanding of ASD as outlined within the most recent version of the American Psychiatric Association Diagnostic and statistical manual of mental disorders (DSM-V) (2013).

2.1 Sedentary Behavior in Children with Autism

In the recently published Canadian ParticipACTION Report Card it was noted that more than one half of Canadian children and youth are exceeding the recommended maximum amounts of sedentary behavior, defined as no more than two hours of daily screen time (ParticipACTION, 2018). Only about one third of children and youth in Canada are meeting the daily recommended level of physical activity, 60-minutes of moderate to vigorous physical activity a day (ParticipACTION, 2018). Within current literature, research specific to sedentary behavior and ASD is limited. However, there appears to be agreement that youth with disabilities

achieve lower levels of physical activity compared to their TD peers. A 2012 US based study conducted by Obrusnikova and Miccinello with parents raising children with ASD reported that sedentary behaviors like video games, cards and Lego were preferred amongst children with ASD, and that often engaging children with ASD to participate in physical activity (PA) outside of school was challenging. The majority of parents reported their children with ASD were difficult to engage and motivate to participate in PA, and it required additional time and energy that parents were unable to provide in addition to the other family and household demands (Obrusnikova & Miccinello, 2012). Parents of children with ASD who participated in a 2015 study conducted by Must, Phillips, Curtin and Bandini, reported children with ASD experienced more barriers to PA participation at the child/family, social and community level than their TD peers. The most commonly reported barrier to PA for children with ASD in this study was family time constraints (Must, Phillips, Curtin and Bandini, 2015). Further, the authors found a significant correlation between total number of barriers to PA reported and total weekly screen time ($r = .32, p = .03$) (Must, Phillips, Curtin and Bandini, 2015, p. 532). It is important to gain a better understanding of the impact these reported barriers have on PA outcomes for this population of children.

The final MeSH search terms utilized in this review of sedentary behavior included: Autism/ASD/Autism Spectrum Disorder AND sedentary behavior/sedentary behavior AND children/adolescent/youth/child/teen. Results were restricted to primary peer reviewed studies, relevant to North American culture, published in English between 2012 through 2018, had an abstract available, and was accessible via the UBC Okanagan Library. A search across five databases including (CINAHL, M EDLINE, psychINFO, EMBASE and ERIC), and additional hand-searching. In many cases results related to sedentary behavior contained additional

components related to PA which are discussed below. This search resulted in four primary quantitative research studies.

In the first study, Boddy, Downs, Knowles and Fairclough (2015) report on their cross sectional observational study exploring play behaviors and physical activity in youth with intellectual disabilities. In this UK based study, children with intellectual disabilities (ID) wore accelerometers for 7 days as well as being observed in the school setting during recess. The children were divided into two groups: ASD, and non-ASD. The initial sample included 70 participants, however only 47% were able to comply with wearing the accelerometers for the prescribed time; which resulted in a small sample for the analysis ($n=34$) (Boddy, Downs & Fairclough, 2015). The authors found that across both groups, less than one quarter of children achieved the recommended 60 min per day of moderate to vigorous physical activity, and argued that this was not enough to benefit their health (Boddy, Downs & Fairclough, 2015, p. 161). No significant differences were noted in amounts of sedentary time or physical activity time between the ASD and non-ASD groups of children with ID. Although, the authors did identify that none of the children in the study were observed playing in large group activities during recess at school, a finding they believed was unique to ID. These findings are of interest because the authors also noted that time spent in smaller size groups was found to positively correlate with amounts of sedentary time (i.e. standing) so that children could socialize with their peers ($r = .54$, $p < 0.01$) (Boddy, Downs & Fairclough, 2015, p. 163). However, the ASD group within this ID study, was found to be active independently during recess and appeared to avoid standing still. The authors argued this was likely related to the challenges the ASD group may have had with social interactions, and suggested that these children were being physically active at recess in-

place of socializing with peers (Boddy, Downs & Fairclough, 2015, p. 164). Although the findings from this study are interesting, they were limited by its small sample size.

Loubenius–Palmer, Sjoqvist, Hurtig-Wennlof and Lunqvist (2018) conducted a cross-sectional epidemiological study in Sweden, where accelerometers were utilized to assess physical activity and sedentary time in youth with disabilities. In this study, youth between the ages of 7-20 years with disabilities (n=102), were compared to typically developed (TD) youth ages 8-16 years (n=800) (Loubenius–Palmer, Sjoqvist, Hurtig-Wennlof & Lunqvist, 2018). The group of youth with disabilities were then further separated into four groups: physical and visual impairments; intellectual disabilities (which also included some youth with ASD); ASD; and hearing impairments. Each group was compared to the group TD youth across three categories including: habitual physical activity, sedentary time and meeting physical activity requirements. Study findings indicated all four groups of youth with disabilities had significantly lower than average time participating in physical activity, and significantly more sedentary time compared to the TD group (Loubenius–Palmer, Sjoqvist, Hurtig-Wennlof & Lunqvist, 2018). In addition, sedentary time increased with age within the TD group, as well as in the groups of youth with intellectual disabilities (some of whom had ASD) and hearing impairments (Loubenius–Palmer, Sjoqvist, Hurtig-Wennlof & Lunqvist, 2018). This research utilized a convenience sample, and was limited in that it did not account for secondary diagnoses. Youth with ASD were included in both the ASD group as well as comprising a significant component of the group with intellectual disabilities, making it difficult to ascertain intellectual disability and ASD specific outcomes.

Bandini, Gleason, Curtin, Lividini, Anderson, Cermak et al. (2013) published a cross-sectional study of physical activity between children with ASD (n=53) and TD children (n=58) in the United States. The study was comprised of two data sources: accelerometer monitoring of

the children; and parent-report of child activity questionnaires. Wherever possible, questionnaire responses were compared to actual accelerometer data collected on the child, adding to the reliability of the questionnaire findings (Bandini, Gleason, Curtin, Lividini, Anderson, Cermack et al., 2013). The results revealed similar levels of physical activity between the two groups, however the intensity of the activity varied with 43% of TD children achieving equal to or greater than 60 minutes of daily physical activity compared only 23% of children with ASD (Bandini, Gleason, Curtin, Lividini, Anderson, Cermack et al., 2013, p.49). A notable finding within this study was that although accelerometer data showed similar physical activity levels in both groups, the parent-reports from the ASD group contradicted the measurements, with parents reporting less physical activity than recorded (Bandini, Gleason, Curtin, Lividini, Anderson, Cermack et al., 2013). The authors hypothesized this finding may be result of parents not recognizing all movement as physical activity, and may discount common characteristics of ASD as movement (i.e. pacing) because they occur during sedentary activities like watching television (Bandini, Gleason, Curtin, Lividini, Anderson, Cermack et al., 2013). Additional results from this study related to sedentary behavior were published in a second article by Must, Phillips, Curtin, Anderson, Maslin, Lividini and Bandini (2014). Within the sedentary component of the study, a positive correlation was identified for the ASD group, between age and weekend screen time (Must, Phillips, Curtin, Anderson et al., 2014, p. 379). In addition, rates of sedentary behaviors including television, computer and total screen time was significantly higher in the ASD group when compared to their TD peers (Must, Phillips, Curtin, Anderson et al., 2014, p. 381).

Montes (2016) conducted an analysis of interview data collected over the telephone from parents as part of the 2011/12 United States National Survey of Children's Health. The researchers assessed differences between two groups children between the ages of 6-17 years

without ASD (n=64163), and children aged 6-17 with ASD (n=1393). The majority of children represented in the study (both ASD and non-ASD) were found to exceed daily screen-time recommendations (Montes, 2016). However, specific findings in Montes's research related to children with ASD and screen time contradicted that of Must, Phillips, Curtin, Anderson et al. (2014) as Montes was unable to identify a significant difference in the amount of screen-based activities when comparing the two groups of children. Usage was found to be similar regardless of the presence of an ASD diagnosis (Montes, 2016, p. 126). A strength of this study was the large sample size. However, it is important to consider that the findings were obtained through parent report, which may limit the accuracy of the data, something noted by Bandini and colleagues (2013).

Despite this literature search being focused on sedentary behavior, the resulting articles often incorporated monitoring physical activity, with the use of accelerometer data (Boddy, Downs & Fairclough, 2015; Loubenius–Palmer, Sjoqvist, Hurtig-Wennlof & Lunqvist, 2018; Bandini, Gleason, Curtin, Lividini, Anderson, Cermak et al., 2013). Although tracking physical activity with accelerometers is valuable, the parent role has been shown to be integral in promoting and supporting children with physical and intellectual disabilities to participate in physical activity (Shields & Synnot, 2016). Thus, increasing understanding of the parent perspective as it relates to physical activity and sedentary behavior in children with ASD would add depth to this body of evidence. ASD is unique in that there is not a 'standard presentation', and can be influenced by factors such as co-occurring medical conditions, socio-economic status and family dynamics. For this reason, additional research is required that includes families living with ASD from a variety of backgrounds to more accurately represent the variance of ASD symptom presentation. In addition to the need for additional research, it is also necessary to

provide clarity in defining what constitutes sedentary behavior; and whether standard parameters surrounding amount and quality of movement that define physical activity should be applied to this unique population of children.

2.2 Parent Perspectives of Safety and Injury in Children with Autism

Current research related to safety and raising children with Autism is also limited and findings specific to ASD are mixed. There is epidemiological evidence that indicates children and youth with ASD are at increased risk of injury requiring treatment or hospitalization (Kalb, Vasa, Ballard, Woods, Goldstein and Wilcox, 2016; McDermott, Zhou and Mann, 2016). However in 2014 Jain, Spencer, Yang, Kelly, Newschaffer, et al., published a large retrospective observational study utilizing a random sample to compare injuries in children with ASD to those children without. The authors determined that on the surface children with ASD had a higher rate of injury than children without ASD however, once adjustment was made for co-occurring diagnoses within the population the rate of injury dropped dramatically. The findings showed that a co-occurring diagnosis (i.e. attention deficit hyperactivity disorder (ADHD)) in addition to the ASD, increased the risk of injury to the child, rather than simply the ASD diagnosis on its own (Jain, Spencer, Yang, Kelly, Newschaffer, et al., 2014). In contrast, a large epidemiological study conducted by Guan and Li in 2017 found that death from unintentional injury occurs approximately three times more often in the ASD population compared to non-ASD with drowning, suffocation and asphyxiation is the leading causes of death by unintentional injury in children with ASD under the age of 15 years old and accounting for more than 76% of cases (Guan and Li, 2017a).

Clearly, serious injuries are an important issue for children with ASD, but the role and perspectives of parents about these safety issues are not as clear. For this literature review on the

parental role, MeSH search terms utilized included: Autism/ASD/Autism Spectrum Disorder AND safety AND parents. Initially, the search included the MeSH term ‘injury prevention’, but was found to be too specific and did not produce useable results, so the broader term ‘safety’ was used in its place. Although findings were still quite limited, they were applicable to the topic. Results were restricted to primary peer reviewed studies, that offered a parent perspective, relevant to North American culture, published in English, between the years 2012 – 2018, had an abstract available, and was accessible via the UBC Okanagan Library. A search across five databases including (CINAHL, MEDLINE, psychINFO, EMBASE and ERIC), in addition to hand-searching, yielded three studies (two quantitative and one qualitative) that met the search criteria, focusing on parent perspectives.

The first study by Bonander, Beckman, Janson and Jernbro (2016) reported similar findings in their survey based study to that of Jain et al. (2014). Findings indicated that an ASD diagnosis did not account for a higher risk of injury (Bonander, Beckman, Janson & Jernbro, 2016). In this study researchers explored both ADHD and ASD with respect to risk of injury. Data was collected through two cross sectional samples of children: the School Health Database in Sweden, which includes information collected from physical examinations, parent surveys, and child interviews are conducted as part routine health screening conducted on school age children (n=18416); and through results from a “Swedish National Survey on children’s experiences” (n=3198) (Bonander, Beckman, Janson & Jernbro, 2016, p. 50). Diagnoses of ADHD and ASD were compared to TD control groups. The findings indicated that children with ADHD had 57% higher risk of injury when compared to children with ASD (Bonander, Beckman, Janson and Jernbro, 2016, p. 53). Similar to the study conducted by Jain et al (2014), the authors clarified that it was important to note their findings also indicated correlation and not

causation (Bonander, Beckman, Janson and Jernbro, 2016). Further, the authors acknowledged that previous evidence has indicated that youth with ASD are at increased risk of death from accidental injury, however these findings were not reflected in this sample of school children (Bonander, Beckman, Janson and Jernbro, 2016, p. 54)

In another recent study, researchers from the United States conducted a multi-site case control study comparing children with ASD, to children with non-ASD developmental delay, and children from the general population. Data was primarily collected from parents through telephone or in-person interviews (DiGuseppi, Levy, Sabourin, Soke, Rosenberg et al., 2017). Findings showed that children with a diagnosis of ASD (n=693) did not have a significantly higher rate of medically attended injury when compared with the control group comprised of a general population children (n=883). However, they did have a 30% increased risk (odds ratio 1.30) of medically attended injury when compared with children non-ASD developmental delays and disorders (n=676) (DiGuseppi et al., 2017). It is important to note that DiGuseppi et al. (2017) did not account for the presence of co-occurring attention deficit disorders which has been shown in previous studies to be a key indicator in increased rate of injury (Jain et al., 2014; Bonander, Beckman, Janson & Jernbro's 2016). In addition, the authors note that the variation in findings could also be related to a variance in the perception of risk and level of supervision, or threshold to seek care in parents of the ASD group versus the non-ASD group with developmental delay. Also of note is lack of fathers' perspective as 99% of the parents reporting on injury in this study were mothers (DiGuseppi, Levy, Sabourin, Soke, Rosenberg, et al., 2017).

