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**AN IN-DEPTH ANALYSIS OF THE HEALTH AND WELLBEING OF INDIVIDUALS  
WITH AUTISM SPECTRUM DISORDER**

by

Brianne Karen Redquest

Bachelor of Arts, Brock University, 2012

Master of Science, Wilfrid Laurier, 2014

DISSERTATION

Submitted to the Department of Kinesiology

In partial fulfillment of the requirement for

Doctor of Philosophy in Kinesiology

Wilfrid Laurier University

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### **Abstract**

Over five studies, this thesis aimed to investigate the overall health and wellbeing of individuals with autism spectrum disorder (ASD). The primary objectives were to: (a) explore the areas of concern among individuals with ASD across the spectrum; (b) understand the differences pertaining to the overall health, social and motor functioning between high functioning and low functioning individuals; (c) understand the sex differences pertaining to the overall health, social, and motor functioning among high and low functioning individuals with ASD; (d) gain in-depth detail regarding the social and motor functioning of children and youth with ASD through the perspectives of caregivers; and (e) examine the association between imitation, social, and motor performance in individuals with ASD. Findings showed that individuals with ASD experience many issues, namely, health, social, and motor issues. These issues vary depending on the level of functioning of individuals, but not the sex of the individuals. Findings further indicated a reciprocal relationship between social and motor functioning, as well as, imitation and motor performance. In addition to providing further insight into the challenges individuals with ASD experience, this thesis offers many well-informed credible suggestions that warrant the attention of health care professionals, caregivers, family members, the school system, and researchers.

### Acknowledgments

I am thankful for the events and experiences that led me to pursue a PhD. As much as this degree was about expanding my academic knowledge, it was also a journey of self-discovery. I developed a confidence in myself that I didn't know was lacking. For that, I am very grateful.

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To my friends, the constant support you have all provided me has never gone unnoticed. your willingness to learn more about disabilities speaks to the devotion you all have towards our friendship- thank you guys so much. Mom, Dad, Elyse- we did it! You were all there at the beginning of the race telling me to pursue my dreams, during the times I was losing my momentum, you told me that I could do it and not to give up, you all waited for me at the finish line to tell me how proud you were. To say that I am appreciative of the positivity, reassurance, and constant encouragement you all have provided me, would be an understatement. I truly could not have done this without you Mom, Dad, and Elyse. Thank you and I love you.

I express my greatest gratitude to my participants, without them this wouldn't be possible. Thank you for letting me into your world and for showing me your vulnerability. In return, I promise to try my best to improve the lives of people with disabilities.

*Dad and Mom- I finished the race!*

**List of Abbreviations**

***ADD:*** Attention deficit disorder

***ADHD:*** Attention deficit hyperactivity disorder

***ANOVA:*** Analysis of variance

***APA:*** American Psychiatric Association

***ASD:*** Autism spectrum disorder

***CDC:*** The Centers for Disease Control and Prevention

***ChYMH-DD:*** Child and Youth Mental Health – Developmental Disabilities

***ChYMH:*** Child & Youth Mental Health

***HF:*** High functioning

***LF:*** Low functioning

***WHO:*** World Health Organization

### Definitions

***Asperger's:*** Significant impairment in social interaction and no impairment in language and cognitive development, suggesting these individuals would be considered as high functioning (American Psychiatric Association [APA], 2000).

***Autism Spectrum Disorder:*** Characterised by deficits in social, communication, and language domains. Deficits within motor functioning, ability to imitate, and intellectual ability may also be evident conversation (APA, 2013).

***ChYMH-DD and ChYMH:*** Comprehensive, multidisciplinary mental-health assessment systems for children and youth from 4 to 18 years of age who are referred to either community-based (outpatient) or residential (inpatient) developmental services (Stewart et al., 2015a; Stewart et al., 2015b).

***Developmental Disability:*** A cognitive impairment that occurs before birth or up to the age of 18 years and lasts throughout one's life span (Developmental Services Ontario, 2016).

***Health Profile:*** Outlines a variety of determinants of health ranging from an individual's physical and mental wellbeing in addition to their social and motor functioning (Kuhlthau et al., 2010). The profile indicates level of concern among these determinants.

***Motor Functioning:*** The ability to perform movements through the use of motor neurons (Nugent, 2013).

***Overall Health:*** An individual's psychosocial, emotional, and physical wellbeing (Kuhlthau et al., 2010).

***Social Functioning:*** An individual's ability to interact with others and appropriately guide social behaviour within the context of social norms (Adolphs, 2001).

***Spectrum:*** Provides an indication of an individual's level of impairments, skills, and symptoms conversation (APA, 2013).

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## **Chapter 1- Introduction**

### **1.1. Thesis Overview**

Chapter 1 outlines a comprehensive literature review of two sections, both of which concern autism spectrum disorder (ASD). Section one reviews literature pertaining to the overall health, social, and motor functioning of individuals with ASD. The second area reviews literature concerning the imitation deficit exhibited by individuals with ASD. It further explores how this deficit may be associated with the social and motor impairments also exhibited by individuals with ASD. Chapter 2 explores the multiple domains affected by ASD in low and high functioning populations. Chapters 3 and 4 describe how overall health, social, and motor functioning differ depending on the level of functioning and the sex of the individuals. Chapter 5 provides in-depth detail concerning the motor and social functioning of individuals with ASD through the perspective of caregivers. Chapter 6 investigates the nature of social and motor impairments in individuals with ASD by examining the association between imitation, social, and motor performance. Finally, Chapter 7 concludes the thesis with a general discussion of main findings and well-informed suggestions for health care professionals, caregivers of children with ASD, family members, the school system, and researchers.

### **1.2. Literature Review**

**1.2.1. Disabilities.** According to Statistics Canada (2013), 174 810 (4.6%) children between the ages of 5 to 14 years have an identified disability. Statistics Canada (2013) contends that for individuals to be considered disabled they must have a physical or mental health condition that interferes with their ability to engage in activities of daily living. Research shows that individuals with disabilities have a poor quality of life, particularly pertaining to the following domains: physical, social, emotional, and material wellbeing (Chen & Cisler, 2011;

Domellof, Hedlund, & Odman 2014; Lau, Chow, & Lo, 2006). Furthermore, persons with disabilities are more likely to use tobacco, be overweight, experience symptoms of psychological distress, and less likely to engage in fitness activities compared to those without disabilities [The Centers for Disease Control and Prevention (CDC, 2010)].

**1.2.1.1. Developmental disability.** A developmental disability is defined as a cognitive impairment that occurs before birth or up to the age of 18 years, and lasts throughout one's life span (Developmental Services Ontario, 2016; Ontario Ministry of Children and Youth Services, 2016). Developmental disability is an umbrella term that includes disorders such as autism spectrum disorder (ASD) (World Health Organization [WHO], 2016). Such disabilities can prevent an individual from being fully independent and therefore individuals may require assistance with daily life. Common characteristics of developmental disabilities include: difficulty learning, social and language deficits, and difficulty understanding others (Developmental Services Ontario, 2016).

According to Statistics Canada (2015b), the most prevalent age group with developmental disabilities is 15 to 24 years of age, in which 160,500 individuals were identified as having a developmental disability. Unfortunately, there were no available statistics for Canadian children 15 years and younger. However, Canadian statistics from the Participation and Activity Limitation Survey noted that 17,090 children aged 0 to 4 years and 53,740 children aged 5 to 14 years had a developmental disability (ParticipACTION, 2006).

Although a developmental disability can be diagnosed up to the age of 18 years, it is most common that developmental disabilities begin before the child is born (CDC, 2010). The cause of a developmental disability may be a complex mix of factors including: genetic factors, parental behaviours during pregnancy (e.g., smoking and drinking alcohol), exposure to high

levels of environmental toxins, infection during pregnancy, premature birth, and untreated newborn jaundice. If the individual is diagnosed post birth the cause is typically injury (e.g., traumatic brain injury) or infection (e.g., bacterial meningitis, measles) (CDC, 2010; Knobler, O'Connor, Lemon, & Najafi, 2004)

Individuals with developmental disabilities are considered a vulnerable population for many reasons. First, developmental disabilities are often diagnosed in conjunction with other disabilities. Statistics Canada (2015a) stated that 9 of 10 individuals that are diagnosed with a developmental disability also have at least one other type of disability. For instance, ASD is often associated with comorbid conditions such as epilepsy, depression, anxiety, and attention-deficit hyperactivity disorder (WHO, 2016). Further, Centers for Disease Control and Prevention (2015) reported that health conditions such as asthma, gastrointestinal symptoms, and migraines are more commonly diagnosed in those with developmental disabilities. Second, adults with developmental disabilities were four times more likely to have not completed high school compared to those without any disabilities (53.6% versus 13.1%). Statistics Canada (2015b) also reported that the employment rate of adults (aged 15 to 64 years) with a developmental disability is only 22.3%, which is well below that of individuals without a disability (73.6%), confirming that individuals with developmental disabilities have the lowest employment rate of any disability type. Given that low education and income are linked with poor health and higher levels of stress, it is concerning that individuals with developmental disabilities have an increased high school dropout rate and lower employment rates (WHO, 2016b). Individuals with disabilities are also more likely to engage in risky health behaviours such as smoking, substance and drug abuse, physical inactivity, and poor diet (WHO, 2016b). For instance, it has been reported that individuals with developmental disabilities are more likely to abuse drugs and

alcohol because it serves as an "avenue to self-esteem" and can fulfill their desire to fit-in (Harris, 2005). Individuals with developmental disabilities may lack the education regarding the harmful effects of such abuse. Often parents, teachers, and doctors feel the need to "shield" them or are unwilling to believe that such issues occur among individuals with developmental disabilities (Harris, 2005). Lastly, this population experiences significant barriers in accessing health care such as the cost of health care services and transportation (WHO, 2016b).

It is evident that individuals with developmental disabilities experience a wide array of challenges across their lifespan, thus, strategies that will minimize these issues are warranted. Developmental disability is an umbrella term that encompasses various disabilities and as such may be associated with different deficits and therefore, different challenges. To effectively implement strategies to assist individuals with developmental disabilities, individual developmental disorders must be assessed. Therefore, the first section of the current dissertation will focus on the examination of the overall health, social functioning, and motor functioning of individuals with ASD (Studies #1, #2, #3, and #4). It is crucial that we understand factors that influence the social and motor deficits among individuals with ASD to effectively address and minimize these deficits. A possible factor influencing these deficits may be the inability for individuals with ASD to imitate. Research has confirmed the following: (1) individuals with ASD do indeed exhibit an imitation deficit and (2) imitation is associated with a child's ability to learn social and motor skills. As such, Study #5 will examine imitation, social, and motor deficits among individuals with ASD.

### **1.2.2. Profiling individuals with high functioning and low functioning ASD.**

According to the World Health Organization (WHO, 2016a) it is estimated that 1 in 160 children have autism spectrum disorder (ASD) worldwide. In Canada, 1 in 66 children are



diagnosed with ASD (Autism Ontario, 2018). ASD is more prevalent in males, with a male to female ratio of 4:1. Those diagnosed with ASD typically experience detriments in social, communication, and language domains. For example, individuals with ASD may misread nonverbal interactions and respond inappropriately in conversation (American Psychiatric Association [APA], 2013). A diagnosis of ASD places individuals on a spectrum, which indicates the level of their impairments, skills, and symptoms. One individual may be categorized as having "low functioning ASD", indicating severe impairments such as being non-verbal or being dependent with toileting, while another individual may be considered as having "high functioning ASD" and have minimal impairments (APA, 2013). Individuals with ASD may be more vulnerable to developing chronic non-communicable conditions such as diabetes and cardiovascular diseases because of behavioural risk factors, such as physical inactivity. Physical inactivity is even more common among individuals with ASD compared to their typically developing counterparts due to barriers such as inaccessibility, lack of available programming, and programs being too costly (Must, Phillips, Carol & Bandini, 2016). Additionally, individuals with ASD are at greater risk of violence, injury, and abuse due to their vulnerability (WHO, 2016a).

Prior to May 2013, the DSM-IV described five separate developmental disorders that were considered as autism spectrum disorders, including: Rett syndrome, autism, Asperger's, childhood disintegrative disorder, and pervasive developmental disorder, not otherwise specified (PDD-NOS) (APA, 2000). Currently, the specific diagnostic labels of Asperger's, autism and PDD-NOS have been replaced by the umbrella term "autism spectrum disorder." Many of the studies that will be discussed within this document were conducted prior to the DSM-V (2013) re-categorizing ASD and thus terms such as "autism" or "Asperger's" were used. As defined by

the DSM IV, Asperger's was characterized as significant impairment in social interaction and no impairment in language and cognitive development, suggesting these individuals would be considered as high functioning (APA, 2000). The terms used by the original authors will remain consistent when discussing their research.

**1.2.2.1. Overall health.** To explore specific challenges experienced by those with ASD, the overall health of these individuals will be reviewed first. In determining one's overall health, researchers will often assess an individual's psychosocial, emotional, and physical wellbeing (Kuhlthau et al., 2010). Researchers have found that children with ASD have lower wellbeing compared to typically developing children (Gurney, McPheeter, & Davis, 2006; Kuhlthau et al., 2010; Potvin, Snider, Prelock, Wood-Dauphinee, & Kehayia, 2015). Factors that contribute to compromised wellbeing include: multiple negative conditions (anxiety, attention deficit disorder, depression, behavioural issues), lower adaptive functioning (e.g., more social impairments, repetitive behaviours, etc.), and severity of symptoms (Gurney et al., 2006; Kuhlthau et al., 2010; Potvin et al., 2015). Gurney et al. (2006) also found that parents of children with autism were more likely to report their children's health as fair or poor, compared to parents of typically developing children. Children with autism were far more likely to use medication, receive physical, occupational and speech therapy, and to need treatment or counselling for emotional, developmental, or behavioural issues (Gurney et al., 2006).

Although those diagnosed with ASD may be affected by the same health issues as the general population, they have specific health care needs related to their comorbid conditions in addition to their ASD health care needs. ASD is often associated with comorbid conditions, such as epilepsy, depression, anxiety, and attention deficit hyperactivity disorder (ADHD) (WHO, 2016a). With regards to depression, Ghaziuddin, Ghaziuddin, and Greden (2005) contended that

it is the most common psychiatric disorder diagnosed in individuals with autism. Similarly, Dubin, Lieberman-Betz, and, Lease (2015) stated that individuals with ASD are more likely to be diagnosed with anxiety, compared to individuals without ASD. Factors that are associated with increased anxiety in individuals with ASD include decreased cognitive functioning, parent-rated social problems, sleep issues, and increased age (Ratcliffe, Won, Dossetor, & Hayes, 2015).

In addition to the above challenges, researchers have also confirmed that children with ASD suffer from sleep disorders (Delahaye et al., 2013; Herrmann, 2016; Hirata et al., 2015). Some of the specific sleep issues reported for children with ASD are: obstructive sleep apnea, parasomnias (e.g., night terrors or sleep talking), insomnia/circadian rhythm disorder, daytime excessive sleepiness, and reduced sleep duration (Hirata et al., 2015). Herrmann (2016) reported that risk factors for sleep disorders among children with ASD included autism severity, age, gender, comorbid behavioural problems, lower IQ, gastrointestinal disturbance, and abnormal melatonin levels. Further, poor sleep in children with ASD has been linked to a number of issues such as behavioural problems (e.g., aggression), difficulties with socialization, generalized anxiety disorder, depression, as well as self-injurious behaviours (Delahaye et al., 2013; Herrmann, 2016; Hirata et al., 2015). Not only do sleep problems affect children with ASD, but they can also affect the family. For example, mothers who have reported that their children with ASD have sleep issues have also reported that they also experience sleep issues (Herrmann, 2015).

**1.2.2.2. Social functioning.** Social functioning is defined as an individual's ability to interact with others and appropriately guide social behaviour within the context of social norms (Adolphs, 2001; Bosc, 2000). Deficits in socialization, such as difficulty with eye contact, speech

abnormalities, and failure to initiate interpersonal interactions, are considered a core component of ASD (Fodstad, Matson, Hess, & Neal, 2009; Tureck & Matson, 2012). Further social deficits that are observed in children with ASD may include: increased interaction with adults opposed to peers, minimal verbal and non-verbal interaction with peers, less mature play, and little engagement in socially complex play (Anderson, Moore, Godfrey, & Fletcher-Flinn, 2004). Such deficits can be identified at very early ages (17 to 37 months) (Fodstad et al., 2009). It has been proposed that social deficits may be due to children's inability to imitate (for more detail re: imitation deficit, refer to section 1.2.3.), and as a result this can hinder their ability to develop the appropriate communication skills needed for social interaction and friendship development (Matson & Wilkins, 2009).

To further understand social impairments, researchers have explored factors that influence these impairments. For instance, Turek and Matson (2012) investigated how intellectual functioning affects the development of the social skills of children with ASD versus children without ASD. They found that children with ASD exhibited more hostile and inappropriate social skills than children without ASD. Further, IQ scores were associated with social skills. Children with ASD who had a higher IQ displayed better social skills than those who had a lower IQ. Furthermore, Ratcliffe and colleagues (2015) found that poor social skills in children with ASD (e.g., poor communication and lack of empathy) and social responsiveness difficulties (e.g., trouble with social awareness and social information processing) were associated with mental health difficulties such as conduct problems and hyperactivity. In fact, underdeveloped social skills explained 49.7% (as reported by parents) and 54.5% (as reported by teachers) of the variance in overall mental health difficulties in children with ASD (Ratcliffe et al., 2015).

Another social challenge children with ASD experience is bullying. Current research suggests that children diagnosed with ASD experience higher rates of bullying compared to neurotypical individuals (Cappadoccia, Weiss, & Pepler, 2011; Kloosterman, Kelley, Craig, Parker, & Javier, 2012; Zeedyk, Rodriguez, Tipton, Baker, & Blacher, 2014). Social (being left out on purpose, lied to), physical (being kicked, hit, punched, locked indoors, etc.), and verbal (teasing, name calling, threats etc.) bullying are the most common forms reported (Cappadoccia et al., 2011; Kloosterman et al., 2012; Zeedyk et al., 2014). Contributing factors for being bullied noted within the literature include features of ASD (communication impairments, social interaction, motor impairments), being male, having higher levels of behaviour problems, younger age, mental health problems, and parental mental health problems (Cappadoccia et al., 2011; Kloosterman et al., 2012; Zeedyk et al., 2014). Further, children with ASD who have experienced bullying also reported having fewer friends, having more emotional disorders (e.g., depression and anxiety), having reduced social skills and were more likely to engage in self-injurious behaviours (Cappadoccia et al., 2011; Kloosterman et al., 2012; Zeedyk et al., 2014).

**1.2.2.3. Motor functioning.** Motor functioning is defined as the ability to perform movements through the use of motor neurons (Nugent, 2013). Motor impairments exhibited by individuals with ASD have been categorized as “associated symptoms” (Ming et al., 2007, p. 566). Ming et al. (2007) found that the most prevalent motor impairments in children with ASD were hypotonia (low muscle tone), followed by motor apraxia (difficulty with motor movements caused by a neurological condition), toe-walking, delayed gross motor milestone and lastly, reduced ankle mobility. Further, Kopp, Beckung, and Gillberg (2009) found that females (aged 7 to 16 years) with autism had greater gross motor impairments (e.g., difficulty with postural stability, walking on toes and heels) and a trend towards increased fine motor impairments (e.g.,

difficulty with buttoning 5 buttons, tying a bow) abilities compared to a group of females with attention deficit hyperactivity disorder (ADHD). These greater motor impairments were associated with sensation issues (i.e., difficulty with deep and superficial sensation), a lower IQ, autism severity, and younger age. Finally, Kopp et al. (2009) concluded that poor motor ability was related to a lower ability to engage and complete daily living skills.

**1.2.2.4. Summary of the overall health, social, and motor functioning in individuals with ASD.** It is evident that individuals diagnosed with ASD experience a wide array of challenges. However, research has highlighted the vastly different challenges experienced by those on opposite ends of the spectrum. For instance, those with a lower IQ and/or more severe ASD report having reduced wellbeing (Gurney et al., 2006; Kuhlthau et al., 2010; Potvin et al., 2015), higher levels of anxiety (Ratcliffe et al., 2015), are at a higher risk for sleep disorders (Herrmann, 2016), are bullied more often (Cappadoccia et al., 2011; Kloosterman et al., 2012; Zeedyk et al., 2014), have reduced social skills (Turek & Matson, 2012), and have greater motor impairments (Kopp et al., 2009), when compared to individuals with ASD who report a higher IQ and less severe ASD. This emphasizes the importance of examining individuals with low functioning ASD separately from those with high functioning ASD. As such, therapies can be developed as spectrum-specific rather than diagnosis-specific. By doing so, therapies will be made more effective for individuals with ASD.

**1.2.2.5. Assessment of developmental disabilities.** Individuals with developmental disabilities, specifically ASD, experience several challenges. It is evident that many of these issues occur concurrently. For example, individuals with ASD experience emotional issues, such as anxiety and depression, which tend to be the result of other issues (e.g., social impairments, bullying, and/or sleep disorders) (see, for example, Cappadoccia et al., 2011; Ghaziuddin et al.,

2005; Kloosterman et al., 2012; Ratcliffe, et al., 2015; Zeedyk et al., 2014). Despite this evidence, oftentimes researchers use multiple measurements to assess only one particular issue (refer to Appendix 1a to see the extensive list of assessments used within each of the studies discussed). In examining the tools used to assess social impairments in children with ASD, the six studies reviewed (Anderson et al., 2004; Cappadoccia et al., 2001; Kloosterman et al., 2012; Ratcliffe et al., 2015; Tureck & Matson, 2012; Zeedyk et al., 2014) used a total of seven different assessment tools, namely: Matson evaluation of social skills for youngsters-II; autism severity and social scale; Parten scale; the teacher and parent report versions of the social skills improvement system-rating scales; promoting relationships and eliminating violence network assessment tool; bullying and victimization questionnaire; and mother and adolescent semi-structure interviews. This makes it difficult to compare issues experienced by individuals with specific developmental disabilities across studies. It also makes it difficult to understand the wide array of challenges when only one issue is assessed. Additionally, if the challenges experienced by individuals with developmental disabilities are obtained from multiple assessments, this will create barriers to developing strategies and make it difficult when coordinating care and sharing information among service providers. As such, it is clear that a comprehensive tool assessing multiple domains is warranted in order to obtain an overall picture of the challenges experienced by individuals with specific developmental disabilities. A comprehensive, multidisciplinary mental-health assessment for children and youth referred to as interRAI Child and Youth Mental Health – Developmental Disabilities Instrument (ChYMH-DD) and the interRAI Child and Youth Mental Health (ChYMH) will now be discussed.

**1.2.2.6. InterRAI instruments: ChYMH-DD and ChYMH.** The ChYMH-DD and ChYMH are comprehensive, multidisciplinary mental health assessment systems for children

and youth from 4 to 18 years of age who are referred to either community-based (outpatient) or residential (inpatient) developmental services (Stewart et al., 2015a; Stewart et al., 2015b). The ChYMH-DD and ChYMH are developed by interRAI, an international group of researchers from over 30 countries. InterRAI is a not-for-profit group that develops instruments for vulnerable populations to improve care. The interRAI assessment system is a comprehensive suite of instruments to improve continuity of care, early identification, and intervention.

The ChYMH and ChYMH-DD consist of approximately 400 items that pertain to behaviours (e.g., socially inappropriate or disruptive behaviours), independence in daily activities, health conditions, family and social relations, communication abilities and, motor functioning, just to name a few. The ChYMH-DD is specific for children and adolescents with developmental disabilities, such as ASD and whose intellectual functioning is under 70, while the ChYMH is designed for children whose intellectual functioning is above 70 (Stewart et al., 2015a; Stewart et al., 2015b). The items on the assessments differ slightly. For example, the ChYMH-DD consists of particular items that may not be applicable to an individual with an IQ greater than 70 (e.g., documented severity of intellectual disability). The ChYMH-DD also has a section that is not on the ChYMH (Section N: psychological wellbeing). Reliability and validity has been confirmed by studies that have been conducted across the family of instruments (See: Carpenter, 2006; Gray et al., 2009; Hirdes et al., 2008; Hirdes et al., 2002; Lau et al., 2017; Poss et al., 2009; Stewart & Hamza, 2017).

The interRAI instruments within the child and youth suite use a semi-structured interview format with the child and family/guardians/caregivers to support the collection of information across a broad range of areas that are known to affect child and youth mental health. The purpose of these comprehensive assessments is to: 1) maximize the young person's functional capacity



and quality of life; 2) address physical and mental health problems; and 3) enhance the young person's level of independence (Stewart et al., 2015a; Stewart et al., 2015b). Specifically, the ChYMH and the ChYMH-DD both provide detailed account of problematic areas the individual exhibits (e.g., compulsive behaviour, indications of self-injurious behaviours) in addition to highlighting the individual's strengths (e.g., possesses notable talent, consistent positive outlook). The completion of these assessments also provides the individual with care planning guidelines, supported by evidence-based practices, triggered by areas of risk. The completed assessment also provides status and outcome measurements, as determined by various scales.

It is difficult to compare and track an individual's wellbeing across the lifespan and to compare his/her functioning from different settings because agency-specific assessments are unstandardized (Stewart & Hirdes, 2015). The interRAI instruments are able to overcome this by obtaining information about an individual from diverse care settings including hospitals, agencies, youth justice facilities, community agencies, and educational settings (Stewart & Hirdes, 2015). Additionally, this tool is able to identify individuals who could benefit from further evaluations of specific problems and who are at risk for declines in health, wellbeing, or function (Stewart et al., 2015a; Stewart et al., 2015b).

**1.2.3. The association among imitation, social, and motor deficits in individuals with ASD.** Imitation is defined as an individual's ability to replicate an observed motor act (Prinz, 2002). Early social development, such as face-to-face interaction with caregivers, in infants and toddlers is significantly influenced by imitation (Ingersoll, 2008). For instance, imitation plays a significant role in learning, social interaction, and goal-directed behaviours (Zachor, Ilanit, & Itzchak, 2010). Further, developmental psychologists suggest that imitation is the foundation of cognitive development, social-emotional communicative functions, social abilities, and the

ability to identify others' mental state, which is commonly referred to as the theory of mind (Lakin & Chartrand, 2003; Meltzoff & Williamson, 2013). This also allows individuals to assess the behaviours of others based on their own actions (Perkins, Stokes, McGillivray, & Bittar, 2010). Such behaviours can include emotions, desires, goals and opinions (Perkins et al., 2010).

Imitation deficits have been identified in ASD research for well over a decade. Early work by Rogers and Pennington (1991) found strong evidence of imitation deficits of simple body parts in individuals with ASD. The specific imitative difficulties Rogers and Pennington (1991) found in subjects with ASD were characterized by difficulties orientation of body parts, role reversal, and imitative tasks that involved self-other perspectives. It was concluded that imitation has an effect on a child's ability to develop social relationships, communication abilities, and to learn efficiently (Lakin & Chartrand, 2003; Meltzoff & Williamson, 2013). More recently, Dziuk et al. (2007) proposed that the consequence of imitation deficits may play a role in other primary problems such as motor difficulties and sensory-motor impairments exhibited by those with ASD.