Finally, Hoogsteen and Woodgate explored the safety perspectives of families living with ASD through a rural lens (2013). This phenomenological qualitative study utilized a convenience

sample of parents (n=28); comprised mostly of mothers (twenty four mothers, and four fathers) living in Canadian rural communities. The findings indicated that although families in these communities sometimes felt isolated from supports and services, including respite and education, they also felt their children with ASD were safer in rural communities due to less traffic hazards and increased familiarity of community members with their child (Hoogsteen, and Woodgate, 2013). Hoogsteen and Woodgate (2013) also noted that factors such as small class sizes and consistent classmates were seen as protective factors for children with ASD in rural schools.

Earlier studies have emphasized the increased risk of mortality from accidental injuries sustained by children with ASD (Guan & Li, 2007). Although, current literature related to parental perspectives on safety and unintentional injury when raising children with ASD is very limited. Parents raising children with disabilities have shown differing attitudes toward accepted levels of safety and risk. In some cases parents raising a child with a disability have been shown to believe their child is at increased risk of injury. Specifically, parents have increased concerns related to their child's lack of understanding of their physical and social environment; and as result, parents increase their level of supervision of the child as a means of protective injury prevention (Olsen, Kruse, Miller, & Brussoni, 2016). However, this increased level of protection can also leave parents of children with disabilities at risk of underestimating their child's ability to cope (both physically and psychologically) in challenging or unfamiliar situations. As result, parents may over protect their child with disabilities (Ozhek, 2008). Additional exploration of how parental attitudes towards safety and risk for children with neuro-developmental challenges such as ASD is warranted. Additional research exploring the variety of ASD symptom presentation, as well as co-occurring conditions with ASD is also needed, to truly clarify safety and risk as it relates to ASD specifically and identify the role conditions like ADHD play (Jain et

al., 2014; Bonander, Beckman, Janson & Jernbro, 2016; DiGuseppi, Levy, Sabourin, Soke, Rosenberg, et al., 2017). Although necessary, it is important to recognize how challenging it would be to achieve this, given the unique presentation of ASD symptoms for each child.

2.3 Parent Self-efficacy: Raising Children with Autism

Existing research on parent self-efficacy (PSE) specifically as it relates to parenting children with Autism is extremely limited, which confirms the timeliness of this research. The search terms utilized included Autism/ASD/Autism Spectrum Disorder AND self-efficacy AND parents. Findings were limited to primary peer reviewed studies, published in English between 2012 – 2018, with abstract available, and accessible via the UBC Okanagan Library. Only those studies relevant to the North American context were included. A search across five databases including (CINAHL, MEDLINE, psychINFO, EMBASE and ERIC) yielded limited results. Two relevant reviews were also identified during the search (Bonis and Sawin, 2016; Boshoff, Gibbs, Phillips, Wiles and Porter, 2016), and these further confirmed the limited resources available on this subject. Hand searching of references within those reviews was also carried out. This search strategy yielded five primary studies (four quantitative and one qualitative) that met the search criteria.

Benson 2016 carried out a prospective longitudinal seven-year study with families living with ASD that investigated links between parent's social network characteristics, their cognitive resources (including PSE) and their psychological adjustment. The study findings indicated that mothers (n = 110) of children with ASD experienced increased levels of anxiety, stress and depression however, there was significant variation in their ability to cope, with social networks found to play a valuable role in PSE. Specifically, the amount of contact a mother had with her social network as well as the level of emotional support that network provided for the mother

predicted the level of PSE she experienced. Further, Benson (2016) also noted that maternal depression decreased, and feelings of psychological wellbeing increased over the course of seven-year study. The authors argued that maternal confidence likely increases over time as mothers adjust to their child's ASD diagnosis (Benson, 2016, p. 1710). Limitations to Benson's study were that participants were limited to mothers, who were primarily Caucasian, married and well educated.

In 2017, Chong and Kua published a Singapore based, qualitative investigation exploring PSE in parents of children with ASD, and found similar results to Benson (2016). Within their small qualitative study, Chong and Kua (2017) interviewed mothers (n=10), and explored the relevance of Bandura's 1997 Social Cognitive Theory for PSE among parents of children with ASD. The authors determined that 'mastery' was the most significant determinant of PSE for mothers in their study (Chong & Kua, 2017). PSE is often at its lowest at the time of diagnosis, when parents are experiencing a steep learning curve. Over time, mothers come to know their children and their ASD diagnosis well, and develop an acceptance of who their child is and their challenges. This aligns with Benson's (2016) findings. Despite the similarity to Benson's (2016) findings, there were several limitations to the generalizability of Chong and Kua's (2017) research. Specifically, the study was very small; and mothers that participated in the study were primarily middle-class and selected as a convenient sample by their child's special-needs school because they displayed high levels of self-efficacy and optimism. These mothers were already well supported and actively engaged in their child's learning and development.

In another qualitative study, García-López, Sarriá, and Pozo (2016) collected data from a convenience sample of couples (n=76 dyads) living in Spain who were co-habiting biological parents raising children with ASD, and explored the impacts of PSE through an 'actor-partner

independence model' (García-López, Sarriá, & Pozo, 2016). This model “places emphasis on examining self and partner personal characteristics as predictors of both negative and positive personal outcomes” (García-López, Sarriá, and Pozo 2016, p. 2387). Couples were recruited through a variety of sources including hospital, an Autism specific school and a professional association of Autism. Participants were asked to complete a series of behavioral and psychological questionnaires independently at home. Data from the questionnaires were loaded into two databases to compare outcomes separately for individuals and for couples (García-López, Sarriá, & Pozo, 2016). Findings indicated that children with a diagnosis of ASD influenced family dynamics as well as being influenced by the family dynamics (García-López, Sarriá, & Pozo, 2016, p. 2395). Further, PSE played a significant role in parenting a child with ASD. High levels of PSE predicted decreased levels of parent stress and anxiety and increased levels of well-being (García-López, Sarriá, & Pozo, 2016). García-López, Sarriá, & Pozo's study (2016) was unique in that they looked at mothers and fathers individually as well as part of dyads. Within their sample, mothers were more stressed than fathers; and further, that fathers' anxiety was directly linked to the mothers' level of self-efficacy. Mothers' feelings of strength and family closeness were positively correlated with PSE, control and well-being whereas fathers indicated decreased feelings of stress and anxiety when their partner demonstrated or perceived increased feelings of PSE (García-López, Sarriá, & Pozo, 2016). Similar to previously discussed studies by Benson (2016) and Chong and Kua (2017), these findings also indicated that parents experienced an increased level of stress at the time of their child's diagnosis which improved over time.

May, Fletcher, Dempsey and Newman's 2015 research was a quantitative cross-sectional cohort study conducted in Australia that explored PSE, parent stress and parenting quality within

co-parenting using equation modeling via a survey administered to mothers and fathers (n=152) recruited through schools and services that support children with ASD in New South Wales. Similar to findings of García-López, Sarriá, and Pozo, 2016) parents in this study reported high levels of stress raising children with ASD, with mothers demonstrating higher levels of parenting stress than fathers (May, Fletcher, Dempsey & Newman, 2015). The authors determined that within the sample there was a moderate to strong negative correlation between quality of the co-parenting relationship and parent stress (May, Fletcher, Dempsey & Newman, 2015). The authors note that although they found correlation, but were not able to determine causation due to the cross sectional nature of the research (May, Fletcher, Dempsey & Newman, 2015).

Luque Salas, Yáñez Rodríguez, Tabernero Urbieto, and Cuadrado's (2017) quantitative study conducted in Spain included a sample of mothers and fathers raising children with Autism (n=129). Although the focus of the study was primarily life satisfaction, PSE was an important independent variable that was utilized throughout. Parents were recruited via a mental health unit in Spain; and were recommended to the study by specialists treating their children. Once enrolled, participants completed three questionnaires on life satisfaction, coping strategies and self-efficacy. Study findings indicated that fathers had higher levels of PSE than mothers, and that there was a positive correlation between high feelings of PSE in parents (both mothers and fathers) and life satisfaction. PSE was also found to have a positive correlation with problem solving, and cognitive restructuring for both parents. Fathers specifically were noted to also have a positive correlation between PSE, social support and problem avoidance. Negative correlations were found for both mothers and fathers between PSE and self-criticism, wishful thinking and social withdrawal. In addition, a negative correlation was found in fathers between PSE and expressing emotions (Luque Salas, Yáñez Rodríguez, Tabernero Urbieto, & Cuadrado, 2017). The

study also included the development of regression models. When the data was separated by parent gender, the model showed that level of PSE was found to most accurately explain life satisfaction in mothers raising children with ASD; whereas fathers' life satisfaction was best explained not by PSE but rather, by their ability to problem solve (Luque Salas, Yáñez Rodríguez, Tabernero Urbieto, & Cuadrado, 2017). Another notable finding was that parents accessed fewer social supports as they aged, and their feelings of PSE and life satisfaction declined as their children aged. Although, the authors did not hypothesize why this phenomenon occurred (Luque Salas, Yáñez Rodríguez, Tabernero Urbieto, & Cuadrado, 2017). This is contradictory to the findings of Benson (2016), Chong and Kua (2017) and García-López, Sarriá, and Pozo (2016) who determined that PSE increases over time, as the parent becomes more familiar with their child's diagnosis and their individual needs.

As evidenced by the presented literature, research related to PSE in parents raising children with ASD is limited. Amongst the studies reviewed, findings were consistent in showing that parents of children diagnosed with ASD are under increased levels of stress due to the emotional and behavioral challenges that accompany this diagnosis (Benson, 2016; Chong & Kua, 2017; García-López, Sarriá, & Pozo, 2016; May, Fletcher, Dempsey & Newman, 2015; Luque Salas, Yáñez Rodríguez, Tabernero Urbieto, & Cuadrado, 2017). However, there were conflicting findings about whether PSE increased or decreased over time. In addition, there is a consistent focus on mother's assuming the primary caregiving role for the child. As result, studies primarily focus on PSE of mothers or mother/father dyads with the latter showing some differences between mothers and fathers in variables that correlate with PSE. There appears to be an absence of research that focuses solely on the PSE of fathers or alternative parenting dyads, along with an absence of research focusing on PSE and safety and risk concepts.

2.4 Summary of Literature Review

When exploring sedentary behavior and physical activity, it is clear that current evidence focuses more on the use of physical measurement of activity or sedentary behavior. However, these methods may not accurately align with ASD and the variability of the symptom presentation. As was reported in many of the studies, it was difficult to attain high levels of subject compliance wearing traditional measurement devices (Boddy, Downs & Fairclough, 2015; Loubenius–Palmer, Sjoqvist, Hurtig-Wennlof & Lunqvist, 2018; Bandini, Gleason, Curtin, Lividini, Anderson, Cermak et al., 2013). Further, it is necessary to consider whether restricting the measure to ‘moderate to vigorous’ physical activity is appropriate for children with ASD, especially if current evidence demonstrates this population of children is active independently at a lower level of exertion (Bandini, Gleason, Curtin, Lividini, Anderson, Cermak et al., 2013; Boddy, Downs & Fairclough, 2015). Children with ASD are often not comfortable participating in large group environments at recess or playing team sports, yet this is where they would be most likely to achieve a higher level of physical activity (Boddy, Downs & Fairclough, 2015; Loubenius–Palmer, Sjoqvist, Hurtig-Wennlof & Lunqvist, 2018). Additional research is needed to incorporate a larger sample of children with ASD from different backgrounds, who present with a variety of symptoms to more accurately represent activity and sedentary behavior patterns in children with ASD (Boddy, Downs & Fairclough, 2015) as well as specifically exploring the impact of intellectual disabilities (Loubenius–Palmer, Sjoqvist, Hurtig-Wennlof & Lunqvist, 2018).

Earlier studies have emphasized the increased risk of mortality from accidental injuries sustained by children with ASD (Guan & Li, 2007), and therefore considerations related to safety are imperative when looking to decrease sedentary behavior and increase participation in

physical activities for an at risk population. This includes a need for better understandings about the role of parent attitudes related to protecting their children from injury and promoting their engagement with risky or challenging physical activities. As with sedentary behavior, additional work exploring the variety of ASD symptom presentation, as well as the impact of co-occurring conditions (i.e. ADHD) is needed to clarify their impact on safety and injury risk (Jain et al., 2014; Bonander, Beckman, Janson & Jernbro, 2016; DiGuseppi, Levy, Sabourin, Soke, Rosenberg, et al., 2017).

Parents of children diagnosed with ASD experience increased stress levels due to the many challenges that accompany this diagnosis (Benson, 2016; Chong & Kua, 2017; García-López, Sarriá, & Pozo, 2016; May, Fletcher, Dempsey & Newman, 2015; Luque Salas, Yáñez Rodríguez, Taberero Urbieto, & Cuadrado, 2017) and current research indicates that PSE is an important component in navigating raising a child with ASD. The majority of the findings indicated that PSE increases over time (Benson, 2016; Chong & Kua, 2017; García-López, Sarriá, & Pozo, 2016), and that PSE improved when parents had a support network or a supportive co-parent (Benson, 2016; García-López, Sarriá, & Pozo, 2016; May, Fletcher, Dempsey & Newman, 2015). Parent reported high levels of PSE was associated with lower reports of stress and anxiety (García-López, Sarriá, & Pozo, 2016) and higher levels of life satisfaction (Luque Salas, Yáñez Rodríguez, Taberero Urbieto, and Cuadrado, 2017). Across this research, there is a consistent focus on mother's assuming the primary caregiving role for the child. As result, studies primarily focus on PSE of mothers or mother/father dyads.

As evidenced by the presented literature, findings on parent factors related to sedentary behavior, safety and self-efficacy in parents raising children with ASD is limited. Current perspectives from caregivers are also dominated by a maternal or maternal/paternal couple

viewpoint. Research reporting the single father's perspective or alternative parenting dyads (e.g. same sex couples) is lacking. Furthermore, the variety of symptom presentation appears to be challenging in ASD research due to the overlap and lack of clarity of influencing factors; it is difficult to determine which factor leads to a specific behavior. The limitations of current evidence only serves to illuminate the importance and timeliness of this research.

Chapter 3.0: Research Questions

This study was theoretically grounded within Social Cognitive Theory (Bandura 1977, Bandura 2004), and was specifically guided by the Sociocognitive Causal Model published by Albert Bandura in 2004 and presented in figure 1 (Bandura, 2004, p.146). This model provided a lens to explore relationships between variables linked to parent experiences of caring for a child with ASD, with the goal of providing them with opportunities for safe recreation and physical activity. Based on current literature about parent perception and self-efficacy as it relates to the complexities of raising a child with ASD, Bandura's model (2004) was an appropriate model to utilize as it incorporates both the psychosocial and physical barriers and facilitators, as well as accounting for a parent's self-efficacy, and how the relationships between these factors impact behavior change and the achievement of health goals. The model provided an overarching theoretical guide to consider how parent self-efficacy, parent perception of protection from injury, risk engagement, and perceived barriers to child's activity are impacted by the child's Autism symptoms and can be conceptualized using the self-efficacy model.

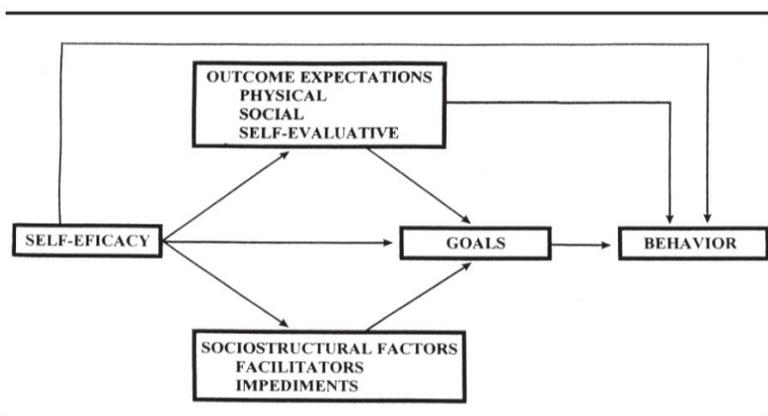


Figure 1. Sociocognitive Causal Model (Bandura, 2004).

Specific research questions and hypotheses were guided by Bandura's Sociocognitive Causal model (2004) and include:

Research Question 1. What differences/similarities exist between the sample population of parents who are raising a child with ASD, and those parents who are raising a child without ASD?

We hypothesized that:

- a) Parents raising a child with ASD would differ from those who are not in reports of: barriers to activity, sedentary behavior/screen time, outside time and type of child activity participation.
- b) Parents raising a child with ASD would differ in their attitudes towards injury protection and risk, with higher total protection from injury scores, lower total risk engagement scores and poorer scores in parent self-efficacy in their confidence to balance their child's protection from injury with risk engagement.

Research Question 2. How does a child's ASD diagnosis, and/or ASD symptoms, impact the parent's perceived barriers to activity, child sedentary behavior/screen time, child physical activity (outside play and activity type), parents' perceptions of protection from injury and risk; and what is the impact on parent self-efficacy in balancing their child's protection from injury and risk?

We hypothesized that:

- a) There is a positive relationship between the Autism symptoms as indexed by the Autism Quotient and parent perceived barriers to activity, and levels of sedentary behavior/screen time, and parent attitude to protection from injury.
- b) there is an inverse relationship between the Autism symptoms as indexed by the Autism Quotient and reported levels of child's physical activity (including outside play and

activity type); as well as parent attitudes toward risk engagement and parent self-efficacy in their ability to balance injury prevention and risk.

Chapter 4.0: Methods

4.1 Context

Since 2012, Dr. Grace Iarocci, and the Autism and Developmental Disorders Lab research team at Simon Fraser University (SFU) have hosted an annual Social Science Camp for children with Autism spectrum disorder (ASD). Parents of children between the ages of 7-12 years, both with and without a diagnosis of ASD are encouraged to register. During the two-day camps, children and parents participate in fun, educational activities and contribute to research (<http://Autismlab.psyc.sfu.ca/Camp2018>). Data for this analysis was collected as part of the larger ‘Social Attention in Autism Study’ led by Dr. Iarocci during the 2017 two- day Social Science Camp held onsite at SFU in Burnaby, British Columbia on two consecutive Saturdays (July 15 & 22, 2017). Measures presented in this thesis include those we chose to include in the 2017 study, as well as those from the larger ‘Social Attention in Autism Study’ led by Dr. Iarocci.

4.2 Study Design and Participants

The larger Autism study is a cross-sectional study comprised of a survey administered to parents, alongside direct measures obtained from children attending the camp. Data were collected from parents (N=69) who attended the 2017 Social Science Camp, held at SFU in Burnaby, BC. The first Saturday (July 15, 2017) was held for parents and their children without ASD (n=37 parent/child dyads; child IQ score range 84 – 135, mean 107 ($SD = 12.62$); child AQ score range 6 - 32, mean 17, ($SD = 6.67$)). The second session (July 22, 2017) was held for parents and their children with ASD (n=32 parent/child dyads; child IQ score range 59-138, mean 101 ($SD = 17.42$); child AQ score range 19-48, mean 33 ($SD = 5.53$)). Families were

recruited through a variety of methods by the SFU research team. Initially, a recruitment email was distributed to newsletter subscribers of the Autism and Developmental Disorders Lab, as well as advertising through provincial Autism community networks and contact with schools that support children with developmental disabilities. Families participating in the second Saturday ASD camp were required to provide a copy of confirmation of their child's diagnosis from a medical practitioner. Children who were unable to participate in camp activities independent of their parent(s) due to being non-verbal; requiring 1:1 supervision to participate; or being unable to toilet independently were excluded from the camp.

4.3 Study Procedures and Measurement Tools

Parents completed the 'Health and Wellness Risk Engagement and Protection Survey' (HWREPS) (see Appendix A) and a Family Demographic questionnaire (see Appendix B) either online prior to the start of camp, or in person on the morning of the camp during the initial session. Child measures of child intelligence quotient (IQ) scores (Wechsler abbreviated Intelligence Scale (WASI-II, 1999), and total child Autism quotient (AQ) scores (Baron-Cohen, Wheelwright, Skinner, Martin, & Clubley, 2001) were collected from the children by ADDL research staff during the camps.

Not all components of the HWREPS survey are presented in this thesis, as the research focus for this analysis was limited to parent factors related to physical activity in children with ASD. The variables used for this study consisted of: the total child IQ score; the total child AQ score and six parent responses taken from the Family Demographics tool (including relationship to child of parent completing the form, age of child, gender of child, parent marital status, estimated family income and caregiver education level). In addition, seven total scores and single question responses were taken from the HWREPS from the following categories: (a) screen

time/sedentary time, (b) outside time, (c) participation in organized activity, (d) protection from injury score, (e) risk engagement score, (f) Self-efficacy related to balancing injury prevention and risk engagement and, and (g) barriers to activity.

The HWREPS was the primary source of data collected from parents. HWREPS is comprised of 35 questions, and is an amalgamation of previously used tools: International Study of Childhood Obesity, Lifestyle and the Environment (ISCOLE) (Katzmarzyk et al., 2013), and the Risk Engagement and Protection Survey (REPS) (Olsen, Ishikawa, Masse, Chan and Brussoni, 2017). Questions 1 through 17 of the HWREPS were guided in their development by ISCOLE (Katzmarzyk et al., 2013) and the Center for Disease Control (CDC) Health-related Quality of Life Index (HRQOL) (<https://www.cdc.gov/hrqol/index.htm>, retrieved December 21, 2018). ISCOLE was a well-known large global, cross sectional study which collected data from 6000 ten year old children across 12 countries, that explored the relationship between lifestyle and obesity and how that relationship is impacted by behavior, physical environment, social environment and policy; as well as variations between countries (Katzmarzyk et al., 2013). ISCOLE is a compilation of multiple validated measurement tools. The lifestyle and behavior measurements used within ISCOLE were relevant to the HWREPS. ISCOLE utilized US Based Risk and Behavior Surveillance System (YRBSS) (U.S. Centers for Disease Control and Prevention, 2012) as a measurement tool to explore health risk behaviors in youth. The most recent test-retest reliability study on the administration of this tool was conducted in 1999 with 4619 high school students over two points in time two weeks apart. Kappa measures the amount of agreement between the two instruments whilst also accounting for chance (Pallant, p. 227, 2017). A Kappa value of .5 = moderate agreement; Kappa value of .7 = good agreement; and Kappa values above .8 indicate very good agreement (Peat, p. 228, 2001). In the YRBSS,

questions with a Kappa measure of agreement <61% or that had significantly different prevalence estimates for time one and time two were removed from all future versions of the tool to ensure reliability (Centers for Disease Control and Prevention (CDC) et al., 2013). The overall validity of the YRBSS tool has not been assessed (Centers for Disease Control and Prevention (CDC) et al., 2013). HWREPS questions 1-17 were also previously tested with different school aged children participating in the Health and Wellness Index for Kelowna Youth study initiated in 2017 by Dr. McManus and Dr. Lutes.

Questions 18 through 32, as well as questions 34 and 35 of the HWREPS were obtained from the REPS. The REPS tool was developed and tested initially with a sample 302 fathers attending an emergency department in British Columbia with their children, and was subsequently tested with a sample of 264 mothers also attending emergency with their children at the same hospital. Factor analysis was carried out separately with both fathers and mothers samples and showed that parents conceptualized protecting their children from injury and encouraging their engagement with risk as two distinct concepts. (Olsen, et al., 2017; Olsen et al., submitted 2019). The REPS tool has also been utilized as a component of the New Zealand State of Play Survey conducted with more than 2000 parents. The state of play survey was a cross-sectional survey of parent attitudes towards their children participating in risky play (Jelleyman, Mcphee, Brussoni, Bundy, & Duncan, 2019).

Cronbach's alpha is a statistical test that measures the internal consistency and inter-relatedness of questions. An acceptable range for Cronbach's alpha is 0.7 – 0.9 (Tavakol & Dennick, 2011). Questions #18 – 25 of the HWREPS were taken from the REPS tool and inform the protection from injury score. These questions were tested and the resulting factor was a Cronbach's alpha of 0.75 (Olsen, Ishikawa, Masse, Chan, Brussoni, p. 3, 2017). Questions #26 –

31 of the HWREPS were also taken from the REPS tool and inform the risk engagement score. These questions were tested as well, and the resulting factor was a Cronbach's alpha of 0.77 (Olsen, Ishikawa, Masse, Chan, Brussoni, p. 3, 2017). The correlation between the concepts of protection from injury and risk engagement was evaluated and found to be low and not significant ($r = -.24, p = .07$) which confirmed that these concepts are not related and can be evaluated separately (Olsen, Ishikawa, Masse, Chan, Brussoni, p. 3, 2017).

Questions 33a through 33e of the HWREPS related to parental perceived barriers for their child's participation in activity. These questions were developed and added to the HWREPS for use in the 2017 SFU camp by Dr. Iarocci, Dr. Olsen and Dr. McManus.