**1.2.3.1. The Mirror Neuron System.** A core component of social behaviour can be observed through one's ability to understand and imitate other's behaviours (Hamilton, Bindley, & Frith, 2007). Briefly, the mirror neuron system (MNS) has been proposed to be the underlying system responsible for controlling and organizing imitation performance. According to work with both humans and monkeys, the MNS has been defined as the regions in the inferior parietal and inferior frontal cortex which responds when an individual performs an action and when another person's actions are observed. The MNS allows for imitation and supports inference of the goals and intentions of other people, in addition to playing a role in further skills such as empathy and language (Hamilton et al., 2007). Thus, the MNS appears to play a role in allowing

children to learn from other people's actions and to generalize through observation and imitation, by mapping such actions onto their own actions and language (Bell, Pineda, & Sharma, 2009). It has been proposed that once the actions of another individual are executed, it is possible to predict the mental state of the observed individual, leading to 'theory of mind' (Bell et al., 2009). Theory of mind refers to the ability to infer another person's mental state, including his/her beliefs and desires, from his/her own experiences and behaviour. Hence, if an individual watches a person reach into a box labelled "crayons," he/she will likely assume that he/she wants a crayon and that the individual believes there are crayons in the box. Theory of mind thus relates to cognitive development and social communication because it provides a fundamental ability to understand the actions and intentions of others, and to communicate the actions and intentions effectively (Bell et al., 2009).

**1.2.3.2. Broken mirror theory of autism.** Research has identified imitation deficits in individuals with ASD and has suggested that these deficits are due to a disruption in the mirror neuron system (MNS). Researchers have proposed that individuals with ASD experience deficits in the MNS, the 'Broken Mirror Theory of Autism'. Specifically, Hamilton (2013) hypothesized that children with ASD experience deficits in imitation, as well as the ability to evaluate the behaviours of others due to an impaired mirror neuron system. Such deficits result in poor "theory of mind" and impaired social functioning.

Oberman et al. (2005) assessed imitation abilities in ten high-functioning males with autism and ten age and gender-matched control participants (mean age of 16.6 years). EEG data was recorded while participants were (1) moving their own hands, (2) watching a video of an individual moving his/her hand in the same manner as the participant did in condition 1, (3) watching a video of two bouncing balls, and (4) watching visual noise/static on the television

(baseline condition). Unlike the control group, the ASD group did not have the expected EEG patterns when observing hand movements. The authors suggested this was due to a possible dysfunction in the mirror neuron system, and resulted in a deficit in imitation ability. However, it should be highlighted that only males and high-functioning individuals were examined and therefore the sample may not be representative (Oberman et al., 2005).

Similarly, Martineau, Cochin, Barthelemy, and Magne (2008) tested the hypothesis that children with autism (n=14) showed dysfunctional mirror neuron activity and compared results to 14 aged-matched neurotypical children (aged 5 to 7 years, ratio of boys to girls = 11:3). Researchers compared EEG activity during observation of videos showing actions and still scenes. The videos were of the following (1) no stimulation (a white screen), no movement sequence (body of water), (2) a non-human movement sequence (waterfall) and, (3) a human movement sequence (a woman performing scissor movements with her legs while lying on her back). Children with ASD did not exhibit the typical EEG activity, which support the hypothesis of the “broken mirror theory in ASD”; again, suggesting that individuals with ASD struggle with imitation (Martineau et al., 2008). However, the sample size of this study was small and therefore the results should be interpreted with caution.

A similar study by Bernier, Dawson, Webb, and Murias (2007) measured imitation more directly. Bernier et al. (2007) analysed the reaction of 14 high functioning males with ASD (aged 19 to 27 years, mean age= 23) and 15 neurotypical adults (gender unknown, aged 18 to 46 years, mean age= 26) during observation, execution, and imitation of movements. Participants observed a videotaped model performing simple hand movements and facial expressions. Following the single trial of each gesture, they were asked to imitate the action performed. Compared to the neurotypical group, individuals with ASD had difficulty imitating the actions. Again, these

results imply that the MNS in individuals with ASD is impaired and therefore confirmed that individuals with ASD struggle with imitation (Bernier et al., 2007). However, the age range of participants varied drastically. There is little knowledge regarding how the imitation deficit may vary throughout the life span, and therefore these results could be slightly flawed if this deficit changes with age and the factors associated with age (e.g., reaching developmental milestones). Furthermore, this study only included participants that were high functioning and consequently is not representative of lower functioning individuals.

**1.2.3.3. Imitation, motor, and social functioning in individuals with ASD.** As will be discussed in Studies #1, 2, and 3 the health status of individuals with disabilities is largely influenced by the nature of their disabilities (Chen & Cisler, 2011; Domellof et al., 2014; Lau et al., 2006). For instance, Domellof et al. (2014) stated that participants who reported having greater levels of impairment also reported having a lower health related quality of life. Considering imitation plays a significant role in the development of specific domains, one would assume that imitation deficits may have an association with other impairments experienced by individuals with disabilities (Lakin & Chartrand, 2003; Meltzoff & Williamson, 2013; Rogers & Pennington, 1991). For example, imitation plays a profound role in early peer interactions and therefore is associated with social and communication development (Ingersoll, 2008). Further, Dzuik (2007) and Jones (2009) have suggested that it is through imitative behaviour that infants acquire motor skills. Therefore, with evidence suggesting that ASD is associated with imitative deficits, and that social and motor skills are learned through imitation, it can be hypothesized that there may be an association between imitation deficits and social and motor impairments in children with ASD. Specifically, it is assumed that if an individual exhibits an imitation deficit, he or she will also experience a social and motor impairment.

Zachor et al. (2010) assessed the effects of autism severity, cognitive delay, and gross and fine motor impairments on imitation tasks performance in children with ASD. Comorbid conditions such as ADHD were not reported. Participants included 25 children (24 boys and 1 girl, aged 2.6 to 4.25 years). ASD-related symptom severity levels were measured using the Autism Diagnosis Observation Schedule (ADOS) along with measuring socio-communication (i.e., social reciprocal interaction and responsiveness deficits) and repetitive restricted behaviours. Motor imitation tasks were also completed, where half of these tasks required manipulating objects, and the other half involved imitation of body movements. Under both conditions “meaningful” and “non-meaningful” tasks were completed. Meaningful tasks included drinking from a cup and brushing hair with a hair brush, while non-meaningful tasks included pushing a brush on a table and pulling both ear lobes simultaneously. Results indicated that imitation abilities were significantly correlated ( $p < .01$ ) with autism severity, specifically with respect to the socio-communication domain (i.e., children with ASD who exhibited higher social reciprocal interaction and responsiveness deficits). Participants also had more difficulty imitating actions that required manipulating objects, in addition to imitating tasks that were considered non-meaningful. Further, participants had more success in imitating body movements and tasks that were considered as meaningful. Zachor et al. (2010) postulated that children's stereotyped tendencies interfere with imitating a movement requiring an object and therefore negatively affected their ability to successfully imitate. Further, they proposed that children are more successful with meaningful tasks because of the relevancy of the task (e.g., individuals tend to brush their hair every day). It appeared that motor skills did not correlate with imitation. Although the results concluded that motor impairments were not correlated with imitation success, it was found that children who exhibited better fine motor skills were more successful in

the imitation of object manipulation as opposed to body movements (Zachor et al., 2010).

Limitations must be noted, as the study did not include a representative sample of females and thus the results may not be generalizable. Additionally, with a sample size less than 30 ( $n=24$ ) and no control group it is questionable whether these results are practically or clinically significant.

Vanvuchelen, Roeyers, and De Weerd (2007) explored the underlying mechanisms of gestural imitation difficulties in autism by manipulating imitation task variables and by comparing imitation performance with performance on general motor tests in low functioning as well as in high functioning males ( $n= 55$ , mean age= 6.2 years). Those with attentional difficulties (e.g., hyperactivity disorder) were excluded. A gestural imitation task consisting of 24 gestural imitation tasks was presented to participants. Twelve meaningful gestures were subdivided into six transitive gestures within imaginary object/tool (e.g. comb hair with an imaginary comb) and six intransitive gestures with a communicative meaning (e.g. to salute). Each gesture was attempted once. The children's motor ability was examined; however, the general motor test was dependent on their mental abilities. Results revealed that boys with autism had more problems in imitating non-meaningful gestures than meaningful gestures in comparison with non-autistic controls. Vanvuchelen et al. (2007) did not find an association between cognitive level and imitation deficits. Such results may indicate that the gestures were meaningful to them. For example, children were able to connect to relative gestures like pretending to comb their hair with an imaginary comb. With regards to the low functioning group, imitation of both meaningful and non-meaningful tasks was correlated with their motor abilities; however, only imitation on non-meaningful tasks were correlated with motor ability for the high functioning group. Significant correlations between gestural imitation scores and motor

performance were not found in the non-autistic control groups. The findings in this study indicated that perceptual-motor components have a key role in imitation difficulties as confirmed by the relationship between imitation performance and general motor abilities in children with autism. These results confirmed that motor imitation problems are common in ASD and are correlated with motor abilities. Some limitations of this study need to be highlighted. First, the sample size of each the four groups were small. Secondly, the low functioning and high functioning groups were administered different motor tasks which may have caused a discrepancy in the results. Finally, the sample consisted of only males and therefore cannot be generalized to females (Vanvuchelen et al., 2007).

In a study conducted by Biscaldi et al. (2014) the cognitive and motor nature of imitation behaviours was assessed in an ASD group (n= 36, ages 6 to 29 years) and typical developing group (n= 34, ages 15 to 28 years). Ten of the children with ASD were also diagnosed with ADHD. The imitation abilities assessment was comprised of facial movements and finger or hand gestures. Similar to the findings from the study conducted by Vancuchelen et al. (2007), results indicated that there was not a correlation between intelligence and imitation; however, there was an association between intelligence and motor performance. Further, imitation was significantly poorer in participants with ASD than in typical developing (TD) participants ( $p < 0.01$ ). It also appeared that imitation was correlated with time performance, coordination, and execution ( $[p < 0.01]$  Biscaldi et al., 2014). Lastly, researchers found that imitation deficits were less severe in participants aged 15 to 29 years with ASD, compared to the children in the study. In conclusion, the results indicated that imitation and motor performance were significantly correlated ( $p < 0.01$ ) but imitation and intelligence were not. One of the study limitations was that imitation deficits seemed to improve with age. However, the study was cross-sectional rather



than longitudinal. Further, the individuals in the younger sample consisted of six females, while the older sample consisted of only males. It is possible that the gender imbalance could have influenced the results as to whether imitations deficits decrease with age.

**1.2.3.4. Gaps in the current literature and future research.** The lack of research within this area makes it difficult to determine the precise association among imitation deficits and motor and social deficits. First, to our knowledge, studies that have clearly investigated the relationship among these three deficits have not yet been published. Further, most of the studies regarding imitation and motor deficits, or social deficits most often include only a male population and a small sample size. As such, further research within this area is warranted. Not only will this research be able to shed light on the imitation deficit exhibited by those with ASD but will also provide further insight into the nature of social and motor deficits exhibited by this population. Given that, social and motor deficits have been associated with greater mental health difficulties (Ratcliffe et al., 2015) and an inability to complete daily life skills (Kopp et al., 2009), identifying the nature of these deficits can improve the health and wellbeing individuals with ASD as this will ultimately contribute to the development and implementation of the most appropriate interventions in minimizing these deficits.

### **1.3. Research Purposes**

Based on the review of the literature, the overall purpose of this dissertation was to investigate the overall health and wellbeing of individuals with ASD. In doing so, this dissertation was guided by the International Classification of Functioning, Disability, and Health framework ([ICF] WHO, 2018). While considering the many factors that can affect one's health (e.g., environmental and social factors, health conditions, impairments, activity limitations etc)

the ICF aims to understand the health status and functioning of individuals. This dissertation includes five studies. The purpose of each of the five studies were as follows:

1. The aim of Study #1 was to provide a complete picture of the multiple domains affected by ASD, using data collected by the Child and Youth Mental Health (ChYMH) and the Child and Youth Mental Health-Developmental Disabilities (ChYMH-DD). Specifically, Study #1 analyzed a series of Collaborative Action Plans (CAPs) triggered by high functioning (HF) and low functioning (LF) individuals.
2. The aim of Study #2 was to compare overall health, social functioning, and motor functioning among individuals with LF and HF ASD through the analysis of items and scales from the interRAI Child and Youth Mental Health – Developmental Disabilities (ChYMH-DD) and the interRAI Child and Youth Mental Health (ChYMH) assessments.
3. The purpose of Study #3 was to investigate sex differences in LF (IQ<70) and HF (IQ>70) individuals with ASD. In doing so, multiple items and scales from the ChYMH-DD and ChYMH assessments were analyzed that related to specific background information and the following three domains: health, social, and motor.
4. The aim of Study #4 was to explore social and motor impairments of children with ASD through the perspectives of eight caregivers of children with ASD using semi-structure interviews.
5. The purpose of Study #5 was to examine imitation, social, and motor impairments among individuals with ASD.

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**APPENDIX 1a: Assessment Tools for Issues in ASD***Assessment tools for overall wellbeing*

<b>References</b>	<b>Assessment Tools</b>
Gurney et al. (2006)	<p><b>The National Survey of Children’s Health (NSCH)</b></p> <ul style="list-style-type: none"> <li>The NSCH was a population-based, cross-sectional, telephone survey using a complex, multicluster, probability sampling design. The purpose of the NSCH was to produce national and state-specific prevalence estimates of health indicators and children’s experiences with the health care system</li> </ul>
Kuhlthau et al. (2010)	<p><b>Pediatric Quality of Life Inventory 4.0 (PedsQL)</b></p> <ul style="list-style-type: none"> <li>The PedsQL a 23-item questionnaire designed to assess children 2–18 years old. The survey evaluates four distinct areas of health related functioning: physical functioning, emotional functioning, social functioning and school functioning</li> </ul>
Potvin et al. (2015)	<p><b>Pediatric Quality of Life (PedsQL)</b></p> <ul style="list-style-type: none"> <li>The PedsQL is a 23-item questionnaire designed to assess children 2–18 years old. The survey evaluates four distinct areas of health related functioning: physical functioning, emotional functioning, social functioning and school functioning</li> </ul>
Dubin et al. (2015)	<p><b>Child Behaviour Checklist (CBCL)</b></p> <p>The CBCL is a standardized parent report questionnaire frequently used to assess behavioural and emotional functioning in children and adolescents</p>
Delahaye et al. (2013)	<p><b>Children’s Sleep Habits Questionnaire (CSHQ)</b></p> <p>The CSHQ is a cross sectional survey that consist of 45-items. It is a parent-report instrument designed to identify medically- and behaviourally based sleep problems in children between the ages of 4 and 12 years and is used to study sleep problems amongst children with several different health conditions, including ASD</p>
Hermann (2016)	<p>* Was a review, please refer to Hermann (2016) for details regarding the tools used in each study</p>
Hirata et al. (2015)	<p><b>The Japanese Sleep Questionnaire for Preschoolers (JSQ-P)</b></p> <ul style="list-style-type: none"> <li>The JSQ-P is a questionnaire that covers common sleep problems in preschool-aged children for caregivers to complete. The questionnaire consists of 39 items that are classified into 10 subscales: Restless Legs Syndrome (RLS)-sensory, RLS-motor, OSA (formerly called OSAS, but changed according to the International Classification of Sleep Disorders 3rd edition), Morning Symptoms, Parasomnias, Insomnia/ Circadian Rhythm</li> </ul>

Disorder, Daytime Excessive Sleepiness, Daytime  
Behaviours, Sleep Habit, and Insufficient Sleep

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*Assessment tools for social functioning*

<b>References</b>	<b>Assessment Tools</b>
Tureck and Matson (2012)	<p><b>Matson Evaluation of Social Skills for Youngsters-II (The MESSY-III)</b></p> <ul style="list-style-type: none"> <li>The MESSY-II includes a series of behaviours in which the informant is then asked to rate how often the child demonstrates each behaviour (1 0 not at all, 2 0 a little, 3 0 some, 4 0 much of the time, 5 0 very much)</li> </ul>
Ratcliffe et al. (2015)	<p><b>Autism Severity and Social (SRS)</b></p> <ul style="list-style-type: none"> <li>The SRS is a standardised, norm-referenced questionnaire designed to capture the severity of autistic behaviours in 4–18-year-old children and youth. The SRS focuses on the child’s reciprocal social interactions, which are core impairments in ASD. The SRS items measure the ASD symptoms in the domains of social awareness, social information processing, reciprocal social communication, social anxiety/avoidance, and stereotypic behaviour/restricted interests</li> </ul>
Ratcliffe et al. (2015)	<p><b>The teacher and parent report versions of the Social Skills Improvement System-Rating Scales (SSIS-RS)</b></p> <ul style="list-style-type: none"> <li>The SSIS-RS is a standardised norm referenced assessment of social skills for children and youth aged 3–18 years. Participants receive a total social skills score, which includes the subscales of communication, cooperation, assertion, responsibility, empathy, engagement, and self-control</li> </ul>
Anderson et al. (2004)	<p><b>The Parten Scale</b></p> <ul style="list-style-type: none"> <li>The Parten scale measure child's free play categorizes children’s free play in accordance with Piaget’s developmental theory, and defines six categories of play: unoccupied behaviour, solitary independent play, onlooker, parallel activity, associative play, and cooperative or organized supplementary play. The scale, is designed for use with children between 3 and 6 years of age</li> </ul>
Cappadoccia et al. (2011)	<p><b>Promoting Relationships and Eliminating Violence Network Assessment Tool (PREVNet tool)</b></p> <ul style="list-style-type: none"> <li>The PREVNet tool, parent version, is a parent report survey that focuses on bullying perpetration and victimization experiences among children</li> </ul>
Kloosterman et al. (2012)	<p><b>Bullying/victimization questionnaire (BVQ)</b></p> <ul style="list-style-type: none"> <li>The BVQ is a self-report measure that assesses the experiences of being physically, verbally, and relationally victimized, and experiences with bullying others. consists of two parts</li> </ul>

Zeedyk et al. (2014)

**Mother and Adolescent Semi-Structured Interviews (Self-Report)**

- Researcher conducted interviews with mothers and youth separately that were approximately 45 min. The interviews addressed topics regarding significant life events (e.g., adolescent relationships with friends and peers, adolescents' experiences with victimization or bullying others)
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*Assessment tools for motor functioning*

References	Assessment Tools
Kopp et al. (2010)	<p data-bbox="605 275 932 304"><b>The Cailler-Asuza Scale</b></p> <ul data-bbox="654 312 1398 485" style="list-style-type: none"> <li data-bbox="654 312 1398 485">• This is a developmental motor assessment tool which measures the age of acquisition of motor milestones. The subscales for evaluation of motor development (postural control, locomotion, fine motor development and visomotor control) were used</li> </ul> <p data-bbox="605 495 1321 525"><b>Movement assessment battery for children (M-ABC)</b></p> <ul data-bbox="654 533 1414 856" style="list-style-type: none"> <li data-bbox="654 533 1414 856">• The MABC is a structured, motor ability assessment consisting of a parent/teacher report checklist measuring everyday movement ability and an individually administered performance test. There are 3 different measurements, these are of: Manual Dexterity (a measure of fine motor ability, 3 tasks), Ball Skills (a measure of both fine and gross motor ability, 2tasks), and Static and Dynamic Balance (a measure of gross motor ability, 3 tasks)</li> </ul>
Ming et al (2007)	<p data-bbox="605 865 769 894"><b>The EB-test</b></p> <ul data-bbox="654 903 1409 1117" style="list-style-type: none"> <li data-bbox="654 903 1409 1117">• This is a physiotherapy protocol comprising 59 items measuring: gross motor function (27 items) (including three main areas: A. Balance, coordination and postural stability, B. Strength, C. Range of movements: fine motor function (8 items), sensation (10 items), perception (5 items) and neurological tests (9 items)</li> </ul> <p data-bbox="605 1125 1284 1155"><b>Motor-neurological-perceptual assessment (MNP)</b></p> <ul data-bbox="654 1163 1422 1854" style="list-style-type: none"> <li data-bbox="654 1163 1422 1549">• The MNP comprises 9 items, each scored as 0 = no signs, 1 = slight dysfunction and 2 = marked dysfunction (total scores range from 0 to 18) and divided into 3 subclasses, gross motor dysfunction (4 items: overall clumsiness, hopping 20 times on one foot, standing 20 s on one foot, jumping back and forth with alternating legs), fine motor dysfunction (3 items: cutting out 10 cm diameter paper circle, Bishop maze-tracing (and finger-tapping) and neurological tests (2 items: diadochokinesis and walking on lateral aspects of feet</li> <li data-bbox="654 1558 1349 1734">• Hypotonia, motor apraxia (including oral and limb muscle), or reduced ankle mobility were physical findings documented by physical examination performed by the pediatric neurologist during office visits</li> <li data-bbox="654 1743 1395 1854">• Toe-walking was determined by historical report from the parents, therapists' records, other physician's records, or by physical</li> </ul>



- Gross motor milestone delay was determined by history according to Denver II Developmental Material which assessed: independent sitting, walking well, walking up steps, jumping up, etc.
  - Reduced ankle mobility was defined as reduced degree of ankle dorsi-flexion with passive stretching of the muscle without producing pain
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**Chapter 2- Study #1: Assessing the Wellbeing of Individuals with Autism Spectrum Disorder Using the interRAI Child and Youth Mental Health (ChYMH) and the interRAI Child and Youth Mental Health – Developmental Disabilities (ChYMH-DD)**

## **2.1. Abstract**

Individuals with autism spectrum disorder (ASD) experience multiple issues affecting their overall health and wellbeing. A comprehensive picture of the numerous domains affected by ASD in children and youth is lacking. To provide a complete picture of the multiple domains affected by ASD, data collected using the Child and Youth Mental Health (ChYMH) Assessment and the Child and Youth Mental Health -Developmental Disabilities (ChYMH-DD) were analysed. Specifically, this study analysed a series of Collaborative Action Plans (CAPs) triggered by high functioning (HF) and low functioning (LF) individuals. Both HF and LF individuals triggered numerous CAPs, suggesting individuals with ASD are at risk for a myriad of issues. The findings also revealed children and youth, who triggered one concern, were also triggering concerns in other domains. Areas highlighted in this paper include social relationship challenges, sleep issues, and aggressive behaviours, and signal issues of concern for caregivers of individuals with ASD and health care professionals. Further research is warranted to determine means by which to manage or prevent these issues from compromising the wellbeing of individuals with ASD.

## 2.2. Introduction

Individuals with autism spectrum disorder (ASD) experience multiple issues affecting their overall health and wellbeing. According to the Center for Disease Control and Prevention (2014) the overall prevalence of ASD has increased 120% since 2000, currently affecting 1 in 66 children (Autism Ontario, 2018). The increasing prevalence, in combination with the deleterious effects of ASD, make this condition one of great concern. A comprehensive picture of the numerous domains affecting children and youth with ASD is lacking. However, multiple studies have highlighted health concerns among those with ASD. For example, co-morbid conditions associated with ASD such as depression, anxiety, and attention-deficit disorder have been confirmed within the literature (Dubin, Lieberman-Betz, & Lease, 2015; Ghaziuddin, Ghaziuddin, & Greden, 2005; World Health Organization [WHO], 2016). ASD is also commonly associated with a myriad of medical conditions including migraines, seizures, eczema, and ear and respiratory infections (Kohane et al., 2012). The presence of co-morbid mental health problems and medical conditions compromises the quality of life of individuals with ASD, particularly when compared to typically developing populations (Gurney, McPheeter, & Davis, 2006; Kuhlthau et al., 2010; Potvin, Snider, Prelock, & Wood-Dauphinee, 2015). Moreover, individuals with ASD are frequently subjected to violence, injury, and abuse (WHO, 2016) which further threatens their wellbeing.

Research suggests individuals with ASD who experience one health issue may be at risk for experiencing other issues. For example, Estes, Rivera, Bryan, Cali, and Dawson (2018) reported children with ASD who had greater social deficits had reduced educational success compared to children with ASD who had stronger social skills. It has also been suggested children with ASD and sleep issues are at a greater risk for social deficits (Johnson et al. 2018;

Richdale & Shreck, 2009). Further, sleep issues among children with ASD have been associated with increased caregiver stress (Johnson et al., 2018; Petrou, Soul, Koshy, McConachie, & Parr, 2018). Moreover, aggression is an additional concern often experienced by individuals with ASD and has been linked to other issues (Kanne & Mazurek, 2011) such as reduced educational success (Chalfant, Rapee, & Carroll, 2007), family stress (Hodgetts, Nicolas, & Zwaigenbaum, 2013) and reduced communicative abilities (Hartley, Sikora, & McCoy, 2008). It is important that concerns among individuals with ASD are addressed so the development of additional issues can be prevented.

As such, to provide a complete picture of the multiple domains affected by ASD, data collected using the Child and Youth Mental Health (ChYMH) Assessment and the Child and Youth Mental Health -Developmental Disabilities (ChYMH-DD) were analyzed.

**2.1.2. interRAI instruments: ChYMH-DD and ChYMH.** interRAI is a not-for-profit international group that develops instruments for vulnerable populations. The interRAI instruments are a validated and reliable comprehensive suite of tools to improve continuity of care, provide early identification of issues, and suggest possible interventions (see, Carpenter, 2006; Gray et al., 2009; Hirdes et al., 2008; Hirdes et al., 2002; Lau, 2017; Poss et al., 2009; Stewart & Hamza, 2017). Within this suite of instruments are the ChYMH and ChYMH-DD, which are comprehensive, multidisciplinary mental-health assessment systems for children and youth from 4 to 18 years of age who are referred to either community-based (outpatient) or residential (inpatient) developmental services (Stewart et al., 2015a and Stewart et al., 2015b). The purposes of these tools are to: 1) maximize the young person's functional capacity and quality of life; 2) address physical and mental health problems; and 3) enhance the young person's level of independence (Stewart et al., 2015a; Stewart et al., 2015b).

The ChYMH and ChYMH-DD use a semi-structured interview format with the child and family/guardian/caregiver to collect information across a broad range of areas known to affect child and youth mental health. With parent consent, additional information can be collected from clinical files and other health care agencies. The ChYMH is designed for children whose intellectual functioning is above 70, while the ChYMH-DD is specific for children and adolescents with developmental disabilities, such as ASD and whose intellectual functioning is under 70. Both tools consist of approximately 400 items regarding multiple areas known to affect health and wellbeing (e.g., independence in daily activities, health conditions, family and social relations, communication abilities) (Stewart et al., 2015a; Stewart et al., 2015b).