Intelligence quotient and Autism quotient. In addition to HWREPS, intelligence quotient (IQ) and Autism quotient (AQ) measures were collected from every child who participated in the camp, and total IQ and AQ scores were supplied by the ADDL research team for the purpose of this analysis. Child IQ scores were obtained using results from the widely recognized Wechsler Abbreviated Scale of Intelligence (WASI IQ) (Wechsler, 1999). The calculation of this score is an important component of Autism research where children with ASD are being compared to TD children. Children with ASD will have varying strengths and weaknesses in cognitive executive functioning levels however, the collection of a total IQ score will aid to identify if the children with ASD are cognitively comparable on average to their TD peers (Russo et al., 2007). A total Autism quotient score was obtained using results from the Autism Spectrum Quotient (AQ) (Baron-Cohen, Wheelwright, Skinner, Martin, and Clubley, 2001). This tool assessed for the presence of autistic traits across five domains including: communication, social, imagination, local details and attention switching (Baron-Cohen et al., 2001). Scores greater than 32 (out of a possible 50) on the AQ have been found to indicate a

strong presence of traits consistent with ASD (Baron-cohen et al., 2001). Although not a diagnostic measure, this 50 question screening tool is widely available online and recognized as a reliable tool to identify the level of autistic traits in individuals of average intelligence levels. Test-retest reliability of the AQ was assessed and found to be stable and strongly correlated ($r = .7, p = .002$) when tests were administered two weeks apart (Baron-Cohen et al., p. 11, 2001). Internal consistency with items across the five domains were all found to be moderate to high using Cronbach's alpha (Communication = .65; Social, = .77; Imagination = .65; Local Details = .63; Attention Switching = .67) (Baron-Cohen et al., p. 11, 2001).

The final source of data collection used in this analysis is the Family Demographics form (Appendix B). This tool was created by the ADDL research team and is utilized for all their annual camps.

4.4 Ethics and Data Management

Initial ethical approval for the original 2017 SFU Social Attention Autism study was obtained through the SFU Research Ethics Board. Ethical approval for the subset of the data used in this thesis research was obtained through the UBC Okanagan Research Ethics Board. The subset of data from the 2017 SFU Social Attention Autism study was obtained using a secure, file transfer protocol. The data was provided in a de-identified format that did not include any personal identifiers. The data was stored on a secure UBC Okanagan network server only accessible by authorized data users: Dr. Lise Olsen, Dr. Alison McManus and MSN student, Ms. Erin McFee. Any paper copies related to the raw data or analysis files were stored in locked file cabinet in the School of Nursing Research Office at UBC Okanagan.

4.5 Data Analysis

Data analysis was conducted using SPSS software Version 25, and guided by the research questions outlined earlier in this paper in section 3.0.

Parents were enrolled into the ASD or non-ASD group according to their child's diagnosis of ASD, which was confirmed from a medical provider prior to attending the camp session. For the analyses, each case was labelled in SPSS as belonging to either the ASD or non-ASD group. Total AQ and IQ scores were collected from children to demonstrate the differences and similarities that existed between the two groups, this data was examined for normal distribution, and then independent *t*-tests were conducted to compare means between the two groups.

Demographic characteristics. An initial descriptive analysis was conducted on all demographic and study variables included in the analysis to provide an overview, identify any errors and confirm normality of distribution of the data collected from both groups of parents (those caring for children diagnosed with ASD and those parents caring for children without ASD). This component of the analysis incorporated the use of measures of central tendency. Specifically, frequencies were checked (including both mode and percentiles) for categorical variables measured at the nominal or ordinal level including: diagnostic group, sex of child, parent marital status, family income, mother's education and father's education. Mean and standard deviation were calculated for the continuous ratio level variables of age of child, as well as child AQ and IQ scores. Both mean and standard deviation were calculated for continuous variables. In addition, continuous variables were assessed for normality using the Kolmogorov-Smirnov statistic to identify if non-parametric tests should be reported.

HWREPS variables. Some variables within the HWREPS required the calculation of a total score. The make-up of the total score measurement for variables collected from the HWREPS is outlined below in table 1.

Table 1. *HWREPS Variables*

Variable description	Comprised of ...	Level of measure
Child's average daily screen time/sedentary time	Total score of questions #1-3 and 6-8; divided by 7	Interval; 7 point Likert scales used for individual questions (<i>none to 5 hours or more</i>).
Child's average weekday time spent outside	Total score of questions #4 and 5; divided by 5	Interval; 7 point Likert scales used for individual questions (<i>none to 5 hours or more</i>).
Child's participation in organized activity	Question #9	nominal
Total protection from injury score	Total score of questions #18 - 25	Interval; 7 point Likert scales used for individual questions (#18-23 <i>very strongly disagree to very strongly agree</i> , and #24-25 <i>never to all of the time</i>).
Total risk engagement score	Total score of questions #26 - 31	Interval; 7 point Likert scales used for individual questions (<i>very strongly disagree to very strongly agree</i>).
Parent self-efficacy in balancing risk and protection from injury	Single question #32	Interval level 7 point Likert scale (<i>not at all confident to completely confident</i>).
Total perceived barriers to activity	Total score of four questions #33a-33d	Interval; 7 point Likert scale used for individual questions (<i>very strongly disagree to very strongly agree</i>).

Note. See appendix A for survey questions

Research question 1. After the initial descriptive analyses were complete, inferential statistical analyses, guided by the hypotheses, were conducted to aid in drawing conclusions about the differences and similarities that exist between the two populations of parents. Variables used in these analyses included: perceived barriers to activity, sedentary behavior/screen time, outside time and activity participation; as well as in comparing parent attitudes to total protection

from injury, total risk engagement and parents' level of self-efficacy to balance protection and risk. Independent t tests were conducted to compare means on normally distributed continuous interval and ratio level data including sedentary behavior/screen time scores and Mann-Whitney U tests were utilized as the non-parametric alternative to compare means of continuous data that were not normally distributed including time spent outside, protection from injury scores, risk engagement scores, parents' self-efficacy score in balancing protection from injury and risk engagement, and barriers to activity.

A Chi-square test for independence was utilized to compare the proportions of ASD and non-ASD groups in relation to their participation in the following activities: 'dance/martial arts', 'art/music', 'sports teams' and 'no participation in the listed activities'. Where Chi-square tests were used, Fisher's exact test was reported in situations where the frequency was <5 ; and the more conservative Yates continuity correction was reported in cases where only two categories in a 2x2 cross tabulation were compared (Pallant, p. 218, 2016).

Research question 2. Once comparison between the ASD and TD groups was complete. Additional analyses focusing on the presence of ASD symptoms represented by the AQ score were conducted utilizing the entire sample ($N = 69$). Initially, the strength and direction of relationships between the ratio level AQ score and parent reported barriers to activity were explored using Spearman's rho correlation coefficient.

In an effort to conduct additional investigations using child's AQ score as an independent variable, total child AQ scores (initially a continuous ratio level variable) was recoded as three category (binned) ordinal variable. Ranges for these categories were selected initially to provide a category that was limited to individuals with clinically significant autistic traits as outlined by (Baron-Cohen et al., 2001), as well as providing an even distribution for analysis. The new

variable was utilized across the entire sample (N = 69) and the resulting categories for the new variable included *'high'*, with scores > 32 (n = 22); *'moderate'*, with scores between 20 -31(n = 22); and *'low'* including scores < 19 (n = 25). This recoded variable was utilized to investigate the hypothesis that a positive relationship existed between AQ scores and barriers to activity, amounts of sedentary/screen time and protection from injury; as well as an inverse relationship between AQ scores and outside time, risk engagement scores and levels of parent self-efficacy to balance risk and injury prevention. A series of one-way analysis of variance (ANOVA) tests were run with this recoded binned AQ score as the independent variable and the parent reported total barriers to activity, measures of sedentary behavior/screen time, physical activity (including outside play and activity type) and total protection from injury, risk engagement, and parent self-efficacy balancing injury and risk as dependent outcome variables.

Chapter 5.0: Results

5.1 Demographic Characteristics

The total case sample used in this analysis ($N = 69$) included parents with a TD child ($n = 37$) and parents raising a child with ASD ($n = 32$). Parent groups were split by their child's diagnosis, and frequencies were calculated for categorical demographic variables measured at the nominal or ordinal level including: diagnostic group, sex of child, parent marital status, family income, mother's education and father's education. In addition, means and standard deviations were calculated for interval and ratio level variables including: age of child, child AQ score and child IQ score (see Table 2). Total AQ and IQ scores collected from children were split by diagnostic group for analysis to demonstrate the differences and similarities that existed between the groups. An independent samples t -test revealed a significant difference in AQ scores was found between the TD group ($M = 16.57$, $SD = 6.669$) and the ASD group ($M = 33.13$, $SD = 5.534$); $t(67) = -11.116$, $p = .000$, two tailed. The magnitude of the differences in the means (mean difference = -16.557 , 95% CI : -19.530 to -13.584) was very large (eta squared = 0.65) and calculated as per guidelines outlined by Cohen (1988).

An independent samples t -test was also conducted to compare the total IQ scores of children in the TD group compared to the ASD group. It is important to note, that some children were unable to complete the IQ tool due to language and communication barriers. Of those children that were able to participate (TD, $n = 36$; ASD, $n = 28$) no significant difference in total IQ scores was found in the TD group ($M = 107.36$, $SD = 12.622$) compared to the ASD group ($M = 101.00$, $SD = 17.423$); $t(62) = 1.694$, $p = .95$, two tailed. The magnitude of the difference in means (mean difference = 6.361 , 95% CI : -1.146 to 13.868) was small (eta squared = 0.04) (Cohen, 1988). As all subjects (including those missing an IQ score) had a total AQ score, and

the focus of this exploratory research was an ASD diagnosis or the presence of ASD symptoms, all analyses were run using the entire sample (TD, n = 37; ASD, n = 32). To assess whether inclusion of the 5 cases with missing IQ scores, impacted the analysis results, all statistical tests were double checked and re-run using the smaller sample sizes (TD, n = 36; ASD, n = 28) that resulted when cases without IQ scores were removed. In the event that the difference in sample size was found to impact the significance of the test results, the variation was reported with the test.

Table 2. *Family Demographics*

Family Demographics	TD (n=37)				ASD (n=32)			
	Female n=10		Male n=27		Female n=8		Male n=24	
	Mean	SD	Mean	SD	Mean	SD	Mean	SD
Child								
Child age in years (n=69)	9.59	1.68	9.50	1.66	11.15	1.84	9.50	1.87
AQ (n=69)	14.70	8.45	17.26	5.92	33.12	4.97	33.13	5.81
IQ (n=64)	111.70	9.84	105.69	13.33	106.29	13.34	99.24	18.53
	<i>f</i>	<i>%</i>	<i>f</i>	<i>%</i>	<i>f</i>	<i>%</i>	<i>f</i>	<i>%</i>
Parent completing form (n=69)								
Mother/Grandmother	7	70.0	22	81.5	6	75.0	21	87.5
Father	3	30.0	5	18.5	2	25.0	3	12.5
Marital status (n=69)								
Single			1	3.7	2	25.0		
Married	9	90.0	24	88.9	6	75.0	20	83.3
Divorced			2	7.4			3	12.5
Separated	1	10.0					1	4.2
Family income (n=69)								
Less than \$20,000			2	7.4				
\$20-49,999	3	30.0	3	11.1	1	12.5	3	12.5
\$50-79,999	4	40.0	8	29.6	1	12.5	6	25.0
\$80-109,000	2	20.0	9	33.3	2	25.0	5	20.8
\$110-140,000			2	7.4			3	12.5
Greater than \$140,000			3	11.1	3	37.5	7	29.2
*Missing data	1	10.0			1	12.5		
Mother Education (n=69)								
High school							3	12.5
Professional diploma	3	30.0	9	33.3	2	25.0	3	12.5
University degree	4	40.0	8	29.6	4	50.0	14	58.3
Graduate degree	2	20.0	9	33.3	1	12.5	3	12.5
Other			1	3.7			1	4.2
*Missing data	1	10.0			1	12.5		
Father Education (n=69)								
High school					1	12.5	4	16.7
Professional diploma	3	30.0	5	18.5	2	25.0	5	20.8
University degree	4	40.0	10	37.0	2	25.0	6	25
Graduate degree	2	20.0	9	33.3	1	12.5	8	33.3
Other					1	12.5		
*Missing data	1	10.0	3	11.1	1	12.5	1	4.2

5.2 Research Question 1

The purpose of the inferential analysis was to identify differences and similarities that existed between the two populations of parents (those raising a child with ASD, and those parents raising a child without ASD). The independent *t*-test and Mann-Whitney U test were utilized to compare means for continuous variables. The groups of parents were found to be similar. Differences in parent reports of their children's sedentary behaviors and physical activity were explored by diagnostic group. An independent samples *t*-test was conducted to compare the reported total daily average screen time. There was no significant difference in scores for TD ($M = 3.4672$, $SD = 1.26601$) and ASD groups ($M = 3.4911$, $SD = 1.00423$; $t(67) = -0.086$, $p = .932$). The magnitude of the difference in means (mean difference = -0.024 , 95% *CI*: -0.579 to 0.531) was very small (eta squared = 0.000) (Cohen, 1988). Reported averages of time spent outside on a school day between the diagnostic groups was not found to be normally distributed, as result a Mann-Whitney U test was utilized as a non-parametric alternative to compare means between the groups. This test revealed no significant difference in total time spent outside on a school day between diagnostic groups of ASD ($Md = 1.8$, $n = 32$) and TD ($Md = 1.8$, $n = 37$), $U = 549.5$, $z = -0.53$, $p = .600$, $r = .06$. Mann-Whitney U tests also revealed no significant difference in parent's total protection from injury score between ASD group ($Md = 34.0$, $n = 30$) and TD group ($Md = 40.0$, $n = 36$), $U = 449.00$, $z = -1.17$, $p = .240$, $r = -0.11$; or for parent's total risk engagement scores between ASD group ($Md = 33.0$, $n = 32$) or TD group ($Md = 34.0$, $n = 37$), $U = 583.00$, $z = -0.11$, $p = .914$, $r = -0.01$. In addition, a Mann-Whitney U test also did not reveal a significant difference in parents' self-efficacy in their ability to balance risk and protection for their child, between the ASD group ($Md = 5.0$, $n = 31$) and TD group ($Md = 5.0$, $n = 37$), $U = 528.00$, $z = -0.584$, $p = .559$, $r = -0.07$. However, a Mann-Whitney U test did reveal a very significant

difference with large effect (Cohen 1988) in parent's perceived total barriers to participation in activities between the ASD group ($Md = 16.5, n = 32$) and the TD group ($Md = 8.0, n = 37$), $U = 194.50, z = -4.81, p = .000, r = -0.58$. The significance of this finding was not impacted when the test was re-run using the smaller sample (table 3). Figure 2 presents a visual representation of the mean individual barriers to activity assessed in the parent groups that were included in the analysis, and comprised the total barriers score. Cases falling outside of the bars in the TD chart are likely not outliers, rather they represent normal variations in child motor coordination skill development.

A Chi-square test for independence was utilized to compare distribution between nominal and ordinal level variables including ASD diagnosis, and activity participation. As all Chi-square tests for independence in this analysis utilized a 2 x 2 cross-tabulation, the more conservative Yates' Continuity Correction result was reported (Pallant, 2016). A Chi-square test for independence indicated no significant association between ASD diagnosis and participation in dance or martial arts, $\chi^2(1, n = 69) = 3.39, p = .066, phi = .25$ or participation in art or music, $\chi^2(1, n = 69) = 2.30, p = .130, phi = .21$. However, A Chi-square test for independence did indicate a significant association with medium effect size (Cohen, 1988) between ASD diagnosis and participation in sports teams, $\chi^2(1, n = 69) = 13.65, p = .000, phi = .47$; 31.3% of parents of a child with ASD reported their child had participated in team sports compared to 78.4% of parents of a TD child. Further, a Chi-square test for independence indicated a significant association with medium effect (Cohen, 1988) between ASD diagnosis and absence of participation in any organized activities over the past 12 months (sports teams, dance/martial arts, or art/music), $\chi^2(1, n = 69) = 5.02, p = .025, phi = -0.31$; 28.1% of parents reported their child with ASD participated in 'no' organized activity, compared to only 5.4% of the TD group (table 4). It

should be noted that this test was found not to be significant when it was re-run with the smaller sample. However, four of the five cases that were removed were from the ASD group, $\chi^2(1, n = 64) = 2.32, p = 0.128, \phi = -0.238$; which resulted in 21.4% of parents reported their child with ASD participated in ‘no’ organized activity, compared to only 5.6% of the TD group. The results in terms of statistical significance for the other Chi-square tests remained the same (table 5).

Table 3. Mann-Whitney U tests: Total barriers to activity

Mann-Whitney U tests: Total barriers to activity											
N = 69					N = 64 (re-run)						
	<i>n</i>	<i>Md</i>	<i>U</i>	<i>z</i>	<i>p</i>		<i>n</i>	<i>Md</i>	<i>U</i>	<i>z</i>	<i>p</i>
ASD	32	16.5	194.5	-4.81	.000**	ASD	28	16.0	166.5	-4.6	.000**
TD	37	8.0				TD	36	8.0			

Note. ** significant at < 0.01

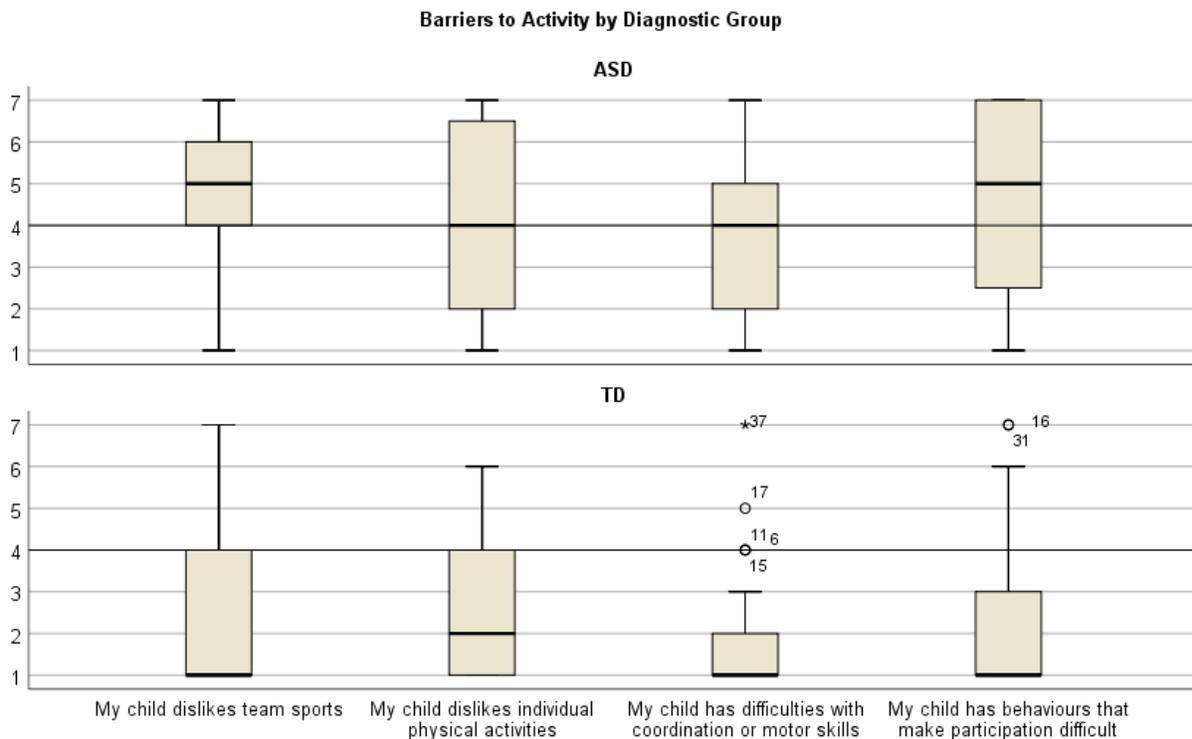


Figure 2. Barriers to activity by diagnostic group

Table 4. Results of Chi-square: Activity participation

Results of χ^2 (N = 69)				
Activity Participation	ASD (n = 32)	TD (n = 37)	χ^2 statistic	p value
Sports Teams	31.3%	78.4%	13.65	0.000**
Dance / Martial Arts	21.9%	45.9%	3.39	0.066 (NS)
Art / Music	43.8%	64.9%	2.30	0.130 (NS)
None	28.1%	5.4%	5.02	0.025 *
<i>Note.</i> * significant at < 0.05, ** significant at < 0.01				

Table 5. Results of Chi-square: Activity participation (re-run)

Results of χ^2 (re-run) (N = 64)				
Activity Participation	ASD (n = 28)	TD (n = 36)	χ^2 statistic	p value
Sports Teams	32.1%	77.8%	11.64	0.001**
Dance / Martial Arts	21.4%	44.4%	2.75	0.097 (NS)
Art / Music	50.0%	63.9%	0.74	0.389 (NS)
None	21.4%	5.6%	2.32	0.128 (NS)
<i>Note.</i> * significant at < 0.05, ** significant at < 0.01				

5.3 Research Question 2

Additional tests were conducted with the complete sample of participants (N=69). The relationship between total AQ score in its ratio form and Total Barriers to Activity score across all parents was investigated using correlation. Preliminary analyses were performed to assess for violations of the assumptions of normality, linearity and homoscedasticity. The variable total barriers to activity was found to not be normally distributed so Spearman's Rho was reported. There was a strong positive and statistically significant correlation between the two variables, $\rho = 0.54$, $n = 69$, $p = .000$ with high AQ scores associated with higher levels of parent perceived barriers to activity. Total child AQ scores helps to explain 29.4% of the variance in parent total barriers to activity scores. The significance of this finding did not change when the test was re-run with the smaller sample as illustrated in table 6 below.

Table 6. Spearman Correlation: Total AQ and total barriers to activity

Spearman Rho – Total AQ and Total Barriers to Activity			
	<i>M(SD)</i>	<i>r</i>	<i>sig</i>
<i>N</i> = 69	24.25(10.33)	0.544	.000**
<i>N</i> = 64 (re-run)	23.64(10.05)	0.538	.000**
<i>Note.</i> * significant at < .05, ** significant at < .01			

The impact of ASD symptoms on key dependent variables was explored further using a recoded total AQ score. Total AQ was recoded into a three category ordinal (binned) variable: *High* with scores > 32 ($n = 22$); *Moderate*, with scores between 20 -31($n = 22$); and *Low* including scores < 19 ($n = 25$)) to identify relationships that existed as result of ASD characteristics rather than simply by diagnostic group. A one-way between groups analysis of variance (ANOVA) was conducted to explore the impact of the recoded total AQ score (binned) on the dependent variables: Total barriers to activity, total average daily screen time, average weekday time spent outside, total protection from injury score, total risk engagement score and parent self-efficacy in balancing their child's protection from injury and risk engagement. The bulk of these tests yielded insignificant results at the $p < .05$ level including: total average daily screen time $F(2, 66) = 0.441, p = .645$; total average weekday time spent outside $F(2, 66) = 0.033, p = .968$; total protection from injury score $F(2, 63) = 0.876, p = .421$; total risk engagement score $F(2, 66) = 2.611, p = .081$; and parent self-efficacy in balancing their child's protection from injury and risk engagement $F(2, 65) = 2.489, p = .091$. However, the one-way ANOVA conducted to explore the relationship between total AQ groupings on total barriers to activity did produce a statistically significant result at the $p < 0.01$ level, $F(2, 66) = 12.076, p = .000$ as shown in table 7. The actual difference in mean scores was very large. The effect size, calculated using eta squared, was 0.3. Post-hoc comparisons using Tukey HSD test indicated that the mean score for total barriers to activity in the high scoring AQ group ($M = 17.14, SD = 5.77$) was significantly different from both the medium group ($M = 12.82, SD = 6.25$) and the low group ($M = 8.76, SD = 5.50$). This test was also re-run using the smaller sample, and results remained significant (table 8).

Table 7. ANOVA

<i>ANOVA – 3 Grouping AQ with Total Barriers to Activity</i>						
ANOVA				Post Hoc testing		
AQ group	<i>M(SD)</i>	F	Sig	Tukey HSD	Mean diff.	Sig
Low (n = 25)	8.76(5.50)	12.076	.000**	High/Mod	4.32	.044*
Moderate (n = 22)	12.82(6.25)			Mod/Low	4.06	.052 NS
High (n = 22)	17.14(5.77)			High/Low	8.38	.000**
<i>Note.</i> * Significant at < .05, ** Significant at < .01						

Table 8. ANOVA (re-run)

<i>ANOVA (re-run) – 3 Grouping AQ with Total Barriers to Activity</i>						
ANOVA				Post Hoc testing		
AQ group	<i>M(SD)</i>	F	Sig	Tukey HSD	Mean diff.	Sig
Low (n = 24)	8.42(5.34)	10.18	.000**	High/Mod	3.63	.126 NS
Moderate (n = 22)	12.82(6.25)			Mod/Low	4.40	.032*
High (n = 18)	16.44(5.69)			High/Low	8.03	.000**
<i>Note.</i> * Significant at < .05, ** Significant at < .01						

Chapter 6.0: Discussion

This study represents an exploratory analysis of data reflecting the perspectives of parents raising children with ASD, and provides a rare opportunity to compare and contrast those findings to parents raising a TD child. Prior to conducting the study we consulted available literature and had hypothesized that parents raising a child with ASD would differ significantly from parents raising a child without ASD in reports of: barriers to activity, child sedentary behavior/screen time, child outside time and type of child activity participation. Specifically, we hypothesized that the child's ASD diagnosis or presence of ASD symptoms would result in positive relationships with barriers to activity, levels of sedentary behavior/screen time, and negative or inverse relationship with child physical activity (including outside play and activity type). In addition, we hypothesized a positive relationship with ASD and parent attitude toward protection from injury and a negative or inverse relationship between ASD and parent attitude toward risk engagement and PSE in their ability to balance the two.