A completed assessment provides care planning guidelines, known as Collaborative Action Plans (CAPs), which are supported by evidence-based practices and “trigger” areas of risk (Stewart et al., 2015a; Stewart et al., 2015b). For each CAP triggered, the tool provides evidenced-based approaches to guide interventions for a child or youth who could benefit from care intervention. The provided guidelines aim to minimize the specific concern targeted, thus enhancing quality of life. Responses from one or several items in combination will trigger specific CAPs. For example, the injurious behaviour CAP is comprised of the following four items: self-injurious behaviour in the last 3 days, physical abuse in the last 3 days, and destructive behaviour toward property in the last 3 days, and violence to others in the last 7 days (Stewart et al., 2015a; Stewart et al., 2015b). Specific responses from these four items will trigger the injurious behavior CAP. CAPs are categorized into the five following domains: safety, health promotion for the ChYMH and health and wellbeing for the ChYMH-DD, functional status, service and supports, and family life and social integration (Stewart et al., 2015a; Stewart et al., 2015b).

As mentioned above, individuals with ASD experience multiple health concerns; however, a study assessing the multiple domains affected by ASD is lacking. The ChYMH and the ChYMH-DD afford the opportunity to comprehensively assess multiple domains affected by ASD. As such, the purpose of this study was to assess the multiple domains affected by ASD through the analysis of the ChYMH and ChYMH-DD. By doing so, the overall health and health needs of children and youth with ASD were revealed, allowing for the development and implementation of specific interventions required to minimize such concerns.

### **2.3. Methods**

**2.3.1. Ethics.** Ethical clearance was obtained from Western University's (i.e., the location where data were stored) and Wilfrid Laurier University's (location of researcher) research ethics board prior to secondary data analyses of the ChYMH and ChYMH-DD data set.

**2.3.2. Procedure.** All data analyzed was gathered using the interRAI ChYMH and ChYMH-DD. Assessments were completed at 14 mental health agencies across Ontario between January 2015 and November 2016. These assessments were completed at health care agencies in which children are often self-referred or referred to by family doctors, pediatricians, or other healthcare professionals. The ChYMH and ChYMH-DD aim to collect information across multiple sources. The assessments are completed using a semi-structured interview format with the child/youth, caregivers, educators, and/or health care clinicians. The assessments also obtain information from records such as previous clinical assessments and school records. Typically, these assessments take between 60 to 90 minutes. All assessors are required to complete two and half days of intensive training, have a diploma or degree in the mental health field, and at least two years of clinical experience with children/youth. This training was developed by local, national, and international experts in the field of children's mental health (interRAI, 2018) It is important to note that

assessments cannot be submitted into the database unless complete, therefore assessments do not consist of any missing data. The assessments are then entered into a database to allow for analysis, where they are de-identified. The databases are password protected, encrypted, not accessible by the internet, and do not have a USB port to ensure confidentiality of all cases.

**2.3.3. Description of data and data analysis.** The participants consisted of 378 individuals with ASD between the ages of 4 and 18 years. Of this sample, 272 individuals were considered HF, while 106 individuals were considered LF. With regards to the HF sample, 212 were males and 80 were females and the mean age was 12.77 years (SD=3.16). For the LF sample, 81 were males and 25 were females and the mean age was 11.8 years (SD=3.29). For this particular analysis, LF (IQ less than 70) and HF (IQ greater than 70) individuals were analyzed separately given the variability between these groups (see Study #1). The ChYMH-DD is specific for children and adolescents with developmental disabilities, such as ASD and whose intellectual functioning is under 70, while the ChYMH is designed for children whose intellectual functioning is above 70 (Stewart et al., 2015a; Stewart et al., 2015b). Refer to Table 2.1 for more demographic information, located at the end of this paper.

In addition to socio-demographic information, descriptive statistics for 30 CAPs from the ChYMH and 23 CAPs from the ChYMH-DD were examined using Statistical Package for Social Sciences (SPSS) 24 (IBM, 2016). Results were then summarized to determine the overall health needs of children and youth with ASD. CAPs were re-coded into ‘not triggered’ and ‘triggered’, even if additional categories were available. By collapsing the response options, this avoided cell counts from being less than five and therefore reducing the potential of revealing the identity of participants, as necessitated by ethical restrictions. It should be noted some CAPs on the



ChYMH and the ChYMH-DD differed and therefore could not be compared. For re-coding of the CAPs see Appendix 2a.

In addition to descriptive statistics mentioned above, the number of individuals triggering two specific CAPs were further analyzed. The selection of these CAPs was based on prior literature. Estes and colleagues (2018) found that children who had increased social deficits also had reduced educational success. Therefore, the number of children who triggered the social and education CAPs was examined. Further, an association between sleep issues and poor social skills, as well as sleep issues and caregiver distress has been revealed in children with ASD (Johnson et al., 2018), which is why the researcher selected the sleep and the caregiver distress CAPs to also analyse. It has been further noted that children with low communication abilities often exhibit more aggressive behaviours and have reduced educational success (Chalfant et al., 2007; Hartley et al. 2008). As well, research has shown that caregivers reported higher stress when their children with ASD exhibited aggressive behaviours (Hodgetts et al., 2013). Such research provided the rationale for further investigating the communication, caregiver distress, injurious behaviour, and educational support CAP. The output was then analyzed to determine how many individuals triggered both of the selected CAPs. For the HF group, see Table 2.2 for the selected CAPs. For the LF group, see Table 2.3 for the selected CAPs.

Note, the focus of this paper was to explore common issues exhibited by LF and HF individuals and therefore, the percentage of children/youth triggering CAPs available on both instruments were reported. This is especially important as this information is not well known and therefore providing the foundation for the area is warranted prior to rigorous statistical testing. As such, statistical tests were not conducted and CAPs between HF and LF groups were not compared.

## 2.4. Results

Results for high and low functioning individuals have been separated and will be discussed in turn. For all data pertaining to CAPs triggered by HF and LF samples, see Appendix 2b.

**2.4.1. High functioning.** Analysis of the ChYMH indicated several domains were “triggered” by more than 50% of the HF sample: social and peer relationships (75% triggered), education (74% triggered), sleep disturbances (64% triggered), and interpersonal conflict (52% triggered). Additionally, more than 30% of the HF sample triggered the following CAPs: traumatic life events (48%), caregiver distress (44%), support systems for discharge (42%), weight management (40%), transitions (39%), strengths (38%), criminality prevention (37%), medication review (35%), life skills (30%), harm to others (30%), and informal support (30%). For the results pertaining to CAPs triggered by the HF group, see Table 2.4 located at the end of this paper.

Upon further analysis, summation of the total number of CAPs triggered by the sample revealed a mere seven individuals did not trigger any CAPs. Fifty percent of HF individuals triggered as many as 7 CAPs. For results pertaining to the total number of CAPs triggered by the HF sample, see Table 2.5 located at the end of this paper.

The number of individuals triggering two specific CAPs were descriptively analysed: (1) 64% of individuals who triggered the social and peer relationships CAP also triggered the education CAP; (2) 52% of individuals who triggered the social and peer relationships CAP also triggered the sleep disturbance CAP; and (3) 32% of individuals who triggered the sleep disturbance CAP triggered the caregiver distress CAP. See Table 2.6.

**2.4.2. Low functioning.** Analysis of the ChYMH-DD indicated several domains “triggered” by more than 50% of the LF sample: play and leisure (94% triggered), injurious (91% triggered), communication (74% triggered), sleep management (72%), transition (67% triggered), strengths (63% triggered), social relationships (61% triggered), education support (59% triggered), and problematic eating disorders (53% triggered). Additionally, more than 30% of the LF sample triggered caregiver distress (47%), medication review (45%), continence (42%), and traumatic life events (40%). For the results pertaining to CAPs triggered by the LF group, see Table 2.7 located at the end of this paper.

Summation of the total number of CAPs triggered by all LF individuals, indicated that individuals triggered at least 1 CAP, and 81% of LF individuals triggered up to 10 CAPs. For results pertaining to the total number of CAPs triggered by the LF sample, see Table 2.8 located at the end of this paper.

The number of individuals triggering two specific CAPs were examined. Sixty-nine percent of individuals who triggered the injurious CAP also triggered the communication CAP. Additionally, 58% of individuals who triggered the injurious CAP also triggered the education support CAP, while 47% of individuals who triggered the injurious behaviour CAP also triggered the caregiver distress CAP. Also, 44% of individuals who triggered the social relationships CAP triggered the sleep management CAP and 40% of individuals who triggered the caregiver distress CAP also triggered the sleep management CAP. Lastly, results revealed 39% of individuals who triggered the social relations CAP also triggered the education support CAP. See Table 2.9.

## **2.5. Discussion**

The purpose of this study was to provide a comprehensive picture of the wide range of concerns affecting the health and wellbeing of individuals with high and low functioning ASD. Data collected using the ChYMH and ChYMH-DD instruments clearly established HF and LF children and youth with ASD are at risk for a myriad of issues. For example, 34 high functioning children and youth triggered 7 CAPs, while 14 LF children and youth triggered 10 CAPs. As well, the data revealed children and youth triggering specific CAPs were also triggering other CAPs, suggesting relationships between these concerns. This means children who experience one specific issue may be at risk for experiencing additional issues. Although all areas triggered are of concern, the discussion will focus on three areas: social and peer relationships, sleep, and aggression.

**2.5.1. Social and peer relationships.** Deficits in socialization, such as difficulty with eye contact, speech abnormalities, and failure to initiate interpersonal interactions, are considered a core component of ASD (Tureck & Matson, 2012; Fodstad, Matson, Hess, & Neal, 2009). Further social deficits observed in children with ASD include increased interaction with adults opposed to peers, minimal verbal and non-verbal interaction with peers, less mature play, and little engagement in socially complex play (Anderson, Moore, Godfrey, & Fletcher-Flinn, 2004). Social deficits among individuals with ASD can hinder the ability to develop appropriate communication skills needed for social interaction and friendship development as supported by the study conducted by Kasari, Locke, Gulsrud, Rotheram-Fuller (2011). Kasari et al. (2011) reported children with ASD had fewer and poorer quality friendships and smaller social networks at school when compared to children without ASD. In the current study, social deficits among children and youth with ASD were evident, as indicated by the high number of children triggering the social CAPs. Specifically, the social and peer relationship CAP was triggered by

75% of HF children and youth, while the social relations CAP was triggered by 61% of LF children and youth.

The social issues exhibited by children and youth with ASD increase their risks for other concerns such as their academic success at school. For example, Estes and colleagues (2018) explored the link between social functioning and educational success in children with ASD. Social functioning was determined by assessing children in assertion, self-control, and cooperation. Results indicated children with ASD who demonstrated high social abilities had high academic achievement levels, whereas children with ASD and low social abilities had low academic achievement levels. This is also supported in the current study as many of the children and youth triggering the social CAPs were also triggering the education CAP. For the HF sample, 65% of individuals who triggered the social and peer relationship CAP also triggered the education CAP. For the LF group, 39% triggered both CAPs and still suggests a possible relationship between social relationships and education support.

Improving social abilities may foster academic success in children with ASD. Teachers and education administrators are in the position to minimize social isolation among children with ASD and consequently improve academic success. In order to do so, education and awareness of ASD in children with and without disabilities, teachers, principals, and other staff members are warranted. Further, identifying children who appear to be socially isolated and subsequently enrolling them in programs aimed to promote friendships and provide social support may aid in reducing the consequences of isolation.

**2.5.2. Sleep.** Sleep issues are highly prevalent in children and adolescence with ASD, ranging from 40 to 80% (Devani & Hedge, 2015). A clinical review exploring sleep issues in children with ASD found sleep onset and maintenance problems, as well as sleep duration were

most commonly reported by parents of children with ASD (Richdale & Schreck, 2009). Parents reported their children wake up during the night for up to three hours at a time. During this time, children would laugh, talk, scream, and/or get up and play. Further, children would fall asleep late (e.g., six-year-old falling asleep at 12 am) and wake up early (e.g., 2 am). Co-morbid conditions such as anxiety, attention deficit hyperactivity disorder (ADHD), depression, and mood disorders all acted as risk factors for sleep issues in children with ASD. Fewer hours of sleep among children with ASD also led to greater social deficits, disruptive behaviours, and stereotypic behaviours (Richdale & Schreck, 2009). Although not specifically geared towards those with ASD, the participACTION report (2016) suggests deficits in sleep may be associated with poor academic success, reduced attention span, and weight gain.

Sleep issues were highly prevalent among individuals in this study, as the sleep disturbance CAP was triggered by 64% of HF sample and the sleep management CAP was triggered by 72% of LF sample. As previously mentioned, sleep issues can lead to greater social deficits (Richdale & Schreck, 2009). Johnson et al. (2018) found children with ASD exhibited more daytime behaviours (e.g., social withdrawal, irritability, hyperactivity) when parents reported their children had poor sleep. This is also supported by the current study as more than half of HF individuals (53%) triggering the sleep disturbance CAP triggered the social and peer relationship CAP. For LF individuals, just less than half of individuals (44%) who triggered the sleep management CAP also triggered the social relations CAP.

There is further support suggesting sleep issues in children with ASD create many difficulties for their caregivers, such as compromised sleep for parents (Herrmann, 2015), strain on the family (Petrou et al., 2018), and significantly high levels of stress (Johnson et al., 2018). In the current study, 40% of LF individuals who triggered the sleep management CAP also

triggered the caregiver distress CAP. As for the HF group, 32% of individuals who triggered the sleep disturbance CAP also triggered the caregiver distress CAP. Given the importance of sleep, it is essential the causes of sleep issues in the ASD population are further investigated. This would allow for prevention and/or strategies to minimize sleep issues in such individuals, and their caregivers, in order to improve their overall wellbeing, and reduce difficulties experienced by their caregivers and other family members.

**2.5.3. Aggression.** Rates of aggression among individuals with ASD are high. A North American study assessing prevalence and risk factors of aggression in a sample of 1380 children and adolescents (age 4 to 17 years,  $M_{\text{age}} = 9$ ) with ASD reported 68% of the sample exhibited aggression towards a caregiver and 49% to non-caregivers (Kanne & Mazurek, 2011). Common forms of aggression in individuals with ASD may include hitting, kicking, biting, throwing objects, and pulling hair, glasses or other personal belongings (Matson & Adams, 2012). For the HF group, the harm to others CAP, as characterised by physical harm towards others, was triggered by 30%. For the LF group this was much higher, with 91% of the LF sample triggering the injurious behaviour CAP, as characterized by aggressive and self-injurious behaviour. This is disconcerting as aggression acts as a risk factor for many other issues. For example, aggression in children with ASD has been linked to reduced quality of life and increased stress levels for the children and their caregivers (Fitzgerald, Srivorakiat, Wink, Pedapati, & Erickson, 2016). As well, teachers have reported aggression in individuals with ASD negatively affects their instructional efforts, thus minimizing the individuals' ability to learn in an educational setting, as well as other students in the class (Chalfant et al., 2007). This is also evident in the current study as more than half (58%) of LF individuals who triggered the injurious behaviour CAP also triggered the education support CAP.

On a family level, aggression in individuals with ASD is associated with financial impact, exhaustion, and fear for personal safety among other family members (Hodgetts et al., 2013). In the current study almost half (47%) of LF individuals who triggered the injurious behaviour CAP also triggered the caregiver distress CAP. It is also likely aggression may be a consequence of difficulty in communication exhibited by LF children and youth. Interestingly, 69% of LF individuals who triggered the injurious behaviour CAP also triggered the communication CAP. This adds to the literature suggesting individuals with non-verbal cognitive ability and low expressive language have a higher risk for aggression (Hartely et al., 2008).

Given the consequences of aggression (see, Chalfant et al., 2007; Fitzgerald et al., 2016; Hodgetts et al., 2013) families need to be educated about reducing and controlling aggressive behaviours in their children with ASD. It appears that children and youth who experience communication difficulties become frustration and can exhibit their frustration through aggression. Improving communication skills will likely result in reduced aggression. Risk factors and consequences of aggression among children with ASD must be relayed to families of children with ASD by medical professionals in order to emphasize the need to provide support to these individuals. It is important research findings are used to provide a framework for the development of support groups, therapies, and strategies to minimize the challenges for the individuals with ASD, as well as their family members.

**2.5.4. Limitations.** Among the LF sample, a low sample size existed for several CAPs. This prohibited analysis of these CAPs for two reasons: (1) the low sample size did not meet the ethical stipulations required for reporting purposes. Cell counts needed to be greater than five in order to avoid the identity of participants from being revealed; (2) analysis of CAPs with low sample sizes might lead to inappropriate and potentially false conclusions and therefore the



number of individuals triggering CAPs with a sample less than five were not examined and therefore could not be reported. A larger sample size among this group would ameliorate this limitation. As well, the sample contained a large age range (age 4 to 18 years); the issues experienced by children aged four may be different than the issues experienced by individuals aged 18. A larger sample size would afford the opportunity to divide the sample into children (12 years and younger) and youth (12 years to 18 years), therefore identifying specific concerns for these age groups.

## **2.6. Conclusion**

The current study provides a comprehensive picture of the wide range of concerns affecting the health and wellbeing of individuals with high and low functioning ASD. The high number of children and youth triggering specific CAPs suggests they are at risk for a myriad of issues. The findings also revealed children and youth, who triggered one concern, were also triggering concerns elsewhere. For example, more than half of the HF individuals triggering the social and peer relationship CAP were also triggering the education CAP. As well, almost two thirds of LF individuals who triggered the injurious behaviour CAP also triggered the communication CAP.

The areas of concern highlighted in this paper, such as social relationship challenges, sleep issues, and aggressive behaviours, must be carefully monitored among individuals with ASD by caregivers and health care professionals. Caregivers of children and youth with ASD must be educated on the common concerns these individuals are at risk for developing. This will allow for early identification of such issues, therefore reducing their effects or better yet, preventing them. Lastly, further research must investigate appropriate measures to prevent individuals with ASD from experiencing issues of concern, and in turn, enhance wellbeing.

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Table 2. 1 *Demographic Characteristics of High Functioning and Low Functioning Groups*

<b>Characteristic</b>	<b>HF</b>	<b>LF</b>
N (total)	272	106
<b>Age</b>		
Children (ages 4 to 11)	120 (44%)	32 (30%)
Youth (ages 12 to 18)	152 (56%)	74 (70%)
<b>Sex</b>		
Males	212 (78%)	81 (76%)
Females	60 (22%)	25 (24%)



Table 2. 2 *Number of HF Individuals Triggering Two Selected CAPS*


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**CAPs Selected to Determine the Number of HF Individual Triggering two Concerns**

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Social and peer relationships CAP & Education CAP

Social and peer relationships CAP & Sleep disturbance CAP

Sleep disturbance CAP & Caregiver distress CAP

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Table 2. 3 *Number of LF Individuals Triggering Two Selected CAPS*


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**CAPs Selected to Determine the Number of LF Individual Triggering two Concerns**

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Social relations CAP & Education support CAP

Social relations CAP & Sleep management CAP

Sleep management CAP & Caregiver distress CAP

Injurious behaviours CAP & Education support CAP

Injurious behaviours CAP & Caregiver distress CAP

Injurious behaviours CAP & Communication CAP

---

Table 2. 4 *Number (and %) of High Functioning Participants Triggering Specific Collaborative Active Plans (CAPs)*

<b>CAPs</b>	<b>Triggered</b>
<b>Social and peer relationships</b>	205 (75%)
<b>Education</b>	101 (74%)
<b>Sleep disturbance</b>	175 (64%)
<b>Interpersonal conflict</b>	106 (52%)
<b>Traumatic life events</b>	114 (48%)
<b>Caregiver distress</b>	121 (44%)
<b>Support systems for discharge</b>	6 (42%)
<b>Weight management</b>	51 (40%)
<b>Transitions</b>	93 (39%)
<b>Strengths</b>	90 (38%)
<b>Criminality prevention</b>	100 (37%)
<b>Medication review</b>	96 (35%)
<b>Life skills</b>	44 (32%)
<b>Harm to others</b>	80 (30%)
<b>Informal support</b>	81 (30%)
<b>Physical activity</b>	72 (27%)
<b>Video gaming</b>	74 (27%)
<b>Communication</b>	70 (26%)
<b>Readmission</b>	63 (23%)
<b>Attachment</b>	24 (22%)
<b>Suicidality and purposeful self-harm</b>	54 (20%)

<b>Sexual behaviour</b>	13 (11%)
<b>Medication adherence</b>	29 (11%)
<b>Parenting</b>	18 (7%)
<b>Hazardous fire involvement</b>	12 (4%)
<b>Tobacco and nicotine use</b>	15 (6%)
<b>Substance use</b>	6 (4%)
<b>Caffeine use</b>	9 (3%)
<b>Control interventions</b>	<b>Violated</b>
<b>Gambling</b>	<b>Violated</b>

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*Note.* The term violated refers to having (a) cell count(s) less than five and therefore could not be reported due to ethical and statistical restrictions.

Table 2. 5 *Number of High Functioning Participants Triggering the Number of Collaborative Active Plans (CAPs)*

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<b>Number of CAPs</b>	<b>Number of HF Individuals</b>
0	7
1	10
2	18
3	19
4	19
5	26
6	19
7	34
8	25
9	27
10	15
11	19
12	11
13	10
14	5
15+	8

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Table 2. 6 *Number (and %) of High Functioning Individuals Triggering Two Specific CAPs*

CAPs	Number of HF individuals triggering both CAPs
<b>Social and peer relationship and Education CAP</b>	87 (64%)
<b>Social and peer relationship CAP and Sleep Disturbance CAP</b>	141 (52%)
<b>Sleep Disturbance CAP and Caregiver Distress CAP</b>	87 (32%)

Table 2. 7 *Number (and %) of Low Functioning Participants Triggering Specific Collaborative Active Plans (CAPs)*

<b>CAPs</b>	<b>Triggered</b>
<b>Play and leisure</b>	76 (94%)
<b>Injurious behaviours</b>	96 (91%)
<b>Communication</b>	79 (74%)
<b>Sleep management</b>	76 (72%)
<b>Transitions</b>	54 (67%)
<b>Strengths</b>	52 (64%)
<b>Social relations</b>	65 (61%)
<b>Education support</b>	61 (59%)
<b>Problematic eating behaviours</b>	57 (54%)
<b>Caregiver distress</b>	50 (47%)
<b>Medication review</b>	48 (45%)
<b>Continence</b>	34 (42%)
<b>Traumatic life events</b>	32 (40%)
<b>Medication adherence</b>	7 (7%)
<b>Parenting</b>	<b>Violated</b>
<b>Modified nutrition</b>	<b>Violated</b>
<b>Accessibility and mobility</b>	<b>Violated</b>
<b>Control interventions</b>	<b>Violated</b>
<b>Hazardous fire involvement</b>	<b>Violated</b>
<b>Sexual behaviour</b>	<b>Violated</b>
<b>Suicidality and purposeful self-harm</b>	<b>Violated</b>

**Life skills**

**Violated**

**Support systems for discharge**

**Violated**

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*Note.* The term violated refers to having (a) cell count(s) less than five and therefore could not be reported due to ethical and statistical restrictions.

Table 2. 8 *Number of High Functioning Participants Triggering the Number of Collaborative Active Plans (CAPs)*

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<b>Number of CAPs</b>	<b>Number of LF Individuals</b>
0	0
1	<5
2	0
3	5
4	5
5	10
6	14
7	13
8	14
9	11
10	14
11	10
12	5
13	<5
14	0
15+	0

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Table 2. 9 *Number (and %) of Low Functioning Individuals Triggering two Specific CAPs*

CAPs	Percentage of individuals triggering both CAPs
<b>Injurious Behaviour and Communication CAP</b>	73 (69%)
<b>Injurious Behaviour and Education Support CAP</b>	60 (58%)
<b>Injurious Behaviour and Caregiver Distress CAP</b>	60 (47%)
<b>Social Relationship CAP and Sleep Management CAP</b>	47 (44%)
<b>Caregiver Distress and Sleep Management CAP</b>	42 (40%)
<b>Social Relationship and Education Support CAP</b>	62 (39%)

**APPENDIX 2a: Recoding of CAPs***Recoding of CAPs*

<b>CAP</b>	<b>Original Code</b>	<b>New Code</b>
<b>Tobacco and nicotine Use</b>	0. Not triggered 1. Triggered	0. Not triggered 1. Triggered
<b>Substance use</b>	0. Not triggered 1. Triggered	0. Not triggered 1. Triggered
<b>Sleep management</b>	0. Not triggered 1. Triggered	0. Not triggered 1. Triggered
<b>Support systems for discharge</b>	0. Not triggered 1. Triggered	0. Not triggered 1. Triggered
<b>Medicine adherence</b>	0. Not triggered 1. Triggered	0. Not triggered 1. Triggered
<b>Medicine review</b>	0. Not triggered 1. Triggered	0. Not triggered 1. Triggered
<b>Sexual behaviour</b>	0. Not triggered 1. Triggered	0. Not triggered 1. Triggered
<b>Caffeine use</b>	0. Not triggered 1. Triggered	0. Not triggered 1. Triggered
<b>Informal support</b>	0. Not triggered 1. Triggered	0. Not triggered 1. Triggered
<b>Parenting</b>	0. Not triggered 1. Triggered	0. Not triggered 1. Triggered
<b>Traumatic life events</b>	0. Not triggered 1. Triggered to reduce the impact of prior traumatic life events 2. Triggered to address immediate safety concerns	0. Not triggered 1. Triggered
<b>Control interventions</b>	0. Not triggered 1. Triggered	0. Not triggered 1. Triggered
<b>Attachment</b>	0. Not triggered 1. Triggered	0. Not triggered 1. Triggered
<b>Strengths</b>	0. Not triggered 1. Triggered	0. Not triggered 1. Triggered
<b>Readmission</b>	0. Not triggered 1. Triggered	0. Not triggered 1. Triggered
<b>Caregiver distress</b>	0. Not triggered 1. Triggered	0. Not triggered 1. Triggered
<b>Life skills</b>	0. Not triggered 1. Triggered for IADL assistance 2. Triggered for ADL assistance	0. Not triggered 1. Triggered (1,2)
<b>Criminality prevention</b>	0. Not triggered 1. Triggered	0. Not triggered 1. Triggered
<b>Education support</b>	0. Not triggered	0. Not triggered

	1. Triggered	1. Triggered
<b>Hazardous fire involvement</b>	0. Not triggered 1. Triggered	0. Not triggered 1. Triggered
<b>Transition</b>	0. Not triggered 1. Triggered	0. Not triggered 1. Triggered
<b>Weight management</b>	0. Not triggered 1. Triggered	0. Not triggered 1. Triggered
<b>Injurious behaviours</b>	0. Not triggered 1. Triggered	0. Not triggered 1. Triggered
<b>Problematic eating behaviours</b>	0. Not triggered 1. Triggered	0. Not triggered 1. Triggered
<b>Gambling</b>	0. Not triggered 1. Triggered	0. Not triggered 1. Triggered
<b>Education</b>	0. Not triggered 1. Triggered	0. Not triggered 1. Triggered
<b>Continence</b>	0. Not triggered 1. Triggered	0. Not triggered 1. Triggered
<b>Video gaming</b>	0. Not triggered 1. Triggered	0. Not triggered 1. Triggered
<b>Social relations</b>	0. Not triggered 1. Triggered to promote social involvement 2. Triggered to improve unsettled relationships	0. Not triggered 1. Triggered (1,2)
<b>Social and peer relationships</b>	0. Not triggered 1. Triggered to reduce or maladaptive or antisocial peer interactions 2. Triggered to reduce social withdrawal or isolation	0. Not triggered 1. Triggered
<b>Communication</b>	0. Not triggered 1. Triggered	0. Not triggered 1. Triggered
<b>Interpersonal conflict</b>	0. Not triggered 1. Triggered to reduce conflict within a specific domain 2. Triggered to reduce widespread conflict	0. Not triggered 1. Triggered
<b>Physical activity</b>	0. Not triggered 1. Triggered	0. Not triggered 1. Triggered
<b>Mobility</b>	0. Not triggered 1. Triggered for high dependence on others for mobility 2. Triggered for moderate dependence for mobility	0. Not triggered 1. Triggered for high dependence on others for mobility 2. Triggered for moderate dependence for mobility

<b>Play</b>	0. Not triggered 1. Triggered	0. Not triggered 1. Triggered
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**APPENDIX 2b: Raw Data**

*Note.* The term violated refers to having (a) cell count(s) less than five and therefore could not be reported due to ethical and statistical restrictions.

*CAPs Triggered by Number (%) of High Functioning and Low Functioning Individuals.*

<b>CAP</b>	<b>Code</b>	<b>High Functioning</b>	<b>Low Functioning</b>	<b>N</b>
<b>Safety</b>				
<b>Control interventions</b>	Triggered	<b>Violated</b>		<b>N/A</b>
	Not Triggered			
<b>Harm to others</b>	Triggered	80 (30%)	<b>CAP not available on ChYMH-DD</b>	272
	Not Triggered	192 (70%)		
<b>Hazardous Fire Involvement</b>	Triggered	17 (6%)	<b>Violated</b>	272
	Not Triggered	255 (94%)		
<b>Sexual behaviour</b>	Triggered	13 (11%)	<b>Violated</b>	122 <sup>a</sup>
	Not Triggered	109 (89%)		
<b>Suicidality and purposeful self-harm to others</b>	Triggered	54 (20%)	<b>Violated</b>	272
	Not Triggered	218 (80%)		
<b>Traumatic life events</b>	Triggered	114 (48%)	32 (40%)	319 <sup>b</sup>
	Not Triggered	124 (52%)	49 (60%)	
<b>Injurious behaviour</b>	Triggered	<b>CAP not available on ChYMH</b>	96 (91%)	106
	Not Triggered		10 (9%)	
<b>Criminality Prevention</b>	Triggered	100 (37%)	<b>CAP not available on ChYMH-DD</b>	272
	Not Triggered	172 (63%)		
<b>Health Promotion</b>				
<b>Caffeine</b>	Triggered	9 (3%)	<b>CAP not available on ChYMH-DD</b>	272
	Not Triggered	263 (97%)		
<b>Medicine Adherence</b>	Triggered	29 (11%)	7 (7%)	378
	Not Triggered	243 (89%)	99 (93%)	
<b>Medicine Review</b>	Triggered	96 (35%)	48 (45%)	378
	Not Triggered	176 (65%)	58 (55%)	
<b>Physical Activity</b>	Triggered	72 (27%)		272

<sup>a</sup> 150 cases responded to the not applicable response option

<sup>b</sup> 34 cases responded to the not applicable response option for the ChYMH and 25 cases responded not applicable on the ChYMH-DD

	Not triggered	200 (73%)	<b>CAP not available on ChYMH-DD</b>	
<b>Sleep Disturbance</b>	Triggered	175 (64%)	<b>CAP not available on ChYMH-DD</b>	272
	Not Triggered	97 (36%)		
<b>Substance</b>	Triggered	6 (4%)	<b>CAP not available on ChYMH-DD</b>	138 <sup>c</sup>
	Not Triggered	132 (96%)		
<b>Tobacco &amp; Nicotine Use</b>	Triggered	15 (6%)	<b>CAP not available on ChYMH-DD</b>	272
	Not Triggered	257 (94%)		
<b>Video gaming</b>	Triggered	74 (27%)	<b>CAP not available on ChYMH-DD</b>	272
	Not Triggered	198 (73%)		
<b>Gambling</b>	Triggered	<b>Violated</b>	<b>CAP not available on ChYMH-DD</b>	N/A
	Not Triggered			
<b>Weight management</b>	Triggered	51 (40%)	<b>CAP not available on ChYMH-DD</b>	138 <sup>d</sup>
	Not Triggered	87 (60%)		
<b>Strengths</b>	Triggered	90 (38%)	52 (64%)	319 <sup>e</sup>
	Not Triggered	148 (62%)	29 (36%)	
<b>Health and Wellbeing</b>				
<b>Sleep Management</b>	Triggered	<b>CAP not available on ChYMH</b>	76 (28%)	106
	Not Triggered		30 (72%)	
<b>Problematic eating behaviours</b>	Triggered	<b>CAP not available on ChYMH</b>	57 (54%)	106
	Not Triggered		49 (46%)	
<b>Modified Nutrition</b>	Triggered	<b>CAP not available on ChYMH</b>	<b>Violated</b>	
	Not Triggered			
<b>Continance</b>	Triggered	<b>CAP not available on ChYMH</b>	34 (42%)	81 <sup>f</sup>
	Not Triggered		47 (58%)	
<b>Functional Status</b>				
<b>Communication</b>	Triggered	70 (26%)	79 (74%)	378
	Not triggered	202 (74%)	27 (26%)	
<b>Life Skills</b>	Triggered	44 (32%)	<b>Violated</b>	137 <sup>g</sup>
	Not Triggered	93 (68%)		

<sup>c</sup> 134 cases responded not applicable<sup>d</sup> 134 responded not applicable<sup>e</sup> 34 responded not applicable on the ChYMH and 25 responded not applicable on the ChYMH-DD<sup>f</sup> 25 cases responded not applicable<sup>g</sup> 135 responded not applicable

<b>Accessibility and mobility</b>	Triggered	<b>CAP not available on ChYMH</b>	<b>Violated</b>	
	Not triggered			
<b>Play and leisure</b>	Triggered	<b>CAP not available on ChYMH</b>	76 (94%)	81 <sup>h</sup>
	Not triggered		5 (6%)	
<b>Service and Supports</b>				
<b>Informal Support</b>	Triggered	81 (30%)	<b>CAP not available on ChYMH-DD</b>	272
	Not Triggered	191 (70%)		
<b>Support system for discharge</b>	Triggered	6 (42%)	<b>Violated</b>	14 <sup>i</sup>
	Not Triggered	8 (58%)		
<b>Education</b>	Triggered	101 (74%)	<b>CAP not available on ChYMH-DD</b>	136 <sup>j</sup>
	Not Triggered	35 (26%)		
<b>Education Support</b>	Triggered	<b>CAP not available on ChYMH-</b>	61 (59%)	103 <sup>k</sup>
	Not Triggered		42 (41%)	
<b>Readmission</b>	Triggered	63 (23%)	<b>CAP not available on ChYMH-DD</b>	272
	Not Triggered	209 (77%)		
<b>Transitions</b>	Triggered	93 (39%)	54 (67%)	319 <sup>l</sup>
	Not Triggered	145 (61%)	27 (33%)	
<b>Family Life and Social Integration</b>				
<b>Attachment</b>	Triggered	24 (22%)	<b>CAP not available on ChYMH-DD</b> N/A	108 <sup>m</sup>
	Not Triggered	84 (78%)		
<b>Caregiver distress</b>	Triggered	121 (44%)	50 (47%)	378
	Not Triggered	151 (56%)	56 (53%)	
<b>Interpersonal conflict</b>	Triggered	106 (52%)	<b>CAP not available on ChYMH-DD</b>	202 <sup>n</sup>
	Not triggered	96 (48%)		

<sup>h</sup> 25 cases responded not applicable<sup>i</sup> 258 cases responded not applicable<sup>j</sup> 136 responded not applicable<sup>k</sup> Not applicable category violated<sup>l</sup> 34 cases responded not applicable on ChYMH and 25 responded not applicable on the ChYMH-DD<sup>m</sup> 196 responded not applicable<sup>n</sup> 70 cases responded not applicable

<b>Parenting</b>	Triggered	18 (7%)	<b>Violated</b>	272
	Not Triggered	254 (93%)		
<b>Social and peer relationships</b>	Triggered	205 (75%)	<b>CAP not available on ChYMH-DD</b>	272
	Not triggered	67 (25%)		
<b>Social Relations</b>	Triggered	<b>CAP not available on ChYMH-</b>	65 (61%)	106
	Not triggered		41 (39%)	



**Chapter 3- Study #2: Overall Health, Social Functioning, and Motor Functioning of  
Individuals with High Functioning and Low Functioning Autism Spectrum Disorder**

### **3.1. Abstract**

Individuals with autism spectrum disorder (ASD) experience a myriad of challenges. For example, it has been documented that individuals with ASD have compromised health, social, and motor impairments. Multiple risk factors play a role in their challenges experienced, as well as the severity of these challenges. One of the main risk factors is the level of functioning of individuals. However, there is a lack of research comparing the differences in overall health, social, and motor impairments individuals with LF and HF ASD experience. For this reason, the current study compared overall health, social functioning, and motor functioning among individuals diagnosed with ASD through the analysis of the interRAI Child and Youth Mental Health – Developmental Disabilities (ChYMH-DD) and the interRAI Child and Youth Mental Health (ChYMH) assessments. The findings revealed minimal differences between LF and HF individuals with regards to their overall health and motor functioning. However, significant differences pertaining to social functioning were revealed. In addition to discussing the differences pertaining to the social functioning of HF and LF individuals, the study highlights implications arising from this research as well as opportunities for future research.

### 3.2. Introduction

An estimated one in 66 children have autism spectrum disorder (ASD) in Canada. ASD is more prevalent in males, with a 4:1 male to female ratio. Common characteristics of ASD include impairments in social and communication abilities, as well as restricted and repetitive patterns of behaviour (Autism Ontario, 2018). The severity of an individual's ASD diagnosis is determined by the amount of support required for impairments, where low functioning (LF) ASD indicates severe impairments including non-verbal communication or limited toileting abilities, while high functioning (HF) ASD indicates minimal impairments (American Psychiatric Association [APA], 2013; Autism Ontario, 2016). The impairments individuals with ASD experience result in a wide array of challenges. The current paper will focus on the challenges individuals with ASD experience with regards to their overall health, social functioning, and motor functioning.

**3.2.1. Overall health.** Children with ASD have compromised wellbeing compared to typically-developing children (Gurney, McPheeter, & Davis, 2006; Kuhlthau, et al., 2010; Potvin, Snider, Prelock, Wood-Dauphinee, & Kehayia, 2015). Factors accounting for compromised wellbeing include multiple negative conditions (e.g., anxiety, attention deficit disorder, depression), lower adaptive functioning (e.g., more social impairments, repetitive behaviours, etc.), and severity of symptoms (Gurney et al., 2006; Kuhlthau et al., 2010; Potvin et al., 2015). ASD is often associated with comorbid conditions, such as epilepsy, depression, anxiety, and attention deficit hyperactivity disorder (ADHD) (World Health Organization [WHO], 2016). In addition to the above challenges, researchers confirmed children with ASD also suffer from sleep disorders, including obstructive sleep apnea, parasomnias (e.g., night terrors or sleep talking), insomnia/circadian rhythm disorder, daytime excessive sleepiness, and

reduced sleep duration (Delahaye et al., 2013; Herrmann, 2016; Hirata et al., 2015). Further, Herrmann (2016) reported autism severity (e.g., greater communication and social deficits), lower IQ, gastrointestinal disturbances, and decreased melatonin levels are risk factors for sleep disorders among children with ASD. Although those diagnosed with ASD may be affected by similar health issues as the general population, they have specific health care needs related to their comorbid conditions, in addition to their ASD health care needs.

**3.2.2. Social functioning.** Deficits in socialization, such as difficulty with eye contact, speech abnormalities, and failure to initiate interpersonal interactions, are considered a core component of ASD (Tureck & Matson, 2012; Fodstad, Matson, Hess, & Neal, 2009). Further social deficits observed in children with ASD include increased interaction with adults opposed to peers, minimal verbal and non-verbal interaction with peers, less mature play, and little engagement in socially complex play (Anderson, Moore, Godfrey, & Fletcher-Flinn, 2004). Ratcliffe, won, Dossetor, and Hayes (2015) concluded children with ASD who had higher IQs displayed better social skills than those with lower IQs.

An additional social challenge experienced by children with ASD is bullying. Contributing factors for being bullied include aspects of ASD (e.g., communication impairments), being male, having higher levels of behaviour problems, younger age, mental health problems, and parental mental health problems (Cappadocia, Weis, & Pepler, 2011; Kloosterman, Kelley, Craig, Parker, & Javier, 2012; Zeedyk, Rodriguez, Tripton, Baker, & Blacher, 2014). In a study conducted by Zablotsky, Bradshaw, Anderson, and Law (2014), it was reported bullying was most common among HF individuals when compared to individuals of moderate and low functioning. Zablotsky et al. (2014) hypothesized bullying was more common among individuals with HF ASD because they likely spent more time in an inclusive, less

protected education setting. Further work in this area is warranted to ensure bullying among individuals with ASD is prevented.

**3.2.3. Motor functioning.** Motor impairments exhibited by individuals with ASD have been categorized as “associated symptoms” (Ming, Brimacombe, & Wagner, 2007, p. 566). Ming et al. (2007) found the most prevalent motor deficits in children with ASD were hypotonia (low muscle tone) and apraxia (difficulty with motor planning). Further motor impairments noted in the literature include difficulties with motor coordination, postural control, and delays in gross and fine motor skills (Bhat, Landa, & Galloway, 2009).

Ament et al. (2015) compared motor functioning among children with ASD, ADHD, and typically developing children. Researchers found that children with ASD and ADHD demonstrated greater overall motor impairments compared to the typically developing group. However, children with ASD exhibited the greatest overall impairment. Greater deficits in catching and balance were evident in the ASD group, and not the ADHD group. Ament et al. (2015) hypothesized the visual and temporal feedback required for motor skills appeared to be deficient in children with ASD.

In a study that investigated motor impairments of females with ASD, greater motor impairments were associated with lower IQs, as well as ASD symptom severity and younger age (Kopp, Beckung, & Gillberg, 2009). Kopp et al. (2009) concluded poor motor ability was related to a lower ability to engage in, and complete, daily living skills. Green et al. (2009) also found low IQ contributed to further impairment in motor skills in children with ASD. The authors hypothesized children with ASD and a low IQ may be more neurologically compromised.

**3.2.4. High functioning vs low functioning.** Individuals diagnosed with ASD clearly experience a wide array of challenges, particularly for individuals considered LF. Many studies

have confirmed low IQ and/or more severe ASD are risk factors for compromised wellbeing (Gurney et al., 2006; Kuhlthau et al., 2010; Potvin et al., 2015), higher levels of anxiety (Ratcliffe, Won, Dossetor, & Hayes, 2015), and reduced social skills (Tureck & Matson, 2012), and motor impairments (Kopp et al., 2009). Although research has confirmed severe ASD is associated with reduced health, and poor social and motor functioning, comparisons of these domains between low and high functioning individuals is missing in the literature. As such, it is important we understand the variability between individuals with ASD in order to facilitate the development and implementation of therapies for individuals across the spectrum. For this reason, the current study compared overall health, social functioning, and motor functioning among individuals diagnosed with ASD through the analysis of the interRAI Child and Youth Mental Health – Developmental Disabilities (ChYMH-DD) and the interRAI Child and Youth Mental Health (ChYMH) assessments. It was anticipated individuals considered LF would be more compromised in most health domains and have greater social and motor deficits compared to their HF counterparts.

### **3.3. Methods**

**3.3.1. Ethics.** Prior to the secondary data analyses of the ChYMH-DD (low functioning [LF]) and ChYMH (high functioning [HF]) data set, ethics was obtained from the Wilfrid Laurier University Research Ethics Board. Previously the lead researcher had obtained ethical clearance from Western University (location of lead researcher collecting the data) and participating health agencies.

**3.3.2. Procedure.** The data analyzed were obtained between January 2015 and November 2016 using the interRAI ChYMH and ChYMH-DD, which were completed at 14 mental healthcare agencies located in Ontario. Children were referred to these agencies through self-

referral, or by family doctor, pediatricians, or other healthcare professionals. All assessors administering the tools completed two and a half days of intensive training, have a diploma or degree in the mental health field, and at least two years of clinical experience with children/youth. This training was developed by local, national, and international experts in the field of children's mental health. Assessors completed the assessments as part of normal clinical practice and took roughly 60 to 90 minutes to complete (interRAI, 2018). The assessments were completed in a semi-structured interview format and information was obtained from various available sources including the child themselves, parents, educators, and/or other health care clinicians, in addition to records such as clinical assessments and school records, with appropriate consent. The assessments do not contain any missing data, as incomplete assessments cannot be submitted into the databases. Completed assessments were entered into a de-identified software which was password protected, encrypted, and stored on computers without internet access or a USB port (Stewart et al., 2015a; Stewart et al., 2015b).

### **3.3.3. Research Tools**

**3.3.3.1. *interRAI instruments: ChYMH-DD and ChYMH.*** The ChYMH-DD (for LF individuals) and the ChYMH (for HF individuals) are comprehensive, multidisciplinary mental health assessments for children and youth aged 4 to 18 years who are referred to either community-based (outpatient) or residential (inpatient) developmental services (Stewart et al., 2015a; Stewart et al., 2015b). Note, the ChYMH-DD is specific for children and adolescents with developmental disabilities, such as ASD and whose intellectual functioning is under 70, while the ChYMH is designed for children whose intellectual functioning is above 70 (Stewart et al., 2015a; Stewart et al., 2015b). The purpose of the ChYMH-DD and the ChYMH are threefold: (1) to maximize the young person's functional capacity and quality of life; (2) to

address physical and mental health problems; and (3) to enhance the young person's level of independence (Stewart et al., 2015a; Stewart et al., 2015b). Overall, the ChYMH-DD and the ChYMH have the ability to identify strengths, preferences, and needs among individuals with ASD. Problem areas for individuals can be identified through the analysis of specific items. Further, Collaborative Action Plans (CAPs) provide guidelines for care in areas triggered as problematic (e.g., interpersonal conflict, caregiver distress). The assessments also include several scales, which provide measurements in a wide range of areas (e.g., aggression scale) (Stewart et al., 2015a; Stewart et al., 2015b). Analysis of individual CAPs and scales allow for the most appropriate and effective interventions to be identified and recommended. The current study analyzed items and scales to gain an understanding of the differences in which LF and HF individuals exhibited in specific areas of need pertaining to overall health, social, and motor functioning. It is important to note, validity and reliability of the interRAI instruments has been confirmed across numerous studies (see, Carpenter, 2006; Gray et al., 2009; Hirdes et al., 2008; Hirdes et al., 2002; Poss et al., 2009; Lau, 2017; Stewart & Hamza, 2017).

*3.3.3.1.2. Variables.* Multiple items were analyzed and compared between LF (individuals with an  $IQ < 70$ ) and HF (individuals with an  $IQ > 70$ ) individuals. Items corresponded with one of the four sections: (1) background information; (2) overall health; (3) social functioning; and (4) motor functioning. Table 3.1, located at the end of this paper, provides a comprehensive list of items within each area. Items were recoded into dichotomous constructs, by doing so this prevented cell counts from being less than five. Ethical guidelines stated that reporting cell sizes less than five was prohibited as this could potentially reveal the identity of the participants. As well, examining expected cell counts less than five violates a chi-square



assumption (Field, 2009). As such, responses less than five were not be reported. See Appendix 3a for recoding of items.

*3.3.3.1.3. Scales.* In addition to items, seven scales were also analyzed. Scales are comprised of a series of items and provide information regarding an individual's outcome measurement and status regarding a specific area (e.g., anxiety scale, sleep scale) (Stewart et al., 2015a; Stewart et al., 2015b). Higher scores on scales indicate a greater degree of impairment of risk in that specific area. Applicable scales present on both the ChYMH and ChYMH-DD were compared between HF and LF individuals. To analyze the scales, the researcher used the same cut-points interRAI clinicians and researchers use to make clinical decisions (Stewart, Fadeyi, Hirdes, & Fries, 2017). However, to avoid having cell counts less than five, there were cases in which cut-points had to be collapsed. For clinical decision cut-points and the cut-points used for each scale see Appendix 3b.

*Anxiety Scale.* This scale measures frequency of anxiety symptoms with scores ranging from 0 to 32. The anxiety scale is comprised of the following items: repetitive anxious concerns, unrealistic fears, obsessive thoughts, intrusive thoughts or flashbacks, episodes of panic, hypervigilance, and nightmares.

*Depression Scale.* This scale assesses depressive indicators with scores ranging from 0 to 36. The depression scale is comprised of the following items: negative statements, sad, pained, worried facial expression, crying or tearfulness, self-deprecation, guilt/shame, hopelessness, irritability, lack of motivation, and withdrawal from activities of interest.

*Communication Scale.* This scale measures participants' ability to understand and be understood. Scores on this scale range from 0 to 8. The communication scale is comprised of the following items: making self-understood and ability to understand others.

*Disruptive/ Aggressive Behaviour Scale.* This scale assesses anger in terms of severity and frequency. Scores on this scale range from 0 to 20. The disruptive/ aggressive behaviour scale is comprised of the following items: verbal abuse, physical abuse, socially inappropriate/ disruptive, destructive behaviour towards property, and outbursts of anger.

*Caregiver Distress Scale.* This scale assesses caregiver stress on a scale from 0 to 5. The caregiver distress scale is comprised of the following items: parent/primary guardian had experienced major life stressors in the last 90 days, parent/primary guardian was unable or unwilling to continue in caring activities, and parent/primary guardian expression feelings of distress, anger, or depression.

*Pain Scale.* This scale measures the intensity and frequency pain is experienced by participants. Scores on this scale range from 0 to 7. The pain scale is comprised of the following items: pain frequency and pain intensity.

*Peer Relationship Scale.* This scale assesses conflict that participants experience with friends and scores range from 0 to 5. The peer relationship scale is comprised of the following items: social inclusion by peers, conflict with or repeated criticism of close friends, friends are persistently hostile or critical of child, pervasive conflict with peers (exclude close friends), and peer group includes individuals with persistent antisocial behaviour.

**3.3.4. Data analysis.** Data were analyzed using Statistical Package for the Social Sciences (SPSS) 24 (IBM, 2016). Multiple steps were taken throughout the data analysis process. The data was cleaned, and 29 cases were removed. These cases were removed because it appeared they were either input incorrectly (had an age outside of 4 to 18 years) or because the case(s) reported an identifying demographic variable. As well, non-ASD cases were removed, in addition to cases assessed prior to 2015. Cases prior to 2015 were removed because new items

were modified on the instrument as a result of a pilot resulting in the lack of comparison across all items.

In the case of four items (conflict with friends, friends are hostile, pervasive conflict with peers, and conflict with family) the non-applicable response option was removed, and therefore resulted in missing data. With regards to these items, the researcher was interested in whether the conflict was present or not present, in the participant's life, not if it was non-applicable. However, it is crucial to note that this response option is still important, although it was not in the scope of the study. Qualitative investigation into why individuals reported 'non-applicable' for these items is warranted (e.g., in cases where individuals responded 'not applicable' to conflict with friends this may be because they did not have friends).

Items with multiple response options were recoded to reflect binary responses (e.g., present, not present). The initial response options were examined. However, due to the limited numbers of participants, the cells sizes often were too small and could not be reported due to ethical and statistical restrictions. Consequently, the response options were dichotomized. For example, the "lack of interest in social interaction" item originally had the following responses (Stewart et al., 2015):

0. Not present
1. Present but not exhibited in last 3 days
2. Exhibited on 1-2 of last 3 days
3. Exhibited daily in last 3 days, 1-2 episodes
4. Exhibited daily in last 3 days, 3 or more episodes or continuously

This item was recoded to have only two responses. In doing so, the item response "not present" was transformed to "no" while item responses one to four were collapsed and transformed into "yes." Please refer to Appendix 3a for recoding of items.

As mentioned above, scales were first analyzed using clinical decision cut-points. However, in cases where cell sizes were less than five, cut-points were collapsed. See Appendix 3b.

Similar to Stewart and Hirdes (2015), chi-square tests were conducted to detect differences between groups, for the current study the groups were: HF and LF. To control for type 1 errors, tests were conducted using Bonferroni adjusted alpha levels (Field, 2009). For background information, the alpha used was .003 (.05/15). For overall health, the alpha used was .002 (.05/24). For social functioning, the alpha used was .003 (.05/15) and for motor items the alpha used was .01 (.05/3). For scales, the alpha used was .007 (.05/7). To quantify the strength of the relationships, odd ratios and confidence intervals were calculated by SPSS on every significantly different item. In addition to odds ratios, Cramer's-V was also computed to determine the strength of the relationships. To determine the location of significant differences, standardized residuals were examined. The results will be presented in five sections: (1) background information, (2) overall health, (3) social functioning, (4) motor functioning, and (5) scales. Within all sections, significantly different items and scales will be briefly discussed. Data pertaining to all chi-square tests for the items analyzed can be found in Appendix 3c. Data pertaining to all chi-square tests for the items analyzed can be found in Appendix 3d.

### **3.4. Results**

**3.4.1. Participants.** The ChYMH-DD and ChYMH data set consisted of 3871 assessments of children and youth who received mental health services across Ontario. Analysis of the secondary data set was limited to individuals with ASD (N = 378, 85 females, 293 males). Two hundred and seventy-two were HF (IQ<70) (60 females, 212 males) with a mean age of 12.77 years (SD=3.16). One hundred and six were LF individuals (IQ>70) (25 females, 81

males) with a mean age of 11.8 years (SD=3.29). Within both groups, more than half of the individuals were 12 years or older. Specifically, 56% of HF individuals (males=114, females=38) and 70% of LF individuals (males=58, females=16) were aged 12 to 18 years. See Table 3.2 for demographic characteristics of HF and LF participants, located at the end of this paper.

Significant differences pertaining to background information, overall health, social functioning, motor functioning, and scales are discussed below. Note, health items were selected based on health indicators discussed in previous literature. The literature listed numerous factors that compromise the health of individuals with ASD (see, Gurney et al., 2006; Kuhlthau et al., 2010; Potvin et al., 2015). As such, health items were a series of health indicators selected based on support from the literature and items available on the ChYMH and ChYMH-DD that would provide insight into one's overall health. Refer to Table 3.3 (at end of paper) for all chi-square significant results pertaining to the items discussed in this section and Table 3.4 for chi-square significant results pertaining to scales discussed in this section. Refer to Appendix 3c for chi-square results pertaining to all items and Appendix 3d for chi-square results pertaining to all scales analyzed.