ASD and the relationship to PA. After careful review of the results, we found very few differences in parent-reported levels of child sedentary behavior, screen time and outside time, regardless of the presence of an ASD diagnosis or ASD symptoms. These findings are aligned with those of Bandini, Gleason, Curtin et al. (2013), as well as those of Montes (2016) who also presented parent report data, and found that most children were exceeding the recommended amounts of sedentary time with no differences found for those with an ASD diagnosis. These researchers also reported that while PA levels were comparable for children with and without ASD the PA participation among children with ASD occurred at lower levels of intensity (Bandini, Gleason, Curtin et al., 2013; Montes, 2016).

Although the lack of difference in PA levels between groups is some-what reassuring, the challenge remains that regardless of ASD diagnosis, children are struggling to meet the recommended requirements of daily PA. Unfortunately, we were limited in the PA data that was collected in this study, and were unable to clarify the quality or intensity of the physical activity of the children in our sample participated in. This would be important information to collect in future studies, especially given that previous evidence has found the presence of an ASD diagnosis can influence the level of intensity of the physical activity the child chooses to engage in (Bandini, Gleason, Curtin et al., 2013; Boddy, Downs & Fairclough, 2015). Children with ID have been shown to have a preference for smaller group activities, and choose to avoid large group play (Boddy, Downs & Fairclough, 2015). Small group participation by children with ID has been found by other researchers to be negatively correlated with sedentary time, such that children with ID who participated in higher levels of small group participation engaged in lower levels of sedentary behavior (Boddy, Downs & Fairclough, 2015). It is difficult to say if this phenomenon is reflected within our study sample, because the ASD group within our study encompassed children within a moderate IQ range making it more challenging to estimate the impact of ID. However, parents raising a child with ASD did report a significantly lower level of sports team participation (a large group physical activity). This potential link further highlights the need for additional research. Future studies related to PA in children living with ASD could shift the focus from large group high intensity PA like sport teams, to lower or moderate intensity, small group or individual PA. Data collection tools could include options for less structured PA activities like skipping, hopscotch, or other small-group playground games.

ASD and barriers to activity. Parents raising children with ASD are under significant pressure and time constraints to accommodate all of the ‘important interventions’ needed to

support their child's development (i.e. therapies and behavioral support). We hypothesized that the child's ASD diagnosis or presence of ASD symptoms would demonstrate a positive relationship with barriers to activity. This hypothesis was supported by the findings. We determined that similar to earlier findings (Obrusnikova & Miccincello, 2012; Must, Phillips, Curtin & Bandini, 2015), the parent group raising children with an ASD diagnosis reported encountering a significantly larger number of barriers to their child participating in activity than the parents raising a child without ASD (Figure 2). These barriers were also likely to have been reflected in the large number of children who did not participate in any organized activity within the ASD group. In spite of the increased level of barriers identified, our findings did not corroborate a positive relationship between total barriers to activity and higher sedentary behavior/screen time for children with ASD as has been noted in earlier research (Must, Phillips, Curtin and Bandini, 2015). However, this analysis was limited by the specific type of organized activities included in the survey. It would be an interesting direction for future research to explore if activity engagement levels would change for a physical activity that provided a clear and measurable benefit for their child i.e. the water safety skills gained as result of participation in swimming lessons. The ability to swim and develop water safety skills has been shown to be a major concern for parents raising children with ASD, especially given that drowning is a significant cause of death resulting from accidental injury in this population (Guan & Li, 2017a; Guan & Li, 2017b). It would also be interesting to explore how parents weigh the importance of the activity against the potential barriers they / their child will encounter. Specifically, if the activity will directly support the child's safety, education, or challenging social behavior, are parents more willing to navigate the barriers?

ASD and parent attitudes towards protection and risk. We had hypothesized that the parents raising children with ASD would measure higher in their total protection from injury scores, and lower in total risk engagement scores; as previous evidence had indicated that children with ASD are at higher risk of serious injury than their TD peers (Kalb, Vasa, Ballard, Woods, Goldstein and Wilcox, 2016; McDermott and Zhou, 2007). In addition, prior research had also indicated that parents raising children living with disabilities also had tendencies to overprotect children from harm (Olsen et al., 2016; Ozhek, 2008). As such, we had anticipated parents in the ASD group would display lower overall scores in PSE in their confidence to balance their child's protection from injury with risk engagement. This was not found to be the case. Parents raising a child with ASD who participated in this study were found to score similarly to parents raising a TD child both in their attitudes towards injury protection and risk, and in their PSE in balancing both. These findings were also very similar when comparing across low, medium and high AQ scores. Although, this finding was surprising, it is possible that it is a result of the level of contact and/or supervision children with ASD receive from their parents. An altered accepted level of supervision for children with ASD is a phenomenon that has been studied by Cavalari and Romanczyk (2012). Parents raising a child living with ASD have been found to anticipate the child's increased risk of injury and provide additional supervision for the child. This level of supervision then becomes normalized for the parent (Cavalari & Romanczyk, 2012a; Cavalari & Romanczyk, 2012b). Similar findings have been noted when children with physical and intellectual disabilities (Olsen, Kruse, Miller & Brussoni, 2016; Ozhek, 2008). This concept of increased supervision or an increased level of protection in parents raising a child with ASD would be interesting to explore further, and could provide insight into the explanation for levels of PSE and parents feeling more confident in their ability to balance injury prevention

and risk. One possible direction for future research in this area may be to explore differences and similarities in parent attitudes towards risk and safety when they are simultaneously raising ASD and TD siblings.

6.1 Links to Theory

This analysis was theoretically grounded in Albert Bandura's Social Cognitive Theory (Bandura 1977, Bandura 2004), and was specifically guided by his Sociocognitive Causal Model published in 2004. This model was presented earlier in this paper in figure 1 and served as a lens to generate understanding of the parent experience of trying to engage their child living with ASD in safe physical activities and recreation; as well as a means to compare that experience to parents raising a more TD child. It was interesting to find that the parent groups in this study did not differ significantly in their attitudes towards protection from injury or risk engagement, or in their feelings of self-efficacy surrounding their ability to balance the two. In spite of the parent groups having several similarities, parents raising children with an ASD diagnosis or with the presence of ASD symptoms differed in two key areas: the amount of barriers they experience when trying to support their children to engage in recreation and PA; and the large amount of children with ASD who were not participating in any organized activities. When these variations are applied Bandura's sociocognitive causal model (2004) they allude to impediments parents encounter as result of sociostructural factors. Bandura (2004) indicated that sociostructural factors can serve as facilitators or impediments to achieving a health goal; and these factors can occur at the personal / situational level or at the larger health systems level. Within this study, the similarities and differences between the parent groups indicate that families living with ASD face impediments to their children participating in safe PA and recreation that cannot be solely controlled by the parents. These impediments are likely related to health system barriers such as

a lack of inclusive programming, potentially due to a lack of community education and resources. Regardless of the source, it is reasonable to assume that these impediments make it more challenging for parents raising children with ASD to attain a goal of providing opportunities for safe PA for their children.

Although this was a unique way to apply Bandura's Sociocognitive Causal model (2004) it provided an interesting theoretical perspective to conceptualize the parent experience. It highlighted the need for consultation that engages families living with ASD, along with community recreation leaders to help identify possible interventions that could help to increase inclusive accessible programming and reduce barriers to participation so that parents can achieve the goal of safe physical activity and recreation participation for all children regardless of the presence of ASD symptoms.

6.2 Future Directions for Research

The findings listed above are important to acknowledge when considering directions for future research. Moving forward, it would be valuable to explore if similar participation discrepancies exist in small group organized physical activity. Specifically looking at activities that may also incorporate a developmental safety skill component such as the water safety knowledge and skills gained from swimming lessons; or the ability to explore physical safety limits in a parkour class that can be transferred to the local playground. In addition, it would be beneficial to explore if the PA of children with ASD should be measured at the same moderate to vigorous level as their TD peers as recommended by current guidelines (ParticipACTION, 2018). This level of exertion is one that often accompanies large group organized activities (i.e. sports teams), and may be counterintuitive to the way children with ASD engage in PA. Perhaps being physically active at a reduced intensity for a longer duration would be a more accurate

measure of physical health for this population. Further, additional exploration is required surrounding perceptions of injury prevention and risk, and resulting feelings of PSE in balancing the two. The HWREPS survey included in this analysis incorporated one specific measurement of this (HWREPS question #32) however it would be interesting to make a deeper dive into the phenomenon of an altered level of supervision by parents raising children with ASD (Cavalari and Romanczyk, 2012); and if parents raising children living with ASD are similar to other parents raising a child with disabilities and maintain stronger feelings protection for their child (Olsen et al., 2016; Ozhek, 2008).

6.3 Limitations

Although this analysis increases our knowledge about parent factors that impact participation in physical activity when raising a child with ASD, there were some limitation that should be considered. ASD presentation is very broad and symptoms can vary drastically in severity and presentation especially when they are impacted by co-occurring health, environment and psychosocial conditions. For these reasons it is very difficult to clearly define a ‘typical ASD presentation’. As result, the sample included in this study may be at risk for sampling bias, and may limit the generalizability of these results. Parents included in this sample were required to be raising a child with ASD of average IQ, in an effort to accurately compare them to their TD peers. However, this restriction may exclude parents raising children with ASD who have more profound intellectual and physical disabilities. In addition, the parents that participated in this study were already linked with sources of education and supportive resources (as this was the means for recruitment). Therefore, families living with ASD who may be not as well connected, and might not have had the opportunity to respond and be included in this sample. Finally, the Social Science Camp is held at SFU, in an urban center. Families living outside Burnaby, BC

who did not have the financial means or physical ability to travel to the camp, or families living in outlying rural communities may have been excluded and not represented.

Chapter 7.0: Conclusion

This research provided valuable insight into the factors that impact parents in their efforts to support their child's participation in safe physical activity and recreation. Prior to beginning this analysis we had understood that children with ASD were at risk for being drawn to sedentary behaviors, as well as decreased participation in physical activity. It was reassuring to find that the groups in this study did not differ significantly in their levels of sedentary behavior / screen time and physical activity. However both groups of children were equally exceeding the daily recommendations for sedentary behavior as reported by their parents. In addition, both groups of parents appeared to accept similar levels of risk engagement, and injury prevention for their children, as well as demonstrating similar feelings of PSE in their ability to balance this.

We were able to identify significant differences in the type of activity children with ASD were participating, with far fewer participating in organized team sports when compared to their TD peers. In addition, there was a significantly larger number of children with ASD who were reported to be participating in no organized activities when compared with their TD peers. These findings were supported by the ASD group also reporting having encountered a significantly higher number of barriers to their child participating in organized activities. Likely, these barriers cannot solely be addressed by parents alone, and require support and intervention from community organizations, recreation providers and government at the regional, provincial and federal levels to improve resources to support and develop more inclusive programming.

In future, it is imperative to engage families living with ASD, along with community recreation leaders and policy makers to identify possible interventions that can increase inclusive and accessible programming, and reduce barriers to participation as result of ASD symptoms. It

is imperative that all parents have access to appropriate programming and supports so they can achieve the goal of providing safe physical activity and recreation participation for their children regardless of the presence of ASD symptoms.