**3.4.2. Background information.** A total of 15 items concerning reason for referral and formal care in which participants have received in the past three years were analysed between the two groups. LF individuals were 2.05 times more likely to have contact with an occupational or physical therapist in the last three years ( $X^2_{(1)}=28.16, p<.001$ ) than HF individuals.

**3.4.3. Overall health.** A total of 24 overall health items were compared between groups. HF individuals were 2.28 times more likely to have a diagnosis of ADHD ( $X^2_{(1)} = 3.91, p<.001$ ) when compared to their LF counterparts.

**3.4.4. Social functioning.** A total of 15 social functioning items were compared between groups. LF individuals were 4.23 times more likely to lack interest in social interaction and were more likely to exhibit socially inappropriate or disruptive behaviour ( $X^2_{(1)}=34.38, p<.001$ ). With regards to communication, the HF group reported having a significantly greater ability to understand others ( $X^2_{(1)} = 53.9, p<.001$ ) when compared to LF individuals, such that HF individuals were 5.80 times more like to understand others. Similarly, HF individuals were 14.51 times more likely to make themselves understood significantly more ( $X^2_{(1)} =62.83, p<.001$ ) than LF individuals. HF individuals were 2.31 times more likely than their LF counterparts to have at least one friend with whom visits/plays/socializes regularly ( $X^2_{(1)} =36.58, p<.001$ ) and 2.85 times more like to have a confidant ( $X^2_{(1)} =58.85, p<.001$ ). Yet, HF individuals were 5.42 times more likely to be bullied ( $X^2_{(1)}=39.90, p<.001$ ) compared to their LF counterparts.

**3.4.5. Motor functioning.** A total of 3 motor functioning items were compared between groups. HF individuals were 2.96 times more likely to report adequate fine motor skills ( $X^2_{(1)} =41.08, p<.001$ ) compared to LF counterparts. It should be noted that initially the response options for gross and fine motor skills were dichotomized into 2 response options; however, to understand the range of difficulty pertaining to gross motor skills, all response options were reviewed (Table 3.4). Response options ‘Moderate difficulty’ and ‘Severe difficulty’ were collapsed to avoid having a cell size less than five, in accordance with ethical and statistical considerations. The majority of HF and LF individuals (>50%) reported adequate gross motor skills. With respect to fine motor skills, more than 60% of HF individuals reported adequate fine motor skills, while more than 50% of LF individuals reported moderate to severe difficulty.

**3.4.5. Scales.** With respect to scales, no significant differences were found for anxiety, depression, disruptive/ aggression, and caregiver distress. The pain scale and peer relationship

scale could not be analyzed because cell sizes were less than five. Analysis of the communication scale revealed individuals were significantly more likely to report greater communication skills ( $X^2_{(3)}=53.05$ ,  $p<.001$ ) when compared to LF individuals.

### **3.5. Discussion**

The purpose of the current study was to examine overall health, social functioning, and motor functioning among individuals diagnosed with ASD through the analysis of the ChYMH and ChYMH-DD. Given prior research (see, Gurney et al., 2006; Kuhlthau et al., 2010; Potvin et al., 2015; Ratcliff et al., 2015; Tureck & Matson, 2012), it was anticipated individuals considered LF would be more compromised in most health domains and have greater social and motor deficits compared to their HF counterparts. There were minimal differences between groups with respect to health concerns. The only significant difference between groups was, HF individuals were more likely to have been diagnosed with ADHD compared to LF individuals. Due to ethical and statistical considerations, many of the health items could not be reported because their cell counts were less than five. With respect to motor skills, HF individuals had significantly greater fine motor skills when compared to their LF counterparts. This was further confirmed when all response options were reviewed for the fine motor skills item; more HF individuals reported adequate fine motor skills, while more LF individuals reported moderate to severe difficulty with fine motor skills. With respect to gross motor skills, more HF individuals (73%) were reporting adequate gross motor skills than LF individuals (53%). In addition to these motor differences, there were also many differences with regards to social functioning between the groups. As such, these social differences will be the focus of the discussion.

**3.5.1. Social deficits.** According to the diagnostic criteria for ASD, a child must exhibit “persistent deficits in social communication and social interaction across multiple

contexts...” (APA, 2013). As a core feature of this disorder, it is no surprise children with ASD exhibited many social impairments. Social impairments in children with ASD include: less mature play behaviour, preference to interact with adults opposed to peers, difficulty with eye contact, speech abnormalities, and failure to initiate interpersonal interactions (Anderson et al., 2004; Fodstad, Matson, Hess, & Neal, 2009; Tureck & Matson, 2012). Lack of social skills are associated with a variety of mental health concerns, poor school performance, lack of friendships, and bullying (Ghaziuddin & Zafar, 2008; Matson, Kozlowski, Neal, Worley, & Fodstad, 2011).

The current study revealed a myriad of results related to the social functionality of children and youth with ASD. Although children and youth with HF ASD appeared to have greater social skills than children and youth with LF ASD, they still displayed a pattern of social deficits similar to the LF ASD sample. For example, more than 64% of HF individuals and 69% of LF individuals demonstrated a lack of emotional and social conventions during socializing. It is understood individuals with ASD have limited social and emotional understanding when attempting to socialize with others (Kasari, Chambelain, & Bauminger, 2001). Individuals with ASD display difficulty in identifying complex emotions (e.g., surprise) and struggle with executing typical social behaviours (e.g., initiating a conversation), which often results in loneliness and depression (Bauminger, 2002).

Previous studies examining the social and emotional understandings of children with ASD have focused primarily on HF populations and not LF populations. Research has recently shifted focus from understanding the social and emotional understanding of children with ASD to investigating interventions to address deficits. Although findings from the current research



focuses primarily on HF individuals it is essential research continues to include LF individuals as they also exhibit a similar deficit and may not have been captured with the current data.

**3.5.2. Communication deficits.** Communication difficulties among children with ASD are very prominent. According to Howlin (2006), between 25% and 50% of all children with ASD do not develop functional language. Further communication difficulties can include: lack of receptive and/or expressive language, limited use of communicative gestures (e.g., pointing), and delayed speech (Manning-Courtney et al. 2003). Poor communication (i.e., non-verbal cognitive ability and low expressive language) is associated with aggression, attentional difficulties, emotional issues such as anxiety and depression (Hartley, Sikora, & McCoy, 2008), and poor social skills (Dworzynski et al., 2007; Hattier & Matson, 2012).

In this study, LF individuals had significantly greater communication deficits compared to HF individuals. In fact, only 7% of LF individuals were able to make themselves understood and only 9% were able to understand others. This was further confirmed, as analysis of the communication scale also revealed LF individuals had significantly greater communication deficits. It is likely this communication deficit acts as a barrier to their ability to socialize, as they were significantly less likely to report having at least one friend in which they socialized with and were less likely to report having a confidant. This is supported by literature as socialization and communication impairments have been found to be significantly correlated in children with ASD (Dworzynski et al., 2007; Hattier & Matson, 2012). Newborg (2005) proposed children with communication deficits also exhibit social deficits because they may feel anxious and/or apprehensive to interact with peers and adults, because of their challenges with communicating.

There is limited research exploring communication differences between LF and HF individuals. It is important these differences are identified so effective communication strategies

and therapies can be tailored to HF and LF individuals. It is crucial communication deficits are identified and addressed early in children with ASD to improve communication skills and minimize the consequences of such deficits. Speech and language therapies are effective in addressing communication impairments in children with ASD, in turn resulting in enhanced social behaviours and therefore should be suggested to parents of children with ASD at the time of diagnosis (Manning-Courtney et al., 2003). Further research is warranted in this area.

**3.5.3. Bullying.** Literature has confirmed children with ASD are at a higher risk for being bullied (Cappadocia et al., 2012; Zablotsky, et al., 2014). Common forms of bullying include being hit by peers, picked on, being scared by peers (Little, 2009), being made fun of, verbal abuse, and physical abuse (being hit, kicked, or pushed) (Bitsika & Sharpley, 2014). Children who display greater autistic traits, have more comorbid conditions, have more difficulty making friends (Zablotsky et al., 2014) and have greater social difficulties (Cappadocia et al., 2011) are at a higher risk for being bullied. It should also be noted bullying tends to be most prominent during middle school (Zablotsky et al., 2014). High levels of anxiety, self-injurious and stereotypic behaviours, hyperactivity, and oversensitivity tend to arise in children with ASD when they have been victimized/bullied (Cappadocia et al., 2011).

Although the literature supports the idea that children with ASD are at risk for being bullied, based on the review of the literature, there are few studies comparing bullying among HF and LF individuals. An exception to this is a study conducted by Zablotsky et al. (2014) who confirmed bullying was most common among HF individuals when compared to individuals of moderate and low functioning. Researchers of the current study hypothesize this may be due to the invisible nature of HF ASD compared to LF ASD. Given that LF individuals did have communication deficits and an IQ less than 70, peers may be more likely to identify these

individuals as having a disability, especially if they are accompanied by an educational assistant (EA), whereas HF individuals had an IQ greater than 70 and displayed stronger communication skills. Therefore, it may be more difficult for their peers to identify their disability. Conflicting findings emerged from a study conducted by Cappadocia et al. (2011) who found individuals with ASD who exhibited greater communication difficulties were roughly five times more likely to be victimized. This may be due to different sample characteristics. For example, the sample from the Cappadocia et al. (2011) study included mostly HF individuals, and the study did not separate their sample into HF and LF groups.

Another possibility accounting for the fact that HF children and youth with ASD may be at a higher risk for being bullied is that in Ontario, they are more likely to be integrated in an inclusive class setting and do not receive the constant supervision and support of an educational assistant (EA). Because LF individuals exhibit greater deficits, they may be enrolled in special classes and require constant support and supervision from an EA, making it less likely for their peers to bully them. This is supported by Zablotsky et al. (2014) who hypothesized bullying among HF individuals was more common because they likely spent more time in an inclusive, less protected education setting.

Bullying can have long-lasting effects on a child and so it is important that efforts are made to minimize or, better yet, prevent bullying. Considering most bullying occurs at school, specifically during middle school (Zablotsky et al., 2014), schools must develop and implement bullying interventions. Bullying solutions recommended by PREVNet should be considered within schools (2018). Such solutions include identifying bullying early, encouraging students to report bullying, and promoting healthy and positive relationships among students. PREVNet has also developed a resource for teachers entitled *Stand Up! The Next Step Teacher's Guide*. This

resource includes various bullying prevention exercises that teach children the different types of bullying and how to deal with bullying. Teachers should be aware of this resource, so these exercises can be practiced in their classrooms (PREVNet, 2018). Further interventions can aim to increase the awareness of the effects bullying has on individuals with ASD, in addition to training teachers to identify and address bullying as soon as possible. It is also important for schools to promote awareness of invisible disabilities such as ASD. If more children are aware of ASD and who is diagnosed with ASD, they may be less inclined to bully them. It is important to further investigate and highlight the consequences and long-term effects resulting from being bullied. Perhaps, if these consequences are highlighted educators and policy makers may feel a stronger responsibility to play a role in bullying prevention among individuals with ASD and other disabilities.

**3.5.4. Limitations.** As with all research, this current study had some limitations. Despite dichotomizing responses, there were still items in which the cell count was less than five for the LF groups, which increased the possibility of revealing the identity of the participants, as well as violating assumptions of the chi-square test. As such, these results could not be reported. This was also the case for the pain scale and the peer relationship scale. As such, differences between these items and scales are unknown, particularly when examining the health concerns across the samples. Only three items pertaining to motor functioning were analysed and compared between the two groups and therefore the findings pertaining to motor functioning fail to provide a full and comprehensive picture. Perhaps assessments capable of identifying subtle nuances with respect to motor capabilities (e.g., visual motor integration) of individuals with ASD would be more appropriate in determining whether differences exist in motor functioning between HF and LF individuals. Additionally, there were multiple comparisons conducted and therefore this

increased the potential of a type 1 error. As well, the researcher chose to conduct chi-square tests rather than a more rigorous analysis such as a logistic regression. Finally, the current study only looked at health, social, and motor domains. Other areas included in the tool such as substance use, excessive behaviour, and harm to others were not explored. Analysis of these areas are warranted.

### **3.6. Conclusion**

Differences between HF and LF individuals pertaining to health were minimal. This is mostly due to the small LF sample size and therefore, spectrum specific health concerns and motor deficits remain unknown. However, as more sites implement use of these tools, more in-depth analyses of these items and scales will be possible. It was evident HF individuals exhibited greater social skills compared to LF individuals. However, this should not overshadow the fact HF individuals still experienced social deficits, some of which were similar to their LF counterparts. This study also revealed HF individuals were significantly more likely to be bullied than LF individuals. Given the consequences of bullying, it is crucial every effort to minimize and prevent bullying is implemented. Increasing ASD awareness and implementing bullying interventions within the educational system are necessary. ASD is a highly variable disorder, in that children with the diagnosis exhibit many different characteristics and deficits. As such, it is important research continues to identify differences across LF and HF individuals allowing for the development of effective spectrum specific interventions and in turn improve quality of life among individuals with ASD. It is anticipated reducing the challenges experienced by individuals with ASD, will in turn reduce stress on their caregivers and family members.

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Table 3. 1 *Analysed Items from ChYMH-DD and ChYMH*

Section	Items
<b>(1) Background Information</b>	<p data-bbox="574 363 862 396"><u>Reason for Admission</u></p> <ul data-bbox="626 405 1354 646" style="list-style-type: none"> <li data-bbox="626 405 976 438">• Threat or danger to self</li> <li data-bbox="626 447 1005 480">• Threat or danger to others</li> <li data-bbox="626 489 1167 522">• Problem with addiction or dependency</li> <li data-bbox="626 531 1354 604">• Specific psychiatric symptoms e.g., severe behaviour problems, depression, hallucinations</li> <li data-bbox="626 613 1305 646">• Involvement with youth justice system symptoms</li> </ul>
	<p data-bbox="574 682 748 716"><u>Formal Care</u></p> <ul data-bbox="626 724 1341 1129" style="list-style-type: none"> <li data-bbox="626 724 824 758">• Psychiatrist</li> <li data-bbox="626 766 854 800">• Social worker</li> <li data-bbox="626 808 1341 842">• Psychologist, psychometric, psychological associate</li> <li data-bbox="626 850 1175 884">• Occupational therapist, physiotherapist</li> <li data-bbox="626 892 1143 926">• Recreation, art, music, play therapist</li> <li data-bbox="626 934 889 968">• Registered nurse</li> <li data-bbox="626 976 883 1010">• Child protection</li> <li data-bbox="626 1018 927 1052">• Behaviour therapist</li> <li data-bbox="626 1060 792 1094">• Dietician</li> <li data-bbox="626 1102 1040 1136">• Speech language pathologist</li> </ul>
<b>(2) Overall Health</b>	<ul data-bbox="626 1144 1377 1503" style="list-style-type: none"> <li data-bbox="626 1144 1187 1178">• Intensity of highest level of pain present</li> <li data-bbox="626 1186 1377 1293">• Repetitive health complaints- e.g., persistently seeks attention for physical symptoms such as headaches and stomach ache; incessant concern with body functions</li> <li data-bbox="626 1302 1200 1335">• Difficulty falling asleep or staying asleep</li> <li data-bbox="626 1344 1268 1377">• Sleep problems related to hypomania or mania</li> <li data-bbox="626 1386 1377 1459">• Frequency with which child/youth complains or shows evidence of pain</li> <li data-bbox="626 1467 959 1501">• Prescribed medication</li> </ul> <p data-bbox="574 1549 688 1583"><u>DSM-IV</u></p> <ul data-bbox="626 1591 1365 1873" style="list-style-type: none"> <li data-bbox="626 1591 1045 1625">• Reactive attachment disorder</li> <li data-bbox="626 1633 1195 1667">• Attentional deficit hyperactivity disorder</li> <li data-bbox="626 1675 1365 1749">• Disruptive behavior disorder e.g., oppositional defiant disorder, conduct disorder</li> <li data-bbox="626 1757 1143 1791">• Learning or communication disorder</li> <li data-bbox="626 1799 1024 1833">• Substance related disorders</li> <li data-bbox="626 1841 1219 1875">• Schizophrenia or other psychotic disorders</li> </ul>

- 
- Mood disorders
  - Eating disorders
  - Anxiety disorders
  - Adjustment disorder
  - Sleep disorders

*Medical Diagnosis*

- Asthma
- Diabetes mellitus
- Epilepsy or seizure disorders
- Fetal alcohol effects/syndrome
- Migraine
- Traumatic brain injury
- Severe allergies

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**(3) Social  
Functioning**

- Socially inappropriate or disruptive behaviour
- Ability to understand others (comprehension)
- Making self understood (expression)
- Demonstrates lack of social and emotional conventions when socializing- e.g., lack of eye contact
- Extreme shyness- e.g., severe inhibition in familiar social situations
- Peer group includes individuals with persistence anti-social behaviours
- Lack of interest in social interaction
- Strong and supportive relationship with friends/peers
- Social inclusion by peers
- Has at least one friend with whom visits/plays/socializes regularly
- Conflict or repeated criticisms of close friends
- Pervasive conflict with peers (exclude close friends)
- Friends are persistently hostile or critical of child/youth
- Reports having a confidant
- Victim of bullying

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**(4) Motor  
Functioning**

- Gross motor skills
  - Fine motor skills
  - Total hours of exercise or physical activity in last 3 days
-

Table 3. 2 *Demographic Characteristics of High Functioning and Low Functioning Groups, n (%)*

<b>Characteristic</b>	<b>HF</b>	<b>LF</b>
N (total)	272	106
<b>Age</b>		
Children (ages 4 to 11)	120 (44%)	32 (30%)
Youth (ages 12 to 18)	152 (56%)	74 (70%)
<b>Sex</b>		
Males	212 (78%)	81 (76%)
Females	60 (22%)	25 (24%)

Table 3. 3 *Health, Social, and Motor Items Compared Among High Functioning and Low Functioning Individuals (df=1), Sample Size (% sample in group) (Highlighted boxes indicate which group was significantly more likely to report the corresponding item)*

Item	Code	HF N (%) Standardized Residuals	LF N (%) Standardized Residuals	N	P value	X <sup>2</sup>	Odds Ratio	Confidence Intervals	Cramer's V
<b>BACKGROUND ITEMS</b>									
<b>Occupational therapist, Physiotherapist</b>	No contact in the past 3 years	162 (68%) <b>1.7</b>	28 (35%) <b>-2.9</b>	319 <sup>o</sup>	<.001	28.16	2.05	1.6-2.6	.297 (p>.001)
	Contact in the past 3 years	76 (32%) <b>-2.1</b>	53 (65%) <b>3.5</b>						
<b>HEALTH ITEMS</b>									
<b>Attentional deficit hyperactivity disorder</b>	Present	152 (56%) <b>2.1</b>	26 (24%) <b>-3.4</b>	378	<.001	30.10	2.29	1.60-2.34	.282 (p>.001)
	Not present	120 (44%) <b>-2.0</b>	80 (76%) <b>3.2</b>						
<b>SOCIAL ITEMS</b>									
<b>Socially inappropriate or disruptive behaviour</b>	No	158 (58%) <b>-2.2</b>	26 (25%) <b>3.5</b>	378	<.001	34.38	4.23	2.55-7.00	.302 (p>.001)
	Yes	114(42%) <b>2.2</b>	80 (75%) <b>-3.6</b>						
	Understands	134 (49%) <b>3.1</b>	9 (9%) <b>-4.9</b>	378	<.001	53.92	5.80	3.07-10.965	.378 (p>.001)

<sup>o</sup> 59 cases missing from item



<b>Ability to understand others (comprehension)</b>	Exhibits Difficulty	138 (51%) <b>-2.4</b>	97 (91%) <b>3.8</b>						
<b>Making self-understood (expression)</b>	Understands	138 (51%) <b>3.3</b>	7 (7%) <b>-5.3</b>	378	<.001	62.83	14.51	6.49-32.33	.408 (p>.001)
	Exhibits Difficulty	134 (49%) <b>-2.6</b>	99 (93%) <b>4.2</b>						
<b>Has at least one friend with whom visits/plays/socializes regularly</b>	No	106 (39%) <b>-2.3</b>	78 (74%) <b>3.7</b>	378	<.001	36.58	2.31	1.66-3.22	.311 (p>.001)
	Yes	166 (61%) <b>2.2</b>	28 (26%) <b>-3.6</b>						
<b>Reports having a confidant</b>	No	89 (33%) <b>-3.0</b>	81 (76%) <b>4.8</b>	378	<.001	58.85	2.85	2.00-4.06	.395 (p>.001)
	Yes	183 (67%) <b>2.7</b>	25 (24%) <b>-4.4</b>						
<b>Victim of bullying</b>	No	154 (58%) <b>-1.9</b>	95 (93%) <b>3.1</b>	369 <sup>p</sup>	<.001	39.90	5.41	2.75-10.70	.329 (p>.001)
	Yes	112 (42%) <b>2.7</b>	8 (7%) <b>-4.4</b>						
<b>MOTOR ITEMS</b>									
<b>Fine motor skills</b>	Adequate	148 (62%) <b>2.2</b>	17 (21%) <b>-3.8</b>	319 <sup>q</sup>	<.001	41.08	2.96	1.92-4.57	.359 (p>.001)
	Exhibits difficulty	90 (38%) <b>-2.3</b>	64 (79%) <b>4.0</b>						

<sup>p</sup> 9 cases missing from item<sup>q</sup> 59 cases missing from item

Table 3. 4 Scales that Differed Significantly Among High Functioning and Low Functioning Individuals (Highlighted boxes indicate which group was significantly more likely to report the corresponding item)

Scale	Code	HF individuals	LF Individuals	df	N	P value	X2	Cramer's V
<b>Communication</b>	Low	49 (29%) <b>2.5</b>	7 (7%) <b>-3.1</b>	3	271	<.001	53.05	.442 (p>.001)
	Moderate	60 (36%) <b>1.4</b>	21 (20%) <b>-1.8</b>					
	High	51 (31%) <b>-1.1</b>	46 (44%) <b>1.4</b>					
	Very High	7 (4%) <b>-3.3</b>	30 (29%) <b>4.2</b>					

Table 3. 5 *Range of Difficulty for Gross and Fine Motor Skills*

<b>Item</b>	<b>Code</b>	<b>HF N (%)</b>	<b>LF N (%)</b>
<b>Fine motor skills</b>	<b>Adequate</b>	148 (62%)	17 (21%)
	<b>Minimal Difficulty</b>	49 (20%)	20 (25%)
	<b>Moderate to severe difficulty</b>	42 (18%)	44 (54%)
	<b>No ability to move body (full paralysis)</b>	0 (0%)	0 (0%)
<b>Gross motor skills</b>	<b>Adequate</b>	179 (75%)	43 (53%)
	<b>Minimal Difficulty</b>	50 (21%)	24 (30%)
	<b>Moderate to severe difficulty</b>	9 (4%)	14 (17%)
	<b>No ability to move body (full paralysis)</b>	0 (0%)	0 (0%)

**APPENDIX 3a: Recoding of Variables***Recoding of Background Information Items*

<b>Item</b>	<b>Original Code</b>	<b>New code</b>
<b>REASON FOR REFERRAL</b>		
<b>Threat or danger to self</b>	0. No 1. Yes	0. No 1. Yes
<b>Threat or danger to others</b>	0. No 1. Yes	0. No 1. Yes
<b>Problem with addiction or dependency</b>	0. No 1. Yes	0. No 1. Yes
<b>Specific psychiatric symptoms- e.g., severe behaviour problems, depression, hallucinations</b>	0. No 1. Yes	0. No 1. Yes
<b>Involvement with youth justice system</b>	0. No 1. Yes	0. No 1. Yes
<b>FORMAL CARE</b>		
<b>Psychiatrist</b>	0. No contact in last 3 years 1. No contact in last 90 days, but contact in last 3 years 2. No contact in last 30 days, but contact 31–90 days ago 3. No contact in last 7 days, but contact 8–30 days ago 4. Contact in last 7 days but not daily 5. Daily contact in last 7 days	0. No contact in last 3 years (0) 1. Contact in last 3 years (1,2,3,4,5)
<b>Social worker</b>	0. No contact in last 3 years 1. No contact in last 90 days, but contact in last 3 years 2. No contact in last 30 days, but contact 31–90 days ago 3. No contact in last 7 days, but contact 8–30 days ago 4. Contact in last 7 days but not daily 5. Daily contact in last 7 days	0. No contact in last 3 years (0) 1. Contact in last 3 years (1,2,3,4,5)
<b>Psychologist, psychometric, psychological associate</b>	0. No contact in last 3 years 1. No contact in last 90 days, but contact in last 3 years 2. No contact in last 30 days, but contact 31–90 days ago 3. No contact in last 7 days, but contact 8–30 days ago 4. Contact in last 7 days but not daily 5. Daily contact in last 7 days	0. No contact in last 3 years (0) 1. Contact in last 3 years (1,2,3,4,5)

<b>Occupational therapist, Physiotherapist</b>	<ul style="list-style-type: none"> <li>0. No contact in last 3 years</li> <li>1. No contact in last 90 days, but contact in last 3 years</li> <li>2. No contact in last 30 days, but contact 31–90 days ago</li> <li>3. No contact in last 7 days, but contact 8–30 days ago</li> <li>4. Contact in last 7 days but not daily</li> <li>5. Daily contact in last 7 days</li> </ul>	<ul style="list-style-type: none"> <li>0. No contact in last 3 years (0)</li> <li>1. Contact in last 3 years (1,2,3,4,5)</li> </ul>
<b>Recreation, art, music, play therapist</b>	<ul style="list-style-type: none"> <li>0. No contact in last 3 years</li> <li>1. No contact in last 90 days, but contact in last 3 years</li> <li>2. No contact in last 30 days, but contact 31–90 days ago</li> <li>3. No contact in last 7 days, but contact 8–30 days ago</li> <li>4. Contact in last 7 days but not daily</li> <li>5. Daily contact in last 7 days</li> </ul>	<ul style="list-style-type: none"> <li>0. No contact in last 3 years (0)</li> <li>1. Contact in last 3 years (1,2,3,4,5)</li> </ul>
<b>Registered nurse</b>	<ul style="list-style-type: none"> <li>0. No contact in last 3 years</li> <li>1. No contact in last 90 days, but contact in last 3 years</li> <li>2. No contact in last 30 days, but contact 31–90 days ago</li> <li>3. No contact in last 7 days, but contact 8–30 days ago</li> <li>4. Contact in last 7 days but not daily</li> <li>5. Daily contact in last 7 days</li> </ul>	<ul style="list-style-type: none"> <li>0. No contact in last 3 years (0)</li> <li>1. Contact in last 3 years (1,2,3,4,5)</li> </ul>
<b>Child protection</b>	<ul style="list-style-type: none"> <li>0. No contact in last 3 years</li> <li>1. No contact in last 90 days, but contact in last 3 years</li> <li>2. No contact in last 30 days, but contact 31–90 days ago</li> <li>3. No contact in last 7 days, but contact 8–30 days ago</li> <li>4. Contact in last 7 days but not daily</li> <li>5. Daily contact in last 7 days</li> </ul>	<ul style="list-style-type: none"> <li>0. No contact in last 3 years (0)</li> <li>1. Contact in last 3 years (1,2,3,4,5)</li> </ul>
<b>Behaviour therapist</b>	<ul style="list-style-type: none"> <li>0. No contact in last 3 years</li> <li>1. No contact in last 90 days, but contact in last 3 years</li> <li>2. No contact in last 30 days, but contact 31–90 days ago</li> <li>3. No contact in last 7 days, but contact 8–30 days ago</li> <li>4. Contact in last 7 days but not daily</li> <li>5. Daily contact in last 7 days</li> </ul>	<ul style="list-style-type: none"> <li>0. No contact in last 3 years (0)</li> <li>1. Contact in last 3 years (1,2,3,4,5)</li> </ul>

<b>Dietician</b>	<ul style="list-style-type: none"> <li>0. No contact in last 3 years</li> <li>1. No contact in last 90 days, but contact in last 3 years</li> <li>2. No contact in last 30 days, but contact 31–90 days ago</li> <li>3. No contact in last 7 days, but contact 8–30 days ago</li> <li>4. Contact in last 7 days but not daily</li> <li>5. Daily contact in last 7 days</li> </ul>	<ul style="list-style-type: none"> <li>0. No contact in last 3 years (0)</li> <li>1. Contact in last 3 years (1,2,3,4,5)</li> </ul>
<b>Speech language pathologist</b>	<ul style="list-style-type: none"> <li>0. No contact in last 3 years</li> <li>1. No contact in last 90 days, but contact in last 3 years</li> <li>2. No contact in last 30 days, but contact 31–90 days ago</li> <li>3. No contact in last 7 days, but contact 8–30 days ago</li> <li>4. Contact in last 7 days but not daily</li> <li>5. Daily contact in last 7 days</li> </ul>	<ul style="list-style-type: none"> <li>0. No contact in last 3 years (0)</li> <li>1. Contact in last 3 years (1,2,3,4,5)</li> </ul>

*Recoding of Overall Health Items*

<b>Item</b>	<b>Original Code</b>	<b>New code</b>
<b>Intensity of highest level of pain present</b>	0. No pain 1. Mild 2. Moderate 3. Severe 4. Times when pain is horrible or excruciating	0. No pain (0) 1. Mild to excruciating pain (1,2,3,4)
<b>Repetitive health complaints- e.g., persistently seeks attention for physical symptoms such as headaches and stomach ache; incessant concern with body functions</b>	0. Not present 1. Present but not exhibited in last 3 days 2. Exhibited on 1-2 of last 3 days 3. Exhibited daily in last 3 days, 1-2 episodes 4. Exhibited daily in last 3 days, 3 or more episodes or continuously	0. Not present (0) 1. Present (1,2,3,4)
<b>Difficulty falling asleep or staying asleep</b>	0. Not present 1. Present but not exhibited in last 3 days 2. Exhibited on 1-2 of last 3 days 3. Exhibited daily in last 3 days, 1-2 episodes 4. Exhibited daily in last 3 days, 3 or more episodes or continuously	0. Not present (0) 1. Present (1,2,3,4)
<b>Sleep problems related to hypomania or mania</b>	0. Never 1. More than 1 year ago 2. 31 days- 1 year ago 3. 8-30 days ago 4. 4-7 days ago 5. In last 3 days	0. Not present (0) 1. Present (1,2,3,4,5)
<b>Frequency with which child/youth complains or shows evidence of pain</b>	0. No pain 1. Present but no exhibited in last 3 days 2. Exhibited on 1-2 of last 3 days 3. Exhibited daily in the last 3 days	0. No pain (0) 1. Pain (1,2,3)
<b>Adherent with medications prescribed by physician-&gt; Prescribed medication</b>	0. Always adherent 1. Adherent 80% of time or more 2. Adherent less than 80% of time, including failure to purchase prescribed medications 8. Not medication prescribed	0. Not prescribed medication (8) 1. Prescribed (0, 1,2)
<b>DSM-IV</b>		
<b>Reactive attachment disorders</b>	0. Not present 1. Most important	0. Not present (0,8)

	2. Second most important 3. Third most important 4. Less important 8. No provisional diagnosis	1. Present (1,2,3,4)
<b>Attentional deficit hyperactivity disorder</b>	0. Not present 1. Most important 2. Second most important 3. Third most important 4. Less important 8. No provisional diagnosis	0. Not present (0,8) 1. Present (1,2,3,4)
<b>Disruptive behavior disorders- e.g., oppositional defiant disorder, conduct disorder</b>	0. Not present 1. Most important 2. Second most important 3. Third most important 4. Less important 8. No provisional diagnosis	0. Not present (0,8) 1. Present (1,2,3,4)
<b>Learning or communication disorders</b>	0. Not present 1. Most important 2. Second most important 3. Third most important 4. Less important 8. No provisional diagnosis	0. Not present (0,8) 1. Present (1,2,3,4)
<b>Substance related disorders</b>	0. Not present 1. Most important 2. Second most important 3. Third most important 4. Less important 8. No provisional diagnosis	0. Not present (0,8) 1. Present (1,2,3,4)
<b>Schizophrenia or other psychotic disorders</b>	0. Not present 1. Most important 2. Second most important 3. Third most important 4. Less important 8. No provisional diagnosis	0. Not present (0,8) 1. Present (1,2,3,4)
<b>Mood disorders</b>	0. Not present 1. Most important 2. Second most important 3. Third most important 4. Less important 8. No provisional diagnosis	0. Not present (0,8) 1. Present (1,2,3,4)
<b>Eating disorders</b>	0. Not present 1. Most important 2. Second most important	0. Not present (0,8)



	3. Third most important 4. Less important 8. No provisional diagnosis	1. Present (1,2,3,4)
<b>Anxiety disorders- e.g., separation anxiety disorder, obsessive compulsive disorder</b>	0. Not present 1. Most important 2. Second most important 3. Third most important 4. Less important 8. No provisional diagnosis	0. Not present (0,8) 1. Present (1,2,3,4)
<b>Adjustment disorder</b>	0. Not present 1. Most important 2. Second most important 3. Third most important 4. Less important 8. No provisional diagnosis	0. Not present (0,8) 1. Present (1,2,3,4)
<b>Sleep disorders</b>	0. Not present 1. Most important 2. Second most important 3. Third most important 4. Less important 8. No provisional diagnosis	0. Not present (0,8) 1. Present (1,2,3,4)
<b>MEDICAL CONDITIONS</b>		
<b>Asthma</b>	0. Not present 1. Primary diagnosis/diagnoses for current stay 2. Diagnosis present, receiving active treatment 3. Diagnosis present, monitored but no active treatment	0. Not present (0) 1. Present (1,2,3)
<b>Diabetes mellitus</b>	0. Not present 1. Primary diagnosis/diagnoses for current stay 2. Diagnosis present, receiving active treatment 3. Diagnosis present, monitored but no active treatment	0. Not present (0) 1. Present (1,2,3)
<b>Epilepsy or seizure disorders</b>	0. Not present 1. Primary diagnosis/diagnoses for current stay 2. Diagnosis present, receiving active treatment 3. Diagnosis present, monitored but no active treatment	0. Not present (0) 1. Present (1,2,3)

<b>Fetal alcohol effects/syndrome</b>	0. Not present 1. Primary diagnosis/diagnoses for current stay 2. Diagnosis present, receiving active treatment 3. Diagnosis present, monitored but no active treatment	0. Not present (0) 1. Present (1,2,3)
<b>Migraine</b>	0. Not present 1. Primary diagnosis/diagnoses for current stay 2. Diagnosis present, receiving active treatment 3. Diagnosis present, monitored but no active treatment	0. Not present (0) 1. Present (1,2,3)
<b>Traumatic brain injury</b>	0. Not present 1. Primary diagnosis/diagnoses for current stay 2. Diagnosis present, receiving active treatment 3. Diagnosis present, monitored but no active treatment	0. Not present (0) 1. Present (1,2,3)
<b>Severe (anaphylactic) allergies- Exclude medication allergies</b>	0. Not present 1. Primary diagnosis/diagnoses for current stay 2. Diagnosis present, receiving active treatment 3. Diagnosis present, monitored but no active treatment	0. Not present (0) 1. Present (1,2,3)

*Recoding of Social Items*

<b>Item</b>	<b>Original Code</b>	<b>New Code</b>
<b>Socially inappropriate or disruptive behaviours- e.g., screamed out during class, smeared or threw food or feces</b>	0. Not present 1. Present but not exhibited in last 3 days 2. Exhibited on 1-2 of last 3 days 3. Exhibited daily in last 3 days, 1-2 episodes 4. Exhibited daily in last 3 days, 3 or more episodes or continuously	0.No (0) 1.Yes (1,2,3,4)
<b>Ability to understand others (comprehension)</b>	0. Understands- <i>Clear comprehension</i> 1. Usually understands- <i>Misses some part/intent of message BUT comprehends most conversation</i> 2. Often understands- <i>Misses some part/intent of message BUT with repetition or explanation can often comprehend conversation</i> 3. Sometimes understands- <i>Responds adequately to simple, direct communication only</i> 4. Rarely or never understands	0.Understands (0) 1. Difficulty understanding (1,2,3,4)
<b>Making self understood (expression)</b>	0. Understood- <i>Expresses ideas without difficulty</i> 1. Usually understood- <i>Difficulty finding words or finishing thoughts BUT if given time, little or no prompting required</i> 2. Often understood- <i>Difficulty finding words or finishing thoughts AND prompting usually required</i> 3. Sometimes understood- <i>Ability is limited to making concrete requests, e.g., regarding food, drink, toilet</i> 4. Rarely or never understood	0.Understood (0) 1. Difficulty being understood (1,2,3,4)
<b>Demonstrates lack of social and emotional conventions when socializing- e.g., lack of eye contact</b>	0. No 1. Yes	0. No 1. Yes
<b>Extreme shyness- e.g., severe inhibition in familiar social situations</b>	0. No 1. Yes	0. No 1. Yes

<b>Peer group includes individuals with persistence anti-social behaviours</b>	0. No 1. Yes	0. No 1. Yes
<b>Lack of interest in social interaction</b>	0. Not present 1. Present but not exhibited in last 3 days 2. Exhibited on 1-2 of last 3 days 3. Exhibited daily in last 3 days, 1-2 episodes 4. Exhibited daily in last 3 days, 3 or more episodes or continuously	0. No (0) 1. Present (1,2,3,4)
<b>Strong and supportive relationship with friends/peers</b>	0. No 1. Yes	0. No 1. Yes
<b>Social inclusion by peers- e.g., playmates at recess</b>	0. No 1. Yes	0. No 1. Yes
<b>Has at least one friend with whom visits/plays/socializes regularly</b>	0. No 1. Yes	0. No 1. Yes
<b>Conflict or repeated criticisms of close friends</b>	0. No 1. Yes 8. Not applicable	0. No 1. Yes *Excluded 8
<b>Pervasive conflict with peers (exclude close friends)</b>	0. No 1. Yes 8. Not applicable	0. No 1. Yes *Excluded 8
<b>Friends are persistently hostile or critical of child/youth</b>	0. No 1. Yes 8. Not applicable	0. No 1. Yes *Excluded 8
<b>Reports having a confidant</b>	0. No 1. Yes	0. No 1. Yes
<b>Victim of bullying</b>	0. Never 1. More than 1 year ago 2. 31 days to 1 year ago 3. 8-30 days ago 4. 4-7 days ago 5. In last 3 days	0. Never (0) 1. Has been bullied (1,2,3,4,5)

*Recoding of Motor Items*

<b>Variable Name</b>	<b>Original Code</b>	<b>New Code</b>
<b>Gross motor skills</b>	<p>0. Adequate- <i>Performs skill with satisfactory speed and quality of movement both indoors and outdoors (including uneven ground)</i></p> <p>1. Minimal difficulty- <i>Slight difficulty maintaining balance or controlling limb movement (e.g., appears clumsy, slower movements)</i></p> <p>2. Moderate difficulty- <i>Noticeable deficits in balance and controlling limb movements (e.g., frequently stumbles, drops objects, walks into objects)</i></p> <p>3. Severe difficulty- <i>Limitations in trunk, head, and limb control resulting in sever difficulty with coordination of own movements (e.g., unable to reach for a glass of water without knocking it over)</i></p> <p>4. <i>No ability to move body (full paralysis)</i></p>	<p>0. Adequate</p> <p>1. Exhibits difficulty (1,2,3,4)</p>
<b>Fine motor skills</b>	<p>0. Adequate- <i>Performs movements within appropriate time frame and with appropriate quality of movement</i></p> <p>1. Minimal difficulty- <i>Slight difficulty controlling movement (e.g., somewhat slow or easily fatigued)</i></p> <p>2. Moderate difficulty- <i>Noticeable deficits in fine motor skill development (e.g., unable to hold pencil properly and produce legible writing)</i></p> <p>3. Severe difficulty- <i>Severe limitation in ability to coordinate small muscle movement (e.g., significant struggle to pick up an object using thumb and forefinger)</i></p> <p>4. <i>No ability to move body (full paralysis)</i></p>	<p>0. Adequate</p> <p>1. Exhibits difficulty (1,2,3,4)</p>

<b>Total hours of exercise or physical activity in last 3 days</b>	0. None	0. 2 hours or less of PA (0,1,2)
	1. Less than 1 hour	1. 3+ hours of PA (3,4)
	2. 1-2 hours	
	3. 3-4 hours	
	4. More than 4 hours	

**APPENDIX 3b: Cut-Points Used for Scales**

<b>Scale</b>	<b>Pre-determined Cut-Points</b>	<b>HF vs LF Cut-Points</b>
<b>Disruptive/Aggressive Behaviour</b>	Low: 1-3 Moderate: 4-9 High: 10-14 Very High: 15-20	Low: 1-3 Moderate: 4-9 High to Very High: 10-20
<b>Anxiety</b>	Low: 1-3 Moderate: 4-9 High: 10-17 Very High: 18-32	Low: 1-3 Moderate: 4-9 High to Very High: 10-32
<b>Communication</b>	Low: 1 Moderate: 2 High: 3-5 Very High: 6-8	Low: 1 Moderate: 2 High: 3-5 Very High: 6-8
<b>Depression Symptoms</b>	Low: 1-8 Moderate: 9-14 High: 15-18 Very High: 19-36	Low: 1-8 Moderate: 9-14 High: 15-18 Very High: 19-36
<b>Pain</b>	Moderate: 1-2 High: 3 Very High: 4	Scale could not be collapsed to ensure cell sizes were not less than 5
<b>Caregiver Distress</b>	Low: 1-2 Moderate: 3 High: 4 Very High: 5	Low: 1-2 Moderate to Very High: 3-5
<b>Peer Relationship</b>	Scale did not have pre-determined cut-points. Original scale of 0-5 to be used	Scale could not be collapsed to ensure cell sizes were not less than 5

**APPENDIX 3c: Chi-Square Results for Items**

*Note:* For all tables below, standardized residuals, odds ratios, confidence intervals and Cramer’s V are only presented in the case the item was significant. As well, for the purpose of this study the term violated is defined as having (a) cell count(s) less than five and therefore could not be reported due to ethical and statistical restrictions.

*Descriptive Statistics Pertaining to Background Information of High Functioning Individuals, Sample Size (% sample in group)*

Item	Code	HF N (%) Standardized Residuals	LF N (%) Standardized Residuals	N	P value	X <sup>2</sup>	Odds Ratio	Confidence Intervals	Cramer’s V
<b>REASON FOR REFERRAL</b>									
<b>Threat or danger to self</b>	Yes	87 (32%)	41 (39%)	378	.217	1.52			
	No	185 (68%)	65 (61%)						
<b>Threat or danger to others</b>	Yes	125 (46%) -1.2	68 (64%) +1.9	378	<.01	10.01	1.396	1.52-1.691	.164
	No	147 (54%) +1.2	38 (36%) -1.9						
<b>Problem with addiction or dependency</b>	<b>Violated</b>								
<b>Specific psychiatric symptoms e.g., severe behaviour problems, depression, hallucinations</b>	Yes	192 (71%)	78 (74%)	378	.562	.35			
	No	80 (29%)	28 (26%)						
<b>Involvement with youth justice system</b>	<b>Violated</b>								
<b>FORMAL CARE</b>									



<b>Psychiatrist</b>	No contact in the past 3 years	79 (33%)	26 (32%)	319 <sup>18</sup>	.856	0.33			
	Contact in the past 3 years	159 (67%)	55 (68%)						
<b>Social worker</b>	No contact in the past 3 years	79 (33%) -1.3	43 (53%) 2.2	319 <sup>19</sup>	<.01	10.12	.702	.548-.900	.178
	Contact in the past 3 years	159 (67%) 1.0	38 (47%) -1.7						
<b>Psychologist, psychometric, psychological associate</b>	No contact in the past 3 years	110 (46%)	41 (51%)	328 <sup>20</sup>	.493	4.69			
	Contact in the past 3 years	128 (54%)	49 (49%)						
	No contact	162 (68%) 1.7	28 (35%) -2.9	319 <sup>21</sup>	<.01	28.16	2.05	1.6-2.6	.297

<sup>18</sup> 59 cases missing from item

<sup>19</sup> 59 cases missing from item

<sup>20</sup> 50 cases missing from item

<sup>21</sup> 59 cases missing from item

<b>Occupational therapist, Physiotherapist</b>	in the past 3 years								
	Contact in the past 3 years	76 (32%) -2.1	53 (65%) 3.5						
<b>Recreation, art, music, play therapist</b>	No contact in the past 3 years	216 (91%) .3	67 (83%) -.6	319 <sup>22</sup>	.048	3.90			
	Contact in the past 3 years	22 (9%) -.9	14 (17%) 1.6						
<b>Registered nurse</b>	No contact in the past 3 years	180 (76%) .9	45 (57%) -1.5	318 <sup>23</sup>	<.01	10.38	1.79	1.28-2.51	.185
	Contact in the past 3 years	58 (24%) -1.4	35 (43%) 2.4						
<b>Child protection</b>	No contact in the past 3 years	134 (56%)	41 (51%)	319 <sup>24</sup>	.374	.80			

<sup>22</sup> 59 cases missing from item

<sup>23</sup> 60 cases missing from item

<sup>24</sup> 59 cases missing from item

	Contact in the past 3 years	104 (44%)	40 (49%)						
<b>Behaviour therapist</b>	No contact in the past 3 years	164 (69%) 1	40 (49%) -1.6	319 <sup>25</sup>	<.01	9.99	1.63	1.22-2.17	.177
	Contact in the past 3 years	74 (31%) -1.3	41 (51%) 2.2						
<b>Dietician</b>	No contact in the past 3 years	225 (95%)	72 (89%)	319 <sup>26</sup>	.083	3.00			
	Contact in the past 3 years	13 (5%)	9 (11%)						
<b>Speech language pathologist</b>	No contact in the past 3 years	163 (69%)	56 (69%)	319 <sup>27</sup>	.913	.012			

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<sup>25</sup> 59 cases missing from item

<sup>26</sup> 59 cases missing from item

<sup>27</sup> 59 cases missing from item

	Contact in the past 3 years	75 (31%)	25 (31%)				
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*Overall Health Items Compared Among High Functioning and Low Functioning Individuals (df=1), Sample Size (% sample in group)*

<b>Item</b>	<b>Code</b>	<b>HF N (%) Standardized Residuals</b>	<b>LF N (%) Standardized Residuals</b>	<b>N</b>	<b>P value</b>	<b>X<sup>2</sup></b>	<b>Odds Ratio</b>	<b>95% Confidence Interval</b>	<b>Cramer's V</b>
<b>Intensity of highest level of pain present</b>	No Pain	235 (86%)	83 (78%)	378	.053	3.74			
	Mild to excruciating pain	37 (14%)	23 (22%)						
<b>Repetitive health complaints</b>	Present	104 (38%) <b>1.2</b>	25 (24%) <b>-1.9</b>	378	<.01	7.28	1.62	1.15-2.36	.139
	Not present	168 (62%) <b>-.8</b>	81 (76%) <b>1.3</b>						
<b>Difficulty falling asleep or staying asleep</b>	Present	174 (64%)	73 (69%)	378	.808	.81			
	Not present	98 (36%)	33 (31%)						
<b>Sleep problems related to hypomania or mania</b>	Present	27 (12%) <b>-1.0</b>	17 (21%) <b>1.7</b>	312 <sup>28</sup>	<.05	4.54	2.05	1.04-4.00	.121
	Not present	205 (88%) <b>.4</b>	63 (79%) <b>-.7</b>						
<b>Frequency with which child/youth complains or shows evidence of pain</b>	No pain	38 (14%) <b>-1.1</b>	25 (24%) <b>1.7</b>	378	<.05	5.08	1.86	1.06-3.27	.116
	Pain	234 (86%) <b>.5</b>	81 (76%) <b>-.8</b>						
<b>Prescribed medication</b>	Not prescribed medication	204 (75%) <b>-.8</b>	96 (91%) <b>1.3</b>	378	<.01	11.28	3.200	1.58-6.49	.173

<sup>28</sup> 66 cases missing from item

	Prescribed medication	68 (25%) <b>1.6</b>	10 (9%) <b>-2.5</b>						
<b>DSM-IV</b>									
<b>Reactive attachment disorder</b>	<b>Violated</b>								
<b>Attentional deficit hyperactivity disorder</b>	Present	152 (56%) <b>2.1</b>	26 (24%) <b>-3.4</b>	378	<.001	30.10	3.91	2.36-6.46	.282
	Not present	120 (44%) <b>-2.0</b>	80 (76%) <b>3.2</b>						
<b>Disruptive behavior disorder</b>	Present	76 (28%) <b>1.6</b>	12 (11%) <b>-2.6</b>	378	<.01	11.80	2.47	1.40-4.35	.177
	Not present	196 (72%) <b>-.9</b>	94 (89%) <b>1.4</b>						
<b>Learning or communication disorder</b>	Present	79 (29%) <b>-1.6</b>	52 (49%) <b>2.5</b>	378	<.001	13.49	2.353	1.48-3.73	.189
	Not present	193 (71%) <b>1.1</b>	54 (51%) <b>-1.8</b>						
<b>Substance related disorders</b>	<b>Violated</b>								
<b>Schizophrenia or other psychotic disorders</b>	<b>Violated</b>								
<b>Mood disorders</b>	Present	34 (13%)	6 (6%)	378	.052	3.77			
	Not present	238 (87%)	100 (94%)						
<b>Eating disorders</b>	<b>Violated</b>								
<b>Anxiety disorders</b>	Present	123 (45%) <b>1.7</b>	24 (23%) <b>-2.7</b>	378	<.001	16.36	2.00	1.37-2.91	.208
	Not present	149 (55%) <b>-1.3</b>	82 (77%) <b>2.1</b>						

<b>Adjustment disorder</b>	<b>Violated</b>						
<b>Sleep disorders</b>	<b>Violated</b>						
<b>MEDICAL DIAGNOSIS</b>							
<b>Asthma</b>	Present	25 (9%)	8 (8%)	378	.611	.259	
	Not present	247 (91%)	98 (92%)				
<b>Diabetes mellitus</b>	<b>Violated</b>						
<b>Epilepsy or seizure disorders</b>	<b>Violated</b>						
<b>Fetal alcohol effects/syndrome</b>	<b>Violated</b>						
<b>Migraine</b>	<b>Violated</b>						
<b>Traumatic brain injury</b>	<b>Violated</b>						
<b>Severe allergies</b>	<b>Violated</b>						

*Social Items Compared Among High Functioning and Low Functioning Individuals (df=1), sample size (% sample in group)*

<b>Social Item</b>	<b>Code</b>	<b>HF N (%) Standardized Residuals</b>	<b>LF N (%) Standardized Residuals</b>	<b>N</b>	<b>P value</b>	<b>X<sup>2</sup></b>	<b>Odds Ratio</b>	<b>95% Confidence Interval</b>	<b>Cramer's V</b>
<b>Socially inappropriate or disruptive behaviours</b>	Yes	114 (42%) <b>-2.2</b>	80 (75%) <b>3.5</b>	378	<.001	34.38	4.23	2.55-7.00	.302 (p>.001)
	No	158 (58%) <b>2.2</b>	26 (25%) <b>-3.6</b>						
<b>Ability to understand others (comprehension)</b>	Understands	134 (49%) <b>3.1</b>	9 (9%) <b>-4.9</b>	378	<.001	53.92	5.80	3.07-10.96	.378 (p>.001)
	Exhibits Difficulty	138 (51%) <b>-2.4</b>	97 (91%) <b>3.8</b>						
<b>Making self-understood (expression)</b>	Understands	138 (51%) <b>3.3</b>	7 (7%) <b>-5.3</b>	378	<.001	62.83	14.51	6.49-32.33	.408 (p>.001)
	Exhibits Difficulty	134 (49%) <b>-2.6</b>	99 (93%) <b>4.2</b>						
<b>Demonstrates lack of social and emotional conventions when socializing</b>	No	97 (36%)	33 (31%)	378	.405	.694			
	Yes	175 (64%)	73 (69%)						
<b>Extreme shyness</b>	No	204 (75%)	82 (77%)	378	.631	.230			
	Yes	68 (25%)	24 (23%)						
<b>Peer group includes individuals with</b>	No	248 (91%)	100 (94%)	378	.307	1.04			



<b>persistence anti-social behaviours</b>	Yes	24 (9%)	6 (6%)						
<b>Lack of interest in social interaction</b>	No	135 (49%) <b>.8</b>	40 (38%) <b>-1.3</b>	378	<.05	4.34	1.63	1.03-2.58	.107
	Yes	137 (51%) <b>-.8</b>	66 (62%) <b>1.2</b>						
<b>Strong and supportive relationship with friends/peers</b>	No	161 (59%) <b>-.9</b>	79 (74%) <b>1.4</b>	378	<.01	7.74	1.60	1.12-2.28	.143
	Yes	111 (41%) <b>1.2</b>	27 (26%) <b>-1.9</b>						
<b>Social inclusion by peers</b>	No	129 (47%) <b>-1.1</b>	69 (65%) <b>1.8</b>	378	<.01	9.54	1.51	1.13-2.00	.159
	Yes	143 (53%) <b>1.2</b>	37 (35%) <b>-1.9</b>						
<b>Has at least one friend with whom visits/plays/socializes regularly</b>	No	106 (39%) <b>-2.3</b>	78 (74%) <b>3.7</b>	378	<.001	36.58	2.31	1.66-3.22	.311 (p>.001)
	Yes	166 (61%) <b>2.2</b>	28 (26%) <b>-3.6</b>						
<b>Conflict or repeated criticisms of close friends</b>	No	220 (89%)	74 (88%)	332 <sup>29</sup>	.888	0.02			
	Yes	28 (11%)	10 (12%)						
	No	198 (76%) <b>-.6</b>	77 (88%) <b>1.0</b>	349 <sup>30</sup>	.011	6.54	2.12	1.14-3.95	.137