References

- Autism Canada. (2017 October, 31). We are all unique. *Autism Canada: See the Spectrum Differently*. Retrieved from <https://Autismcanada.org/about-Autism/characteristics/>
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders (DSM-5®)*. American Psychiatric Pub.
- Autism Society of America. (2017 December, 22). What is Autism? *The Autism Society*. Retrieved from <http://www.Autism-society.org/what-is/>
- Bandini, L. G., Gleason, J., Curtin, C., Lividini, K., Anderson, S. E., Cermak, S. A., et al. (2013). Comparison of physical activity between children with Autism spectrum disorders and typically developing children. *Autism, 17*(1), 44-54.
- Bandura, A. (1977). Self-efficacy: Toward a unifying theory of behavioral change. *Psychological Review, 84*(2), 191-215. <http://dx.doi.org/10.1037/0033-295X.84.2.191>
- Bandura, A. (2004). Health promotion by social cognitive means. *Health Educ Behav, 31*(2), 143-164. doi:10.1177/1090198104263660
- Baio J, Wiggins L, Christensen DL, et al. Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2014. *MMWR Surveill Summ 2018;67*(No. SS-6):1–23. DOI: <http://dx.doi.org/10.15585/mmwr.ss6706a1>.
- Baron-Cohen, S., Wheelwright, S., Skinner, R., Martin, J., & Clubley, E. (2001). The Autism-spectrum quotient (AQ): Evidence from Asperger Syndrome/High-functioning Autism, males and females, scientists and mathematicians. *Journal of Autism and Developmental Disorders, 31*(1), 5-17. doi:10.1023/A:1005653411471

- Batool, S. S., & Khurshid, S. (2015). Factors associated with stress among parents of children with Autism. *Journal of the College of Physicians and Surgeons--Pakistan: JCPSP*, 25(10), 752-756. doi:10.2015/JCPSP.752756
- Benson, P. R. (2016). The longitudinal effects of network characteristics on the mental health of mothers of children with ASD: The mediating role of parent cognitions. *Journal of Autism and Developmental Disorders*, 46(5), 1699-1715.
- Boddy, L. M., Downs, S. J., Knowles, Z. R., & Fairclough, S. J. (2015). Physical activity and play behaviours in children and young people with intellectual disabilities: A cross-sectional observational study. *School Psychology International*, 36(2), 154-171.
- Boddy, L. M., Downs, S. J., Knowles, Z. R., & Fairclough, S. J. (2015). 'Physical activity and play behaviours in children and young people with intellectual disabilities: A cross-sectional observational study': Erratum. *School Psychology International*, 36(3), 333-333. doi:10.1177/0143034315585262
- Bonander, C., Beckman, L., Janson, S., & Jernbro, C. (2016). Injury risks in schoolchildren with attention-deficit/hyperactivity or Autism spectrum disorder: Results from two school-based health surveys of 6- to 17-year-old children in Sweden. *Journal of Safety Research*, 58, 49-56. doi:10.1016/j.jsr.2016.06.004
- Bonis, S. A., & Sawin, K. J. (2016). Risks and protective factors for stress self-management in parents of children with Autism spectrum disorder: An integrated review of the literature. *Journal of Pediatric Nursing*, 31(6), 567-579. doi:10.1016/j.pedn.2016.08.006
- Boshoff, K., Gibbs, D., Phillips, R. L., Wiles, L., and Porter, L. (2016). Parents' voices: 'why and how we advocate'. A meta-synthesis of parents' experiences of advocating for their child

- with Autism spectrum disorder. *Child: Care, Health and Development*, 42, pp. 784–797.
doi: [10.1111/cch.12383](https://doi.org/10.1111/cch.12383).
- Branche, C., Hyder, A. A., Ozanne-Smith, J., Oyebite, K., Bartolomeos, K., & Rivara, F. (2008).
World report on child injury prevention. World Health Organization.
- Braunstein V. L., Peniston N., Perelman A., Cassano M. C. (2013). The inclusion of fathers in
investigations of autistic spectrum disorders. *Res. Autism Spectr. Disord.* 7:7
10.1016/j.rasd.2013.03.005
- Brussoni, M., & Olsen, L. (2011). Striking a balance between risk and protection: fathers'
attitudes and practices toward child injury prevention. *Journal of Developmental &
Behavioral Pediatrics*, 32(7), 491-498.
- Canadian Society for Exercise Physiology. (2016). *Canadian 24 hour movement guidelines for
children and youth (ages 5–17 years): An integration of physical activity, sedentary
behavior and sleep*. Canada: CSEP Retrieved July 14, 2018
<http://csepguidelines.ca/children-and-youth-5-17/>
- Cavalari, R. N., & Romanczyk, R. G. (2012). Caregiver perspectives on unintentional injury risk
in children with an Autism spectrum disorder. *Journal of Pediatric Nursing*, 27(6), pp.
632-641.
- Cavalari, R. N. S., & Romanczyk, R. G. (2012). Supervision of children with an Autism
spectrum disorder in the context of unintentional injury. *Research in Autism Spectrum
Disorders*, 6(2), 618–627. <https://doi.org/10.1016/j.rasd.2011.09.012>
- Centers for Disease Control and Prevention (CDC), Brener, N. D., Kann, L., Shanklin, S.,
Kinchen, S., Eaton, D. K., ... Centers for Disease Control and Prevention (CDC). (2013).
Methodology of the Youth Risk Behavior Surveillance System--2013. *MMWR*.

Recommendations and Reports : Morbidity and Mortality Weekly Report.

Recommendations and Reports, 62(RR-1), 1–20. <https://doi.org/rr6201a1> [pii]

- Chong, W. H., & Kua, S. M. (2017). Parenting self-efficacy beliefs in parents of children with Autism: Perspectives from Singapore. *The American Journal of Orthopsychiatry*, 87(3), 365-375. doi:10.1037/ort0000169
- Cohen, J. W. (1988). *Statistical power analysis for the behavioral sciences* (2nd ed, e-text). Hillsdale, NJ: Lawrence Erlbaum Associates. Retrieved from <https://www-taylorfrancis-com.ezproxy.library.ubc.ca/books/9780203771587> .
- DiGuseppi, C., Levy, S. E., Sabourin, K. R., Soke, G. N., Rosenberg, S., Lee, L., . . . Schieve, L. A. (2018). Injuries in children with Autism spectrum disorder: Study to explore early development (SEED). *Journal of Autism and Developmental Disorders*, 48(2), 461-472. doi:10.1007/s10803-017-3337-4
- Dreyer Gillette, M.,L., Borner, K. B., Nadler, C. B., Poppert, K. M., Odar Stough, C., Swinburne Romine, R., & Davis, A. M. (2015). Prevalence and health correlates of overweight and obesity in children with Autism spectrum disorder. *Journal of Developmental and Behavioral Pediatrics: JDBP*, 36(7), 489-496. doi:10.1097/DBP.0000000000000198
- Elder, J. H., Kreider, C. M., Brasher, S. N., & Ansell, M. (2017). Clinical impact of early diagnosis of Autism on the prognosis and parent-child relationships. *Psychology Research and Behavior Management*, 10, 283–292. <https://doi.org/10.2147/PRBM.S117499>
- Feehan, K., O'Neil, M.,E., Abdalla, D., Fragala-Pinkham, M., Kondrad, M., Berhane, Z., & Turchi, R. (2012). Factors influencing physical activity in children and youth with special

- health care needs: A pilot study. *International Journal of Pediatrics*, 2012, 583249-583249. doi:10.1155/2012/583249
- García-López, C., Sarriá, E., & Pozo, P. (2016). Parental self-efficacy and positive contributions regarding Autism spectrum condition: An actor-partner interdependence model. *Journal of Autism & Developmental Disorders*, 46(7), 2385-2398. doi:10.1007/s10803-016-2771-z
- Guan, J., & Li, G. (2017). Injury mortality in individuals with Autism. *American journal of public health*, 107(5), 791-793.
- Guan, J., & Li, G. (2017). Characteristics of unintentional drowning deaths in children with Autism spectrum disorder. *Injury Epidemiology*, 4(1). <https://doi.org/10.1186/s40621-017-0129-4>
- Healy, S., Haegele, J. A., Grenier, M., & Garcia, J. M. (2017). Physical activity, screen-time behavior, and obesity among 13-year olds in Ireland with and without Autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 47(1), 49-57. doi:10.1007/s10803-016-2920-4
- Hemenway, D., Aglipay, G. S., Helsing, K. L., & Raskob, G. E. (2006). Injury prevention and control research and training in accredited schools of public health: a CDC/ASPH assessment. *Public health reports (Washington, D.C. : 1974)*, 121(3), 349-51.
- Hoogsteen, L., & Woodgate, R. L. (2013). Embracing Autism in Canadian rural communities. *The Australian Journal of Rural Health*, 21(3), 178-182. doi:10.1111/ajr.12030
- Jain A., Spencer D., Yang W., Kelly J. P., Newschaffer C. J., et al. (2014). Injuries among children with Autism spectrum disorder. *Academy of Pediatrics*, 14, pp. 390–97

- Jelleyman, C., McPhee, J., Brussoni, M., Bundy, A., & Duncan, S. (2019). A Cross-Sectional Description of Parental Perceptions and Practices Related to Risky Play and Independent Mobility in Children : *The New Zealand State of Play Survey, 1–19*.
<https://doi.org/10.3390/ijerph16020262>
- Kalb, L. G., Vasa, R. A., Ballard, E. D., Woods, S., Goldstein, M., & Wilcox, H. C. (2016). Epidemiology of injury-related emergency department visits in the US among youth with Autism spectrum disorder. *Journal of Autism and developmental disorders, 46*(8), 2756-2763.
- Kuhn, J. C. and Carter, A. S. (2006), Maternal self-efficacy and associated parenting cognitions among mothers of children with Autism. *American Journal of Orthopsychiatry, 76*, pp. 564–575. doi:10.1037/0002-9432.76.4.564
- Lobenius-Palmér, K., Sjöqvist, B., Hurtig-Wennlöf, A., & Lundqvist, L. (2018). Accelerometer-assessed physical activity and sedentary time in youth with disabilities. *Adapted Physical Activity Quarterly, 35*(1), 1-19. doi:10.1123/apaq.2015-0065
- Luque Salas, B., Yáñez Rodríguez, V., Taberero Urbieto, C., & Cuadrado, E. (2017). The role of coping strategies and self-efficacy as predictors of life satisfaction in a sample of parents of children with Autism spectrum disorder. *Psicothema, 29*(1), 55-60.
doi:10.7334/psicothema2016.96
- McDermott, S., Zhou, L., & Mann, J. (2008). Injury treatment among children with Autism or pervasive developmental disorder. *Journal of Autism and developmental disorders, 38*(4), 626-633.
- May, C., Fletcher, R., Dempsey, I., & Newman, L. (2015). Modeling relations among co-parenting quality, Autism-specific parenting self-efficacy, and parenting stress in mothers

- and fathers of children with ASD. *Parenting: Science & Practice*, 15(2), 119-133.
doi:10.1080/15295192.2015.1020145
- Montes, G. (2016). Children with Autism spectrum disorder and screen time: Results from a Large, Nationally Representative US Study. *Academic Pediatrics*, 16(2), pp. 122-128.
<https://doi.org/10.1016/j.acap.2015.08.007>
- Must, A., Phillips, S. M., Curtin, C., Anderson, S. E., Maslin, M., Lividini, K., & Bandini, L. G. (2014). Comparison of sedentary behaviors between children with Autism spectrum disorders and typically developing children. *Autism: The International Journal of Research and Practice*, 18(4), 376-384. doi:10.1177/1362361313479039
- Must, A., Phillips, S., Curtin, C., & Bandini, L. G. (2015). Barriers to physical activity in children with Autism spectrum disorders: relationship to physical activity and screen time. *Journal of Physical Activity and Health*, 12(4), 529-534.
- Niehues, A. N., Bundy, A., Broom, A., & Tranter, P. (2016). Reframing healthy risk taking: parents' dilemmas and strategies to promote children's well-being. *Journal of Occupational Science*, 23(4), 449-463.
- Obrusnikova I., Miccinello D. L. (2012). Parent perceptions of factors influencing after-school physical activity of children with Autism spectrum disorders. *Adap Phys Act Qu.* 29(1), 63-80.
- Ozhek, S. R. (2008). Overprotection and adolescents with physical disabilities. *Journal of Special Education and Rehabilitation*, 9(1-2), 100-106.
- Olsen L. L., Ishikawa T., Mâsse LC, Chan, G. & Brussoni, M. (2017). Risk Engagement and Protection Survey (REPS): developing and validating a survey tool on fathers' attitudes

- towards child injury protection and risk engagement. *Injury Prevention*, Published Online First: 28 September 2017. doi: 10.1136/injuryprev-2017-042413
- Olsen, L. L., Kruse, S., Miller, A. R., & Brussoni, M. (2016). Safety-related concerns of parents for children with disabilities and chronic conditions. *Journal of Developmental and Behavioral Pediatrics*, 37(2), 121–131. <https://doi.org/10.1097/DBP.0000000000000256>
- Olsen, L., Lin, Y., Ishikawa, T., Chan, G., Masse, L., Brussoni, M. (2019). *Comparison of Risk Engagement and Protection Survey (REPS) among Mothers and Fathers of Children aged 6-12 Years*. Submitted to *Injury Prevention* (April 2019)
- Pallant, J. (2016). *SPSS Survival Manual (6th ed)*. England: Open University Press.
- Peat, J. (2001). *Health science research: A handbook of quantitative methods*. Sydney: Allen & Unwin.
- ParticipACTION. The Brain + Body Equation: Canadian kids need active bodies to build their best brains. (2018). *The 2018 participACTION report card on physical activity for children and youth*. Toronto:ParticipACTION. Retrieved on July 11, 2018 from: <https://www.participaction.com/en-ca/thought-leadership/report-card/2018>
- Public Health Agency of Canada. (2018). *Autism spectrum disorder among children and youth in Canada 2018: A report of the national Autism spectrum disorder surveillance system*. Retrieved from the Public Health Agency of Canada website: <https://www.canada.ca/en/public-health/services/publications/diseases-conditions/Autism-spectrum-disorder-children-youth-canada-2018.html>
- Risk. (2018). English Oxford Living Dictionaries *online*. Retrieved from <https://en.oxforddictionaries.com/>

- Russo, N., Flanagan, T., Iarocci, G., Berringer, D., David, P., & Burack, J. A. (2007). Deconstructing executive deficits among persons with Autism : Implications for cognitive neuroscience, *65*, 77–86. <https://doi.org/10.1016/j.bandc.2006.04.007>
- Safety. (2018). English Oxford Living Dictionaries *online*. Retrieved from <https://en.oxforddictionaries.com/>
- Shields, N., & Synnot, A. (2016). Perceived barriers and facilitators to participation in physical activity for children with disability: A qualitative study. *BMC Pediatrics*, *16*(1), 1–10. <https://doi.org/10.1186/s12887-016-0544-7>
- Tavakol, M., & Dennick, R. (2011). Making sense of Cronbach's alpha. *International journal of medical education*, *29*(53). <https://doi.org/10.5116/ijme.4dfb.8dfd>
- U.S. Centers for Disease Control and Prevention: Youth Risk Behavior Surveillance System (YRBSS). 2012. Available at: www.cdc.gov/HealthyYouth/yrbs/
- Weiss, J. A., Tint, A., Paquette-Smith, M., & Lunsky, Y. (2016). Perceived self-efficacy in parents of adolescents and adults with Autism spectrum disorder. *Autism*, *20*(4), 425-434. doi:10.1177/1362361315586292
- Wechsler, D. (1999). The Wechsler abbreviated scale of intelligence. San Antonio, TX: The Psychological Corporation

Appendices

Appendix A

Health & Wellness and Risk Engagement & Protection Survey – Camp 2017

Child's Name: _____ Parent's Name: _____ Date: _____

Instructions: Please read the questions carefully and indicate on the scale the amount of time your child engages in the described behavior.