<sup>29</sup> 46 cases missing as “Not applicable” category was removed

<sup>30</sup> 29 cases missing as “Not applicable” category was removed

<b>Pervasive conflict with peers (exclude close friends)</b>									
	Yes	64 (24%) <b>1.1</b>	10 (12%) <b>-2.0</b>						
<b>Friends are persistently hostile or critical of child/youth</b>	<b>Violated</b>								
<b>Reports having a confidant</b>	No	89 (33%) <b>-3.0</b>	81 (76%) <b>4.8</b>	378	<.001	58.85	2.85	2.00-4.06	.395 (p>.001)
	Yes	183 (67%) <b>2.7</b>	25 (24%) <b>-4.4</b>						
<b>Victim of bullying</b>	No	154 (58%) <b>-1.9</b>	95 (93%) <b>3.1</b>	369 <sup>31</sup>	<.001	39.90	5.42	2.76-10.70	.329 (p>.001)
	Yes	112 (42%) <b>2.7</b>	8 (7%) <b>-4.4</b>						

*Motor Items Compared Among High Functioning and Low Functioning Individuals (df=1), Sample Size (% sample in group)*

<sup>31</sup> 9 cases missing from item

Item	Code	HF N (%) Standardized Residuals	LF N (%) Standardized Residuals	N	P value	X <sup>2</sup>	Odds Ratios	95% Confidence Interval	Cramer's V
<b>Gross motor skills</b>	Adequate	179 (75%) <b>1.0</b>	43 (53%) <b>-1.8</b>	319 <sup>32</sup>	<.001	13.98	1.41	1.14-1.76	.209
	Exhibits difficulty	59 (25%) <b>-1.6</b>	38 (47%) <b>2.7</b>						
<b>Fine motor skills</b>	Adequate	148 (62%) <b>2.2</b>	17 (21%) <b>-3.8</b>	319 <sup>33</sup>	<.001	41.08	2.96	1.92-4.357	.359
	Exhibits difficulty	90 (38%) <b>-2.3</b>	64 (79%) <b>4.0</b>						
<b>Hours of PA (in the last 3 days)</b>	Less than 2	163 (60%) <b>1.1</b>	45 (42%) <b>-1.7</b>	378	<.01	9.41	.70	.56-.87	.158
	More than 3	109 (40%) <b>-1.2</b>	61 (58%) <b>1.9</b>						

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<sup>32</sup> 59 cases missing from item

<sup>33</sup> 59 cases missing from item

**APPENDIX 3d: Chi-Square Results for Scales**

*Scales Compared Among High Functioning and Low Functioning Individuals, Sample Size (% sample in group)*

<b>Scale</b>	<b>Code</b>	<b>HF individuals</b>	<b>LF Individuals</b>	<b>df</b>	<b>N</b>	<b>P value</b>	<b>X2</b>	<b>Cramer's V</b>
<b>Anxiety</b>	Low	45 (21%)	13 (13%)	2	307	.061	5.58	
	Moderate	82 (39%)	52 (53%)					
	High to Very High	81 (40%)	34 (34%)					
<b>Depression</b>	Low	97 (37%)	36 (34%)	3	368	.944	.383	
	Moderate	91 (35%)	36 (34%)					
	High	33 (12%)	14 (14%)					
	Very High	42 (16%)	19 (18%)					
<b>Pain</b>	<b>Violated</b>							
<b>Peer</b>	<b>Violated</b>							
<b>Communication</b>	Low	49 (29%) <b>2.5</b>	7 (7%) <b>-3.1</b>	3	271	<.001	53.05	.442 (p>.001)
	Moderate	60 (36%) <b>1.4</b>	21 (20%) <b>-1.8</b>					
	High	51 (31%) <b>-1.1</b>	46 (44%) <b>1.4</b>					
	Very High	7 (4%) <b>-3.3</b>	30 (29%) <b>4.2</b>					
	Low	88 (41%) <b>1.4</b>	22 (23%) <b>-2.1</b>	2	309	<.001	17.99	.241 (p>.001)

<b>Disruptive/ Aggressive behaviour</b>	Moderate	104 (49%) <b>.1</b>	49 (51%) <b>.2</b>					
	High to Very High	21 (10%) <b>-1.9</b>	25 (26%) <b>2.8</b>					
<b>Caregiver Distress</b>	Low	145 (82%)	52 (76%)	1	246	.381	.768	
	Moderate to Very High	33 (18%)	16 (24%)					

**Chapter 4- Study #3: Sex Differences Among High Functioning and Low Functioning  
Individuals with Autism Spectrum Disorder**

#### **4.1. Abstract**

Sex differences among individuals with ASD are evident, however findings concerning these differences are inconsistent. Previous studies have examined primarily high functioning (HF) samples, rather than low functioning samples (LF) or did not state the level of functioning of the participants. As well, previous research has collapsed item scores to get an overall score, preventing subtle differences from being identified. As such, the purpose of this study was to investigate sex differences in LF (IQ<70) and HF (IQ>70) individuals with ASD. In doing so, multiple items and scales from the interRAI Child and Youth Mental Health – Developmental Disabilities (ChYMH-DD) and the interRAI Child and Youth Mental Health (ChYMH) assessments related to three domains: health, social, and motor were analyzed. Findings confirmed there were no sex differences among individuals with HF and LF ASD. Despite finding no sex differences, the study was able to highlight areas in which individuals with ASD may be at risk.

## 4.2. Introduction

In Canada, one in 42 males and one in 165 females are diagnosed with autism spectrum disorder (ASD) (Autism Ontario, 2018). This translates to males being four times more likely to be diagnosed with ASD than females. That said, in high functioning (HF) populations, males are eight to nine times more likely to be diagnosed with ASD (Mandy, Charman, Gilmour, & Skuse, 2011). There is a body of literature suggesting ASD characteristics may manifest in males and females differently. One theory to support the sex differences in ASD is the ‘female protective effect’ (FPE) model (Halladay et al., 2015) which suggests females are protected against some of the symptoms associated with ASD and therefore must exhibit additional risk factors (e.g., genetic variants or environmental influences) to meet the criteria for ASD when compared to their male counterparts (Halladay et al., 2015; Werling & Geschwin, 2013). The factors that protect females remain unknown. Interestingly, the increased risk factors females with ASD must exhibit increases the potential for their siblings to also be diagnosed with ASD. Consequentially, a higher rate of ASD is expected in female siblings compared to male siblings; this is known as the Carter Effect ([CE] Halladay et al. 2015). Although researchers have hypothesized why sex differences exist, the precise sex differences are not exactly clear. The inconsistencies in research concerning sex differences in ASD will be briefly highlighted below. For further information regarding the purpose, participants, methods, and results pertaining to each of the studies discussed, refer to Table 4.1, located at the end of this paper.

Sex differences relating to the core ASD characteristics have been widely researched. Core characteristics of ASD include repetitive and stereotyped behaviours, and deficits in social and communication domains (American Psychiatric Association [APA], 2016; World Health Organization [WHO], 2017). While some studies have suggested males exhibit greater repetitive



and stereotyped behaviors when compared to females (Hartley & Sikora, 2009; Mandy, Chilvers, Chowdhury, Salter, Seigal, & Skuse, 2012) other studies found there were no sex differences (Carter, Black, Tewani, Connolly, Kadlee, & Tager-Flusber, 2007; Holtmann, Bolte, & Poustka, 2007; Sutherland, Hodge, Bruck, Costley, & Kleve, 2017). Conflicting findings also extend to the social and communication deficits exhibited by females and males with ASD. For example, Carter et al. (2007) stated males had significantly better language and social skills than females. Similarly, Hartley and Sikora (2009) found females had greater communication deficits and Holtmann et al. (2007) found females had greater social deficits when compared to males. On the contrary, Hartley and Sikora (2009) revealed there were no sex difference in social reciprocity. Despite stating that females had greater social deficits, Holtmann et al. (2007) concluded there were no sex differences pertaining to social interaction and communication. Sutherland et al. (2017) also concluded there were no significant sex differences pertaining to social and communication strengths and difficulties. Similar conclusions have been found by Mandy and colleagues (2012).

The inconsistencies in the findings with respect to sex differences are also evident in motor functioning and overall health of individuals with ASD. With regards to motor functioning, Carter et al. (2007) concluded males demonstrated stronger fine and gross motor skills, while Mandy et al. (2012) found females had greater fine motor skills but sex differences pertaining to gross motor skills were not evident. With respect to overall health, studies have suggested females experienced higher levels of emotional symptoms (Mandy et al. 2012) and anxious and depressed affect (Hartley & Sikora, 2009) compared to males. It was also reported females experienced greater sleep problems (Hartley & Sikora, 2009) and attentional problems than males, which was highly correlated with an attention-deficit-hyperactivity disorder (ADHD)

diagnosis (Holtman et al. 2007). In contrast, Mandy et al. (2012) concluded males, compared to females, had greater difficulty with attention, as perceived by their teachers.

Limitations within the aforementioned research may be contributing to the inconsistency of findings. For example, Holtmann et al. (2007) only included participants considered high functioning ( $IQ > 70$ ), while the study by Mandy et al. (2012) only included 10% low functioning participants. The remaining studies did not explicitly state the level of functioning of their participants (Carter et al. 2007; Hartley & Sikora, 2009; Sutherland et al., 2017). Moreover, the instruments used in the studies may not have been able to detect more subtle differences between males and females with ASD. For instance, studies (Carter et al., 2009; Hartley & Sikora, 2009; Holtmann et al. 2007; Mandy et al., 2012) have commonly utilized the Autism Diagnostic Observation Schedule (ADOS). Within the ADOS there are three domains: reciprocal social interaction, communication, and repetitive stereotyped behaviours. Each of these domains consist of individual items. Scores from these items are added and then divided by the number of items in the corresponding domain (Hartley & Sikora, 2009). This may prevent researchers from identifying specific differences pertaining to individual items, resulting in potential subtle differences being missed.

To avoid the limitations discussed above, the current study investigated sex differences in LF ( $IQ < 70$ ) and HF ( $IQ > 70$ ) individuals with ASD. In doing so, the study compared functioning across items and scales specific to background information (i.e., reason for referral and formal care utilized) and three domains: health, social, and motor.

### **4.3. Methods**

**4.3.1. Ethics.** Secondary data analysis of the ChYMH and ChYMH-DD ensued after ethical clearance was received from the Wilfrid Laurier University research ethics board. The research was also approved by the ethics board at University of Western, where the data was stored.

**4.3.2. Procedure.** The ChYMH and ChYMH-DD were used in gathering the data that was analyzed for this study. These assessments were completed 14 mental health agencies across Ontario between January 2015 and November 2016. These assessments are completed as part of standard clinical practice in specific healthcare agencies. Children/youth are referred to these agencies through self-referral, or are referred there by family doctors, pediatricians, or other healthcare professionals (Stewart et al., 2015a; Stewart et al., 2015b). The assessments are completed during 60 to 90 minutes semi-structured interview format. The information used to complete the assessment is obtained by available sources including the child themselves, parents, educators, other health care clinicians and through records such as clinical assessments and school records, with appropriate consent. All assessors have completed a two and half day intensive training course, which was developed by local, national, and international experts in the field of children's mental health. Assessors are also required to have a diploma or degree in the mental health field, and at least two years of clinical experience with children/youth (interRAI, 2018). When the assessment has been completed, it is entered into a database where it is de-identified. The computers used to store this data are password protected and do not have access to the internet and do not have a USB port. Assessments cannot be submitted into the database, unless it is complete, as such the assessments do not consist of any missing data (Stewart et al., 2015a; Stewart et al., 2015b).

#### **4.3.3. Research tools**

**4.3.3.1. ChYMH-DD and ChYMH.** The ChYMH-DD and the ChYMH are comprehensive, multidisciplinary mental-health assessments for children and youth aged 4 to 18 years who are referred to either community-based (outpatient) or residential (inpatient) developmental services (Stewart et al., 2015a). The purpose of the ChYMH-DD and the ChYMH are threefold: (1) to maximize the young person's functional capacity and quality of life; (2) to address physical and mental health problems; and (3) to enhance the young person's level of independence (Stewart et al., 2015a; Stewart et al., 2015b). Overall, the ChYMH-DD and the ChYMH have the ability to identify strengths and areas of need among individuals with ASD. Problem areas for individuals can be identified through the analysis of specific items. Further, Clinical Assessment Protocols (CAPs) provide guidelines for care in areas triggered as problematic (e.g., interpersonal conflict and social relations). Analysis of individual CAPs allow for the most appropriate and effective interventions to be identified and recommended (see, Study #1). The current study analyzed items and scales to gain an understanding of the subtle differences in which HF females differed from HF males and LF females differed from LF males. Validity and reliability of the interRAI instruments has been confirmed in previous research (see, Carpenter, 2006; Gray et al., 2009; Hirdes et al., 2008; Hirdes et al., 2002; Poss et al., 2009; Lau, 2017; Stewart & Hamza, 2017).

**4.3.3.1.2. Variables.** Multiple items were analyzed and compared between HF females and HF males, as well as LF females and LF males. Items were analyzed to allow for detection of specific and subtle differences pertaining to one of the four areas: (1) background information; (2) overall health; (3) social functioning; and (4) motor functioning. Table 4.2, located at the end of this paper, provides a comprehensive list of items within each area. Note, items were

dichotomized to prevent cell counts from being less than five as necessitated by ethical and statistical restrictions. See Appendix 4a for recoding of items.

*3.3.3.1.3. Scales.* Comprised of specific items, scales provide detail regarding an individuals' outcome measurements and status regarding a specific area (i.e., social inclusion) (Stewart et al., 2015a; Stewart 2015b). A higher score on a scale indicates greater issues in that specific area. Applicable scales that were present on both the ChYMH and ChYMH-DD were compared between HF females and males, and then LF females and males individuals. To analyze the scales, the researcher used the same cut-points interRAI clinicians and researchers use to make clinical decisions (Stewart, Fadeyi, Hirdes, & Fries, 2017). However, to avoid having cell counts less than five, there were cases in which cut-points had to be collapsed. For clinical decision cut-points and the cut-points used for each scale see Appendix 4b.

*Anxiety Scale.* This scale measures frequency of anxiety symptoms with scores ranging from 0 to 32. The anxiety scale is comprised of the following items: repetitive anxious concerns, unrealistic fears, obsessive thoughts, intrusive thoughts or flashbacks, episodes of panic, hypervigilance, and nightmares.

*Depression Scale.* This scale assesses depressive indicators with scores ranging from 0 to 36. The depression scale is comprised of the following items: negative statements, sad, pained, worried facial expression, crying or tearfulness, self-deprecation, guilt/shame, hopelessness, irritability, lack of motivation, and withdrawal from activities of interest.

*Communication Scale.* This scale measures participants' ability to understand and be understood. Scores on this scale range from 0 to 8. The communication scale is comprised of the following items: making self-understood and ability to understand others.

*Disruptive/ Aggressive Behaviour Scale.* This scale assesses anger in terms of severity and frequency. Scores on this scale range from 0 to 20. The disruptive/ aggressive behaviour scale is comprised of the following items: verbal abuse, physical abuse, socially inappropriate/ disruptive, destructive behaviour towards property, and outbursts of anger.

*Caregiver Distress Scale.* This scale assesses caregiver stress on a scale from 0 to 5. The caregiver distress scale is comprised of the following items: parent/primary guardian had experienced major life stressors in the last 90 days, parent/primary guardian was unable or unwilling to continue in caring activities, and parent/primary guardian expression feelings of distress, anger, or depression.

*Pain Scale.* This scale measures the intensity and frequency pain is experienced by participants. Scores on this scale range from 0 to 7. The pain scale is comprised of the following items: pain frequency and pain intensity.

*Peer Relationship Scale.* This scale assesses conflict that participants experience with friends and scores range from 0 to 5. The peer relationship scale is comprised of the following items: social inclusion by peers, conflict with or repeated criticism of close friends, friends are persistently hostile or critical of child, pervasive conflict with peers (exclude close friends), and peer group includes individuals with persistent antisocial behaviour.

**4.3.3.2. Data analysis.** Chi-square tests of independence were calculated using Statistical Package for the Social Sciences (SPSS) 24 (IBM, 2016). Multiple steps were taken throughout the data analysis process. Data was cleaned and in doing so 28 cases were removed. Such cases were removed because they were input incorrectly (age fell outside the range of 4 to 18 years) or because the case(s) reported an identifying demographic variable. Further non-ASD cases were removed, in addition to cases input prior to 2015. Cases prior to 2015 were removed because

new items may have been added or dropped from the assessment resulting in the lack of comparison across all items

For the following items, the ‘non-applicable’ response choice was removed: conflict with friends; friends are hostile; pervasive conflict with peers; and conflict with family. With regards to these items, the researcher was interested in whether the conflict was present or not present in the participant’s life, not if it was non-applicable. The ‘non-applicable’ response does provide crucial information but was outside the scope of this study. Next, items were recoded into binary responses sets (present, absent) if they had multiple response options. This recoding decreased the number of items having cell sizes less than five, as having cell counts less than five was prohibited for two reasons. First it violated ethical guidelines, as reporting a cell count less than five could potentially reveal a participant’s identity and secondly it violated the assumption of the chi-square analysis. See Appendix 4a for recoding of items.

As mentioned above, scales were first run using clinical decision cut-points. However, in cases where cell sizes were less than five, cut-points were collapsed. See Appendix 4b.

HF individuals and LF individuals were analyzed separately. Similar to Stewart and Hirdes (2015), a chi-square analysis was conducted to detect differences between groups. Analysis was performed using the cross-tabulations command in SPSS for both data sets. To control for type 1 errors, tests were conducted using Bonferroni adjusted alpha levels (Field, 2009). For background information, the alpha used was .003 (.05/15). For overall health, the alpha used was .002 (.05/24). For social functioning, the alpha used was .003 (.05/15) and for motor items the alpha used was .01 (.05/3). For scales, the alpha used was .007 (.05/7). To quantify the strength of the relationships, odd ratios and confidence intervals were conducted by SPSS on every significantly different item. In addition to odds ratios, Cramer’s-V was also

computed to determine the strength of the relationship. To determine the location of significant differences, standardized residuals were examined. The results will be presented in five sections for both the HF group and LF group: (1) background information, (2) overall health, (3) social functioning (4) motor functioning, and (5) scales.

#### **4.4. Results**

**4.4.1. Participants.** The participants consisted of 378 (85 females, 293 males) children and youth with ASD between the ages of 4 and 18 years. Of this sample, 72% (n=272, males=212, females=60) were high functioning (IQ<70) with a mean age of 12.77 years (SD=3.16) and 38% (n=106, 81 males, 25 females) were low functioning individuals (IQ>70) with a mean age of 11.8 years (SD=3.29). See Table 4.3 for demographic characteristics of HF and LF samples, located at the end of this paper.

**4.4.2. High functioning females vs high functioning males.** For chi-squares results pertaining to the HF sample, see Tables 4.4 to 4.8 located at the end of this paper. Background information and the overall domains of health, social, motor, and scales will be discussed in turn.

**4.4.2.1. Background Information.** There were no significant differences between HF males and HF females with regards with regards to background information concerning reasons for referral and formal care received in the past 3 years.

**4.4.2.2. Overall health.** There were no significant differences between HF males and HF females with regards to their overall health.

**4.4.2.3. Social functioning.** There were no significant differences between HF males and HF females with regards to their social functioning.

**4.4.2.4. Motor functioning.** There were no significant differences between HF males and HF females with regards to their motor functioning.



**4.4.2.5. Scales between high functioning females and high functioning males.** With respect to scales, no significant differences were found for anxiety, depression, communication, aggression, and caregiver distress. The pain scale and peer relationship scale could not be analyzed because cell sizes were less than five.

**4.4.3. Low functioning females vs low functioning males.** For chi-squares results pertaining to the LF sample, see Tables 4.9 to 4.13 located at the end of this paper. Background information as well as the overall domains of health, social, motor, and scales will be discussed in turn.

**4.4.3.1. Background information.** There were no significant differences between LF males and LF females with regards to background information concerning reasons for referral and formal care received in the past 3 years.

**4.4.3.2. Overall health.** There were no significant differences between LF females and LF males with regards to their overall health.

**4.4.3.3. Social functioning.** There were no significant differences between LF females and LF males with regards to their social functioning.

**4.4.3.4. Motor functioning.** There were no significant differences among motor items compared between LF females and LF males.

**4.4.2.5. Scales between low functioning females and low functioning males.** With respect to scales, no significant differences were found for anxiety, depression, communication, and aggression. The caregiver distress, pain scale, and peer relationship scale could not be analyzed because cell sizes were less than five.

## 4.5. Discussion

Four areas pertaining to sex differences in individuals with HF and LF ASD were analyzed, including background information, overall health, social functioning, and motor functioning. Within all areas sex differences were not found in the LF and HF sample. Each of these areas will be briefly discussed.

**4.5.1. Overall health: Co-morbidity: ADHD and anxiety.** The current study found there were no sex differences pertaining to the overall health in HF and LF individuals, however a pattern of findings related to ADHD and anxiety were revealed.

Although not significant, there was a trend that HF males were more likely to be diagnosed with ADHD than high functioning females, in that HF males were twice as likely to have been diagnosed with ADHD compared to HF females. This is agreement with Mandy et al. (2012) who concluded males had greater difficulty with attention. However, these results conflict with findings from Holtmann et al. (2007) who reported HF females reported significantly more attentional problems, which was highly correlated to the diagnoses of ADHD. With regards to the LF sample, the ADHD item had cell counts less than five and could not be reported due to ethical and statistical restrictions. As a result, the ADHD item could not be reported.

Although no sex differences were found, it is still important to highlight the number of HF males and females with ADHD. Specifically, 60% of HF males and 40% of HF females were diagnosed with ADHD. Research suggests children with a diagnosis of ASD as well as ADHD are at an increased risk for poor physical and psychosocial quality of life (Thomas, Sciberras, Lyvett, Papadopoulos & Rinehart, 2015). Children diagnosed with both ASD and ADHD tend to have greater emotional and behavioural problems, compared to children with ASD. Further, children with comorbid ASD and ADHD are also more likely to have issues with their peers

(Thomas et al., 2015). ADHD diagnoses places children with ASD at higher risk for experiencing motor impairments, which can act as a barrier to participation in meaningful life activities (e.g., sports, engagement with peers, activities of daily living etc.) (Thomas et al., 2015). Given the frequent co-occurrence of ASD and ADHD and the potential consequences, it is important for children with ASD to be screened for ADHD in order for interventions to be implemented. Interventions should aim to minimize impairments associated with comorbidity addressing potential emotional, behavioural and, motor problems may be of benefit. Future research needs to continue to investigate the differences in females and males with ASD and their risk of being diagnosed with ADHD for both HF and LF individuals with ASD.

Despite having found no sex differences pertaining to the anxiety item among the HF sample, it is important to note 50% of HF females and 53% of HF males reported having an anxiety disorder. Unfortunately, the anxiety item could not be reported in the LF sample due to having a cell count less than five and therefore violated ethical and statistical restrictions. However, the anxiety scale for the LF group revealed there were no significant differences between females and males. It was further revealed that more than 30% of LF males and females scored high to very high on the anxiety scale. Anxiety disorders among individuals across the spectrum is common (Tantum, 2000) and occur at greater levels than in the general public (Bellini, 2004). Further, anxiety in children with ASD can present many challenges such as relationship issues with family members, peers, and teachers (Green et al., 2000; Kim et al. 2000). It has also been reported high social anxiety is associated with low social assertiveness, in that children who display higher levels of social anxiety may be less likely to initiate social interactions (Bellini, 2004). Considering ASD is already associated with social impairments,

having anxiety may further compromise their social development. Higher levels of anxiety in children with ASD has also been associated with aggression and self-injury (Canitano, 2006).

Given the high prevalence of anxiety among individuals with ASD it is important health care professionals complete thorough assessments of anxiety in all individuals diagnosed with ASD. This is especially important for individuals with ASD who do not have the verbal means to communicate the signs and symptoms associated with anxiety. Conducting mandatory anxiety assessments on individuals with ASD would allow for early identification and intervention, thereby minimizing the effects anxiety can have on the children. Finally, it is important for future research to investigate sex differences in anxiety in LF population to determine if sex is a risk factor for anxiety in LF individuals.

**4.5.2. Social functioning: universal social strengths and weaknesses.** The current study found no sex differences in the items corresponding to social functioning of HF and LF individuals with ASD. This finding supports previous research which also concluded males and females did not differ in social interaction (Mandy et al., 2012), social behaviours (Sutherland et al., 2017), and communication (Mandy et al., 2012; Sutherland et al., 2017); however, this finding does conflict with previous research suggesting females exhibited greater social issues (Holtmann et al., 2007) and inferior verbal and communication abilities (Carter et al., 2007; Harley & Sikora., 2009).

It is important to highlight that eight of the 15 social items pertaining to the LF sample had actual cell counts less than five, such that the results could not be reported, due to the possibility of identifying participants. With regards to the peer relationship scale, this also violated statistical and ethical guidelines and therefore could not be reported. As such, further research concerning the social functioning of females and males with LF ASD is warranted. This

will provide insight regarding the specific social impairments LF females are more likely to exhibit compared to LF males, and vice versa. This can also assist in developing male and female specific therapies to minimize social deficits.

Sex differences pertaining to the HF sample were not found, and therefore may suggest males and females with HF ASD exhibit similar social strengths and weaknesses. For example, more than 50% of males and females exhibited the following impairments: lacked social and emotional conventions when socializing and lacked interest in social interaction, whereas more than 50% of males and females reported the following social strengths: social inclusion by peers, has at least one friend with whom visits/plays/socializes regularly and has a confidant. The listed social impairments and strengths may be universal among all HF individuals with ASD, regardless of sex. That said, further investigation into specific items corresponding to social domains is required is warranted.

**4.5.3. Motor functioning: fine motor skills and physical activity.** Examining all response options would allow for insight into the range of difficulties pertaining to gross and fine motor skills. However, response options had to be dichotomized into two response options to avoid cell counts less than five. Sex differences did not exist with regards to motor functioning for both HF and LF samples. It can be noted that although not significant, HF females did appear to have greater fine motor skills than males. This finding is supported by Mandy et al. (2012) who found females had greater fine motor skills but conflicts with Carter et al. (2007) who concluded males demonstrated stronger fine motor skills. Unfortunately, the fine motor skills item had a cell count less than five, and therefore could not be reported due to ethical and statistical concerns. Consequentially, sex differences pertaining to LF individuals with regards to fine motor skills could not be analyzed. Research investigating sex differences in motor skills

is lacking and therefore future research is necessary. If differences in motor skills exist, it is important to determine the nature of these differences. For example, are differences the result of gender-based practices? Females may express a stronger interest or are encouraged more often to participate in activities requiring fine motor skills such as colouring, drawing, and making bracelets, more so than males and therefore develop better fine motor skills.