Questions 1-3 and 6-8 refer to your child's TV or computer use that is for **NON-THERAPEUTIC PURPOSES**.

1. On an <u>average school day</u> , how many hours did your child watch TV?	None	Less than 1 hour	1 hour	2 hours	3 hours	4 hours	5 hours or more
2. On an <u>average school day</u> , how many hours did your child play video or computer games (count time spent on things like Xbox, PlayStation, Wii) or use a computer (e.g. YouTube, Facebook, watching TV shows or movies) for something that was <u>not</u> school work?	None	Less than 1 hour	1 hour	2 hours	3 hours	4 hours	5 hours or more
3. On an <u>average school day</u> , how many hours did your child spend on a smartphone or tablet (e.g. texting, YouTube, Instagram, Facebook, Snapchat, or other social media) that was <u>not</u> school work?	None	Less than 1 hour	1 hour	2 hours	3 hours	4 hours	5 hours or more
4. On an <u>average school day</u> , how much time did your child spend outside before school?	None	Less than 1 hour	1 hour	2 hours	3 hours	4 hours	5 hours or more
5. On an <u>average school day</u> , how much time did your child spend outside after school?	None	Less than 1 hour	1 hour	2 hours	3 hours	4 hours	5 hours or more
6. On an <u>average weekend day</u> , how many hours did your child watch TV?	None	Less than 1 hour	1 hour	2 hours	3 hours	4 hours	5 hours or more
7. On an <u>average weekend day</u> , how many hours did your child play video or computer games (count time spent on things like Xbox, PlayStation, Wii) or use a computer (e.g. YouTube, Facebook, watching TV shows or movies) for something that was <u>not</u> school work?	None	Less than 1 hour	1 hour	2 hours	3 hours	4 hours	5 hours or more

Health & Wellness and Risk Engagement & Protection Survey – Camp 2017

<p>8. On an <u>average weekend day</u>, how many hours did your child spend on a smartphone or tablet (e.g. texting, YouTube, Instagram, Facebook, Snapchat, or other social media) that was not school work?</p>	None	Less than 1 hour	1 hour	2 hours	3 hours	4 hours	5 hours or more
<p>9. During the <u>past year</u> (12 months), did your child do any of these activities?</p>	Sports teams	Dance/ martial arts classes	Art/ Music classes	None of these			
<p>10. During the <u>past week</u>, what time has your child usually turned out the light and gone to sleep on school days?</p>	Time: _____ AM/PM (<i>circle AM or PM</i>)						
<p>11. During the <u>past week</u>, what time has your child usually woken up in the morning on school days?</p>	Time: _____ AM/PM (<i>circle AM or PM</i>)						
<p>12. During the <u>past week</u>, what time has your child usually turned out the lights and gone to sleep on <u>weekend days</u>?</p>	Time: _____ AM/PM (<i>circle AM or PM</i>)						
<p>13. During the <u>past week</u>, what time has your child usually woken up in the morning on <u>weekend days</u>?</p>	Time: _____ AM/PM (<i>circle AM or PM</i>)						
<p>14. During the <u>past week</u>, how would you rate your child's sleep quality overall (how well your child sleeps)?</p>	Very good	Fairly good	Fairly bad	Very bad			
<p>15. During the <u>past week</u>, how would you rate your child's sleep quantity overall (how much your child sleeps)?</p>	Very good	Fairly good	Fairly bad	Very bad			
<p>16. Do you have a television in your child's bedroom?</p>	YES / NO (<i>circle one</i>)						

Health & Wellness and Risk Engagement & Protection Survey – Camp 2017

17. Please put a mark in one box that best describes how often your child eats the described food items while watching television or playing on a tablet/phone or computer.

Food Item	Never	Less than once a week	Once a week	2-4 days a week	5-6 days a week	Once a day, every day	Every day, more than once
Potato chips or peanuts							
Fried food such as chicken wings, chicken fingers, french fries etc.							
Cookies, chocolate or candy bars							
Ice cream							
Fast food such as pizza, hamburgers etc.							
Fruit or vegetables							

The following are statements about protecting your child from injuries. Using the scale below, please rate how much you agree with the following statements:		1	2	3	4	5	6	7
		Very strongly disagree			Neither agree nor disagree			Very strongly agree
18.	I am concerned about the things I cannot control that can physically injure my child.	1	2	3	4	5	6	7
19.	Fewer injuries happen to children when parents plan ways to prevent them.	1	2	3	4	5	6	7
20.	I am concerned about the potential hazards in my home.	1	2	3	4	5	6	7
21.	Children should play in places where there is low risk of injury.	1	2	3	4	5	6	7
22.	Good supervision of my child means knowing what my child is doing at all times.	1	2	3	4	5	6	7
23.	Letting my child engage in physical activities without supervision greatly increases their chance of injury.	1	2	3	4	5	6	7

Health & Wellness and Risk Engagement & Protection Survey – Camp 2017

The following are protective actions you can take when your child engages in physical activity. Please rate how often you do each one:		1	2	3	4	5	6	7
		Never			Some of the time			All the time
24.	Encouraging physical activity with the least risk of injury.	1	2	3	4	5	6	7
25.	Limiting the types of activities my child is allowed to do.	1	2	3	4	5	6	7
The following questions are about your thoughts on your child's engagement in physically challenging activities, and the risk of injury for your child. Please rate how much you agree with the following statements:		1	2	3	4	5	6	7
		Very strongly disagree			Neither agree nor disagree			Very strongly agree
26.	It is important for my child to engage in physically challenging experiences.	1	2	3	4	5	6	7
27.	I like to let my child find his or her own physical limits.	1	2	3	4	5	6	7
28.	I value opportunities for my child to explore new environments.	1	2	3	4	5	6	7
29.	Benefits of physical activity for my child outweigh the risk of experiencing minor injuries.	1	2	3	4	5	6	7
30.	I prefer to teach my child how to manage risky situations rather than avoid them.	1	2	3	4	5	6	7
31.	Participating in challenging and potentially risky physical activities will help my child develop self-confidence.	1	2	3	4	5	6	7
Please use the following scale to answer question 32:		1	2	3	4	5	6	7
		Not at all confident			Moderately confident			Completely confident
32.	How confident are you that you can help your child be physically active while keeping them safe from injury?	1	2	3	4	5	6	7

Barriers to Activity:

33.	To what extent do the following make it difficult for you to help your child engage in physical activity and sports?	1	2	3	4	5	6	7
		Very strongly disagree			Neither agree nor disagree			Very strongly agree
	a. My child dislikes team sports	1	2	3	4	5	6	7
	b. My child dislikes individual physical activities	1	2	3	4	5	6	7
	c. My child has difficulties with coordination or motor skills	1	2	3	4	5	6	7
	d. My child has behaviours that make participation difficult	1	2	3	4	5	6	7
	e. Other Barriers to Activity (please write any barriers that you know of): _____							

Injury History:

34.	Has your child had any injuries in the <u>past 12 months</u> that required medical attention by a doctor, nurse or dentist?	YES / NO / DO NOT RECALL (<i>circle one</i>) If yes, how many injuries? _____
35.	Has your child had any minor injuries in the <u>past 12 months</u> ? (<i>Minor injury = injuries that result in observable tissue damage that lasted for at least 30 minutes but did not require medical attention</i>)	YES / NO / DO NOT RECALL (<i>circle one</i>) If yes, how many injuries? _____

Appendix B

Camp 2017 – Family Demographics

Social Science Camp 2017 - Family Demographics Questionnaire

Date (month, day, year): _____

Name of person completing this form (first, last): _____

Relationship to child: _____

Name of **child** in study (first, last): _____

Birth date of child (month, day year): _____

Gender of child: Male Female Transgender

Please list both and check which form of contact is most preferred

Telephone: _____ Email: _____

Please select handedness of your child: Left Right

Does he/she wear glasses? Yes No

Is he/she colour blind? Yes No

What is your child's cultural or ethnic background? (E.g., Italian, Métis, Cantonese, English, Canadian): _____

Child's parents are: Single Married Common Law Divorced Separated

With whom does the child live? (please list ALL members of the household, and include all siblings even if they do not live with the family anymore)

Name	Age	Date of Birth	Relationship (e.g., mother, brother, aunt)

Camp 2017 – Family Demographics

Approximate gross family income:

- Less than \$20,000 \$20-49,999 \$50-79,999
 80-109,999 \$110- 139,999 Greater than \$140,000

What is the highest level of education for the child's primary caregivers? (please select ONE answer for each caregiver):

Caregiver 1 (e.g., mother)

- Elementary School
 High School
 Professional Diploma (technical programs such as plumbing, hair dressing, etc.)
 Bachelor's Degree
 Master's Degree or higher
 Other: Please specify: _____

Caregiver 2 (e.g., father, 2nd mother)

- Elementary School
 High School
 Professional Diploma (technical programs such as plumbing, hair dressing, etc.)
 Bachelor's Degree
 Master's Degree or higher
 Other: Please specify: _____

Educational Information

- Is your child: Home schooled
 Attends Public School
 Other: Please Specify: _____

What grade will you child enter in September? _____

Diagnostic & Medical Information

Please check one or more of the following:

- Autism Spectrum Disorders (e.g., Autism, Asperger's Syndrome, PDD-NOS (Pervasive Developmental Disorder- Not Otherwise Specified)
 Other (Please state all e.g., Intellectual Disability; ADHD, anxiety disorder, depression, learning difficulties, sleeping disorder) _____
 No Diagnosis

Has your child had a:

- Brain Injury
 Brain surgery: if yes, please state date and reason: _____
 Metal implant

*** If your child has any diagnosis(es), please describe answer a, b, c:**

a) Where was your child diagnosed: _____

b) Professional who diagnosed your child? _____

c) When was your child diagnosed (year and age)? _____

What kind of professional diagnosed your child?:

- Pediatrician Family Doctor Psychologist Psychiatrist
 Diagnosis received through the British Columbia Autism Assessment Network (BCAAN)

List all current professional services received: _____

Which agency provides your family with funding for services?

- BC Ministry of Children and Family Development (Autism Funding Program)
 Community Living BC None Other

If 'Other,' please specify: _____

Does your child have any other medical conditions? (E.g. seizures, Tourette's syndrome, etc.): Yes No

If Yes, what are they?: _____

Does your child take any prescription medications regularly? Yes No

If Yes, please list: _____

Do any other family members experience significant medical or emotional problems, in particular, Autism Spectrum Disorder? Yes No

If Yes, please explain:

Language

Primary language spoken at home (First language): _____

Other language(s) spoken (Second Language): _____

***If more than one language is spoken, please answer a, b, c:**

a) How old was your child when he/ she started hearing two or more languages on a regular basis? _____

b) How often is your child exposed to their second language? Daily Weekly Monthly

c) Please list the approximate number of hours per week your child:*Children are usually at school 35 hours per week

- Listen to conversations in the first language (e.g., watching or overhearing people speaking, being read stories): _____ hours per week
- Listen to the first language (e.g., television, music, radio, internet): _____ hours per week
- Listen to conversations in the second language (e.g., watching or overhearing people speaking, being read stories): _____ hours per week
- Listen to the second language (e.g., television, music, radio, internet): _____ hours per week

In general, is there any other information we should know about your child?

Thank you very much for completing this form!