Despite not finding sex differences pertaining to the hours of physical activity, the findings are still notable. For HF sample 59% of males and 65% of females, and for the LF sample 38% of males and 56% of females were participating in less than two hours of physical activity in the last three days. These findings are consistent with previous literature stating individuals with ASD are not meeting the physical activity guidelines (Bandini et al., 2013; Pan, & Frey, 2006). These findings are concerning as the benefits of physical activity can mitigate many of the issues highlighted above such as social challenges (Lee & Vargo, 2017; Pan, 2010) and anxiety (Hillier, Murphy, & Ferrar, 2011). A meta-analysis conducted by Sowa and Meulenbroek (2012) reviewed the effects of physical exercise on ASD, in which multiple benefits were reported. Such benefits included improvements in motor function (e.g., balance, flexibility, muscular strength and endurance), improvements in social skills (e.g., reduction in anti-social behavior), reduction in aggressive behaviors, enhanced quality of life, increased academic engagement, improved attention, and decreased distractibility (Sowa & Meulenbroek, 2012). It is important physical activity is encouraged among individuals with ASD. Further, educating individuals with ASD, as well as their caregivers, of the benefits of physical activity is warranted. It is also important physical activity programs meet the needs of individuals with ASD, including having adaptable equipment and ensuring the instructors are knowledgeable about ASD. Future research must investigate how physical activities can be developed to

promote sustained participation for individuals with ASD and the long-term effects of physical activity on the overall health and, social, and motor development of individuals with ASD.

**4.5.4. Limitations.** There are a few limitations with this study that need to be noted. First, there were multiple comparisons conducted and therefore this increased the potential of a type 1 error. As well, the researcher chose to conduct chi-square tests rather than a more rigorous analysis such as a logistic regression. Another limitation was that there were only 25 females in the LF sample. As a result, there were many items that had a cell count less than five and therefore the sex differences among these items could not be reported due the ethical and statistical restrictions and require further examination. This was also the case for three scales (caregiver distress, peer relationship, and pain intensity). The age range of individuals within the study is quite large (4 to 18 years). Perhaps, sex differences may be more evident in samples consisting of participants of similar ages. According to the ChYMH and ChYMH-DD participants under the age of 12 years are referred to as children, and participants between the ages 12 and 18 are considered youth (Stewart et al., 2015a; Stewart et al., 2015b). As such, there is a possibility that sex differences are more evident in children under the age of 12 years, however these deficits may be addressed with therapies and supports therefore minimizing the evidence of such differences in older populations. Unfortunately, the small sample sizes did not afford the opportunity to divide each of the groups into children and youth, as this would have resulted in the violation of ethical and statistical restrictions, therefore the current study sacrificed age division for power. As data continues to be collected utilizing these tools, more analyses will be possible. As such, research investigating sex differences in participants of similar age groups is warranted.

#### **4.6. Conclusion**

The purpose of this study was to investigate sex differences in LF and HF individuals with ASD. In doing so, the study compared functioning across items and scales specific to four areas: background information (i.e., reason for referral, formal care utilized), health, social, and motor. After a thorough analysis of multiple items and scales, it was confirmed there were no sex differences among individuals with HF and LF ASD. As the name states, ASD is a spectrum disorder meaning individuals with the diagnosis will likely exhibit very different characteristics. Perhaps the differences in individuals with ASD are not dependent on sex, but rather the nature of the disorder itself.

Despite finding no sex differences, the study was able to highlight areas in which individuals with ASD may be at risk. For example, many HF individuals reported having diagnoses of ADHD and anxiety disorders. It is important individuals with ASD are screened for ADHD and anxiety to ensure they receive the appropriate interventions. Low physical activity levels of individuals with LF and HF ASD was also reported. Physical activity among individuals with ASD must be encouraged, as physical activity can minimize the challenges associated with ASD, as well any co-morbid conditions. In doing so, it is important individuals with ASD as well as their caregivers and health professionals are educated on the benefits of physical activity and are aware of inclusive physical activity programming in their communities. Finally, the current study was not able to examine many items, as well as three scales, pertaining to the LF group due to a small sample size. As such, future research investigating sex differences among LF population is warranted.



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Table 4. 1 *Details of Studies Investigating Sex Differences in Individuals with ASD*

Researchers	Carter et al. (2007)	Hartley and Sikora (2009)	Holtmann et al. (2007)	Mandy et al. (2012)	Sutherland et al. (2017)
<b>Purpose</b>	To examine sex differences in toddlers with ASD with respect to profiles of developmental functioning, including verbal, non-verbal, and motor abilities, and clinical manifestations of ASD, including social functioning, communication, and repetitive and stereotypical behaviours	To investigate developmental profiles and coexisting behaviour problems in boys and girls with ASD	To examine possible differences between high-functioning males and females with ASD regarding the core symptoms of autism and coexisting psychopathology	To investigate sex the presence and stability of ASD sex differences throughout childhood and adolescence	To gain an understanding of the real-life characteristics of school-aged girls and boys with autism, including both diagnosis criteria and associated features, as described by their parents
<b>Participants</b>	<ul style="list-style-type: none"> <li>• 90 participants between the ages 18 to 33 months (<math>M_{age}=28.1</math> month)               <ul style="list-style-type: none"> <li>○ 22 girls (<math>M_{age}=27.1</math> months)</li> <li>○ 68 boys (<math>M_{age}=28.4</math> months)</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• 199 participants between the ages 1.5 to 3.9 years               <ul style="list-style-type: none"> <li>○ 157 boys (<math>M_{age}=35.51</math> months)</li> <li>○ 42 girls (<math>M_{age}=35.98</math> months)</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• 56 participants between the ages 5 and 20 years               <ul style="list-style-type: none"> <li>○ 23 boys (<math>M_{age}=11y\ 9mo</math>)</li> <li>○ 23 boys (<math>M_{age}=12years</math>)</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• 325 participants between the ages 3 and 18 years               <ul style="list-style-type: none"> <li>○ 273 boys (<math>M_{age}=10.2</math> years)</li> <li>○ 52 girls (<math>M_{age}=9.7</math> years)</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• 334 parents if children between ages 5 and 18 years               <ul style="list-style-type: none"> <li>○ 171 parents of girls with ASD</li> <li>○ 163 parents of boys with ASD</li> </ul> </li> </ul>
<b>Methods</b>	<ul style="list-style-type: none"> <li>• ADI-R</li> <li>• Autism Diagnostic Observation Schedule (ADOS)</li> <li>• Vineland Adaptive Behaviours Scales, Interview Edition</li> </ul>	<ul style="list-style-type: none"> <li>• Vineland Adaptive Behaviour Scales, second edition, survey interview form</li> <li>• ADOS-G A semi-structured diagnostic interview of the</li> </ul>	<ul style="list-style-type: none"> <li>• Autism Diagnostic Interview-Revised (ADI-R)</li> <li>• ADOS</li> <li>• CBCL</li> </ul>	<ul style="list-style-type: none"> <li>• The Developmental, Dimensional and Diagnostic Interview (3Di)</li> <li>• ADOS</li> <li>• The Strengths and Difficulties Questionnaire (SDQ)</li> </ul>	<ul style="list-style-type: none"> <li>• Surveyed parents of children with ASD regarding their son' and daughters' strengths and difficulties in</li> </ul>

	<ul style="list-style-type: none"> <li>• The Infant-Toddler Social and Emotional Assessment</li> <li>• The Mullen Scales of Early Learning (MSEL)</li> </ul>	<ul style="list-style-type: none"> <li>• Diagnostic and Statistics Manual, Fourth Edition</li> <li>• Child Behaviour Checklist (CBCL)</li> </ul>		<ul style="list-style-type: none"> <li>• Intelligence Quotient (IQ)</li> </ul>	<p>communication and social skills, as well as their special interests, repetitive behaviours and sensory needs.</p>
<b>Results</b>	<ul style="list-style-type: none"> <li>• Boys had significantly better language, motor skills (gross and fine) and social competence</li> <li>• Girls had significantly better visual reception</li> <li>• No sex differences in repetitive and stereotypical movements</li> </ul>	<ul style="list-style-type: none"> <li>• Boys had more restricted repetitive, and stereotyped behaviours</li> <li>• Girls had greater communication deficits, sleep problems, and anxious and depressed affect</li> <li>• No differences in social reciprocity</li> </ul>	<ul style="list-style-type: none"> <li>• Females had greater social, attention, and thought problems</li> <li>• No differences in deficits pertaining to reciprocal social interaction, communication, and repetitive, stereotyped behaviours</li> </ul>	<ul style="list-style-type: none"> <li>• Boys had greater restricted, repetitive behaviours</li> <li>• Teachers reported males had greater difficulty hyperactivity/inattention and prosocial behaviour</li> <li>• No differences in reciprocal social interaction or communication</li> <li>• Females had greater fine motor skills, and higher levels of emotional symptoms (as noted by parents)</li> <li>• No sex differences for visuo-spatial impairments, gross motor impairment, auditory sensitivity, feeding difficulties and sensitivity to sound</li> </ul>	<ul style="list-style-type: none"> <li>• Few differences in terms of communication and social strengths and difficulties and in repetitive behaviours</li> <li>• Differences pertaining to interests</li> <li>• Girls tried to mask their difficulties</li> </ul>

Table 4. 2 *Analysed Items from ChYMH-DD and ChYMH*

Section	Items
<b>(5) Background Information</b>	<p data-bbox="581 365 862 394"><u>Reason for Admission</u></p> <ul data-bbox="630 407 1354 646" style="list-style-type: none"> <li data-bbox="630 407 971 436">• Threat or danger to self</li> <li data-bbox="630 449 1003 478">• Threat or danger to others</li> <li data-bbox="630 491 1166 520">• Problem with addiction or dependency</li> <li data-bbox="630 533 1354 604">• Specific psychiatric symptoms e.g., severe behaviour problems, depression, hallucinations</li> <li data-bbox="630 617 1305 646">• Involvement with youth justice system symptoms</li> </ul> <p data-bbox="581 659 748 688"><u>Formal Care</u></p> <ul data-bbox="630 701 1338 1102" style="list-style-type: none"> <li data-bbox="630 701 824 730">• Psychiatrist</li> <li data-bbox="630 743 850 772">• Social worker</li> <li data-bbox="630 785 1338 814">• Psychologist, psychometric, psychological associate</li> <li data-bbox="630 827 1175 856">• Occupational therapist, physiotherapist</li> <li data-bbox="630 869 1143 898">• Recreation, art, music, play therapist</li> <li data-bbox="630 911 889 940">• Registered nurse</li> <li data-bbox="630 953 883 982">• Child protection</li> <li data-bbox="630 995 932 1024">• Behaviour therapist</li> <li data-bbox="630 1037 792 1066">• Dietician</li> <li data-bbox="630 1079 1040 1108">• Speech language pathologist</li> </ul>
<b>(6) Overall Health</b>	<ul data-bbox="630 1121 1377 1472" style="list-style-type: none"> <li data-bbox="630 1121 1192 1150">• Intensity of highest level of pain present</li> <li data-bbox="630 1163 1377 1268">• Repetitive health complaints- e.g., persistently seeks attention for physical symptoms such as headaches and stomach ache; incessant concern with body functions</li> <li data-bbox="630 1281 1203 1310">• Difficulty falling asleep or staying asleep</li> <li data-bbox="630 1323 1273 1352">• Sleep problems related to hypomania or mania</li> <li data-bbox="630 1365 1377 1436">• Frequency with which child/youth complains or shows evidence of pain</li> <li data-bbox="630 1449 959 1478">• Prescribed medication</li> </ul> <p data-bbox="581 1484 688 1514"><u>DSM-IV</u></p> <ul data-bbox="630 1526 1365 1883" style="list-style-type: none"> <li data-bbox="630 1526 1045 1556">• Reactive attachment disorder</li> <li data-bbox="630 1568 1192 1598">• Attentional deficit hyperactivity disorder</li> <li data-bbox="630 1610 1365 1682">• Disruptive behavior disorder e.g., oppositional defiant disorder, conduct disorder</li> <li data-bbox="630 1694 1143 1724">• Learning or communication disorder</li> <li data-bbox="630 1736 1024 1766">• Substance related disorders</li> <li data-bbox="630 1778 1219 1808">• Schizophrenia or other psychotic disorders</li> <li data-bbox="630 1820 873 1850">• Mood disorders</li> <li data-bbox="630 1862 883 1892">• Eating disorders</li> </ul>



- 
- Anxiety disorders
  - Adjustment disorder
  - Sleep disorders

Medical Diagnosis

- Asthma
  - Diabetes mellitus
  - Epilepsy or seizure disorders
  - Fetal alcohol effects/syndrome
  - Migraine
  - Traumatic brain injury
  - Severe allergies
- 

**(7) Social  
Functioning**

- Socially inappropriate or disruptive behaviour
  - Ability to understand others (comprehension)
  - Making self understood (expression)
  - Demonstrates lack of social and emotional conventions when socializing- e.g., lack of eye contact
  - Extreme shyness- e.g., severe inhibition in familiar social situations
  - Peer group includes individuals with persistence anti-social behaviours
  - Lack of interest in social interaction
  - Strong and supportive relationship with friends/peers
  - Social inclusion by peers
  - Has at least one friend with whom visits/plays/socializes regularly
  - Conflict or repeated criticisms of close friends
  - Pervasive conflict with peers (exclude close friends)
  - Friends are persistently hostile or critical of child/youth
  - Reports having a confidant
  - Victim of bullying
- 

**(8) Motor  
Functioning**

- Gross motor skills
  - Fine motor skills
  - Total hours of exercise or physical activity in last 3 days
-

Table 4. 3 *Demographic Characteristics of High Functioning and Low Functioning Groups, n (%)*

<b>Characteristic</b>	<b>HF</b>	<b>LF</b>
N (total)	272	106
<b>Age</b>		
Children (ages 4 to 11)	120 (44%)	32 (30%)
Youth (ages 12 to 18)	152 (56%)	74 (70%)
<b>Sex</b>		
Males	212 (78%)	81 (76%)
Females	60 (22%)	25 (24%)

*Note:* For all tables below, standardized residuals, odds ratios, confidence intervals and Cramer's V are only presented in the case the item was significant. As well, for the purpose of this study the term violated is defined as having (a) cell count(s) less than five and therefore could not be reported due to ethical and statistical restrictions.

Table 4. 4 *Background Information Items Compared Between High Functioning Males and High Functioning Females (df=1), sample size (% sample in group)*

Item	Code	Males N (%) Standardized Residuals	Females N (%) Standardized Residuals	N	P value	X <sup>2</sup>	Odds Ratio	95% Confidence Interval	Cramer's V
<b>REASON FOR REFERRAL</b>									
<b>Threat/danger to self</b>	Yes	62 (29%)	25 (42%)	272	.069	33.17			
	No	150 (71%)	35 (58%)						
<b>Threat/danger to others</b>	Yes	105 (49%) .8	20 (33%) -1.4	272	.026	4.94	.673	.459-.987	.135
	No	107 (51%) -.7	40 (67%) 1.3						
<b>Problem with addiction or dependency</b>	<b>Violated</b>								
<b>Specific psychiatric symptoms e.g., severe behaviour problems, depression, hallucinations</b>	Yes	145 (68%)	47 (78%)	272	.136	22.22			
	No	67 (32%)	13 (22%)						
<b>Involvement with youth justice system</b>	<b>Violated</b>								
<b>FORMAL CARE</b>									

<b>Psychiatrist</b>	No contact in the past 3 years	62 (34%)	17 (39%)	238	.536	.38	
	Contact in the past 3 years	119 (66%)	40 (61%)				
<b>Social worker</b>	No contact in the past 3 years	62 (34%)	17 (30%)	238	.536	.38	
	Contact in the past 3 years	119 (66%)	40 (70%)				
<b>Psychologist, psychometric, psychological associate</b>	No contact in the past 3 years	88 (49%)	22 (39%)	238	.186	1.75	
	Contact in the past 3 years	93 (51%)	35 (61%)				
<b>Occupational therapist, Physiotherapist</b>	No contact in the past 3 years	118 (65%)	44 (77%)	238	.090	2.87	
	Contact in the past 3 years	63 (35%)	13 (23%)				
<b>Recreation, art, music, play therapist</b>	<b>Violated</b>						
<b>Registered nurse</b>	No contact in the past 3 years	140 (77%)	40 (70%)	238	.271	1.21	
	Contact in the past 3 years	41 (23%)	17 (30%)				
<b>Child protection</b>	No contact in the past 3 years	99 (55%)	35 (61%)	238	.373	.79	
	Contact in the past 3 years	82 (45%)	22 (39%)				
<b>Behaviour therapist</b>	No contact in the past 3 years	123 (68%)	41 (72%)	238	.572	.32	
	Contact in the past 3 years	58 (32%)	16 (28%)				

Dietician	Violated						
<b>Speech language pathologist</b>	No contact in the past 3 years	124 (69%)	39 (61%)	238	.99	.000	
	Contact in the past 3 years	57 (31%)	18 (39%)				

Table 4. 5 Overall Health Items Compared Between High Functioning Males and High Functioning Females ( $df=1$ ), sample size (% sample in group)

Item	Code	Males N (%) Standardized Residuals	Females N (%) Standardized Residuals	N	DF	P value	X <sup>2</sup>	Odds Ratios	95% Confidence Interval	Cramer's V
<b>Pain Intensity</b>	No Pain	187 (88%)	48 (80%)	272	1	.101	2.68			
	Mild to excruciating pain	25 (12%)	12 (20%)							
<b>Repetitive health complaints</b>	Not present	140 (66%) <b>0.75</b>	28 (47%) <b>-1.41</b>	272	1	<.01	7.43	2.21	1.25-3.97	.165
	Present	72 (34%) <b>-0.95</b>	32 (53%) <b>1.79</b>							
<b>Difficulty falling asleep or staying asleep</b>	Not present	81 (38%)	17 (28%)	272	1	.160	1.98			
	Present	131 (62%)	43 (72%)							
<b>Sleep problems related to hypomania or mania</b>	Not present	56 (75%)	49 (87%)	132	1	.516	.42			
	Present	19 (25%)	8 (13%)							
<b>Frequency with which child/youth complains or shows evidence of pain</b>	No pain	25 (12%)	13 (22%)	272	1	.051	3.79			
	Pain	187 (88%)	47 (78%)							
<b>Prescribed medication</b>	Not prescribed medication	158 (75%)	46 (77%)	272	1	.736	.11			
	Prescribed medication	54 (25%)	14 (23%)							

DSM-IV										
<b>Reactive attachment disorder</b>	<b>Violated</b>									
<b>Attentional deficit hyperactivity disorder</b>	Not present	84 (40%) <b>-0.93</b>	36 (60%) <b>1.76</b>	272	1	<.01	7.87	1.51	1.09-2.10	.170
	Present	128 (60%) <b>0.83</b>	24 (40%) <b>-1.56</b>							
<b>Disruptive behavior disorder</b>	Not present	153 (72%)	43 (72%)	272	1	.939	.01			
	Present	59 (28%)	17 (28%)							
<b>Learning or communication disorder</b>	Not present	148 (82%)	45 (75%)	272	1	.434	.61			
	Present	64 (18%)	15 (25%)							
<b>Substance related disorders</b>	<b>Violated</b>									
<b>Schizophrenia or other psychotic disorders</b>	<b>Violated</b>									
<b>Mood disorders</b>	Not present	189 (89%)	49 (82%)	272	1	.122	2.39			
	Present	23 (11%)	11 (18%)							
<b>Anxiety disorder</b>	Not present	85 (47%)	27 (50%)	235 <sup>34</sup>	1	.695	.15			
	Present	96 (53%)	27 (50%)							
<b>Adjustment disorder</b>	<b>Violated</b>									
<b>Eating disorders</b>	<b>Violated</b>									

<sup>34</sup> 43 items missing from item

<b>Sleep disorders</b>	<b>Violated</b>
<b>MEDICAL DIAGNOSIS</b>	
<b>Asthma</b>	<b>Violated</b>
<b>Diabetes mellitus</b>	<b>Violated</b>
<b>Epilepsy or seizure disorders</b>	<b>Violated</b>
<b>Fetal alcohol effects/syndrome</b>	<b>Violated</b>
<b>Migraine</b>	<b>Violated</b>
<b>Traumatic brain injury</b>	<b>Violated</b>
<b>Severe allergies</b>	<b>Violated</b>



Table 4. 6 *Social Items Compared Between High Functioning Males and High Functioning Females, (df=1), sample size (% sample in group)*

<b>Social Item</b>	<b>Code</b>	<b>Males N (%) Standardize d Residuals</b>	<b>Females N (%) Standardize d Residuals</b>	<b>N</b>	<b>P value</b>	<b>X<sup>2</sup></b>	<b>Odds Ratio</b>	<b>95% Confidence Interval</b>	<b>Cramer's V</b>
<b>Socially inappropriate or disruptive behaviours</b>	No	121 (57%)	37 (62%)	272	.525	.40			
	Yes	91 (43%)	23 (38%)						
<b>Ability to understand others (comprehension)</b>	Understands	103 (49%)	31 (52%)	272	.673	.18			
	Understands but with difficulty	109 (51%)	29 (48%)						
<b>Making self understood (expression)</b>	Understood	104 (49%)	34 (57%)	272	.298	1.08			
	Understood but with difficulty	108 (51%)	26 (43%)						
<b>Demonstrates lack of social and emotional conventions when socializing</b>	No	70 (33%)	27 (45%)	272	.087	2.93			
	Yes	142 (67%)	33 (55%)						
<b>Extreme shyness</b>	No	161 (76%)	43 (71%)	272	.499	.456			
	Yes	51 (24%)	17 (28%)						
<b>Peer group includes</b>	No	194 (92%)	54 (90%)	272	.716	.13			

<b>individuals with persistence anti-social behaviours</b>	Yes	18 (8%)	6 (10%)				
<b>Lack of interest in social interaction</b>	No	105 (49%)	30 (50%)	272	.950	.00	
	Yes	107 (51%)	30 (50%)				
<b>Strong and supportive relationship with friends/peers</b>	No	126 (59%)	35 (58%)	272	.878	.02	
	Yes	86 (41%)	25 (42%)				
<b>Social inclusion by peers</b>	No	98 (46%)	31 (52%)	272	.456	.55	
	Yes	114 (54%)	29 (48%)				
<b>Has at least one friend with whom visits/plays/socializes regularly</b>	No	82 (39%)	24 (40%)	272	.853	.03	
	Yes	130 (61%)	36 (60%)				
<b>Conflict or repeated criticisms of close friends</b>	No	175 (90%)	45 (85%)	248 <sup>35</sup>	.323	.97	
	Yes	20 (10%)	8 (15%)				

<sup>35</sup> 24 cases missing as “Not applicable” category was removed

<b>Pervasive conflict with peers (exclude close friends)</b>	No	153 (75%)	45 (76%)	262 <sup>36</sup>	.685	.16	
	Yes	51(25%)	13 (24%)				
<b>Friends are persistently hostile or critical of child/youth</b>	No	186 (94%)	50 (91%)	252 <sup>37</sup>	.345	0.90	
	Yes	11 (6%)	5 (9%)				
<b>Reports having a confidant</b>	No	72 (34%)	17 (28%)	272	.412	.67	
	Yes	140 (66%)	43 (72%)				
<b>Victim of bullying</b>	No	123 (80%)	85 (76%)	266 <sup>38</sup>	.438	.60	
	Yes	31 (20%)	27 (24%)				

<sup>36</sup> 10 cases missing as “Not applicable” category was removed

<sup>37</sup> 14 cases missing as “Not applicable” category was removed

<sup>38</sup> 14 cases missing as “Not applicable” category was removed

Table 4. 7 Motor Compared Between High Functioning Males and High Functioning Females, ( $df=1$ ), sample size (% sample in group)

Item	Code	Males N (%) Standardized Residuals	Females N (%) Standardized Residuals	N	P value	X <sup>2</sup>	Odds Ratios	95% Confidence Interval	Cramer's V
<b>Gross motor skills</b>	Adequate	133 (74%)	46 (81%)	238	.271	1.21			
	Exhibits difficulty	48 (26%)	11 (19%)						
<b>Fine motor skills</b>	Adequate	106 (59%) <b>-0.57</b>	42 (74%) <b>1.02</b>	238 <sup>39</sup>	<.05	4.21	1.57	.99-2.51	.133
	Exhibits difficulty	75 (41%) <b>0.73</b>	15 (26%) <b>-1.3</b>						
<b>Hours of PA (in the last 3 days)</b>	Less than 2 hours	124 (59%)	39 (65%)	272	.364	8.25			
	More than 3 hours	88 (41%)	21 (35%)						

<sup>39</sup> 34 missing to new item

Table 4. 8 Scales Compared Among High Functioning Males and Females, Sample Size (% sample in group)

Scale	Code	HF Males	HF Females	df	N	P value	X2	Cramer's V
<b>Anxiety</b>	Low	39 (25%)	6 (12%)	2	208	.085	4.93	
	Moderate	63 (40%)	19 (38%)					
	High to Very High	56 (35%)	25 (50%)					
<b>Depression</b>	Low	79 (39%)	18 (30%)	3	263	.655	1.62	
	Moderate	68 (34%)	23 (28%)					
	High	25 (12%)	8 (13%)					
	Very High	31 (15%)	11 (18%)					
<b>Pain</b>	<b>Violated</b>							
<b>Peer</b>	<b>Violated</b>							
<b>Communication</b>	Low	39 (29%)	10 (29%)	2	167	.602	1.02	
	Moderate	50 (38%)	10 (29%)					
	High to Very High	44 (22%)	14 (41%)					
	Low	68 (40%)	20 (44%)	2	213	.798	.450	
	Moderate	84 (50%)	20 (44%)					

<b>Disruptive/ Aggressive Behaviour</b>	High to Very High	16 (10%)	5 (11%)					
<b>Caregiver Distress</b>	Low	117 (83%)	28 (76%)	1	178	.309		
	Moderate to Very High	24 (17%)	9 (24%)					

Table 4. 9 *Background Information Items Compared Between Low Functioning Males and Low Functioning Females, (df=1), sample size (% sample in group)*

Item	Code	Males N (%) Standardized Residuals	Females N (%) Standardized Residuals	N	P value	X <sup>2</sup>	Odds Ratio	95% Confidence Intervals	Cramer's V
<b>REASON FOR REFERRAL</b>									
<b>Threat/danger to self</b>	Yes	47 (58%)	18 (72%)	106	.210	1.57			
	No	34 (42%)	7 (28%)						
<b>Threat/danger to others</b>	Yes	53 (65%)	15 (60%)	106	.621	.25			
	No	28 (35%)	10 (40%)						
<b>Problem with addiction or dependency</b>	<b>Violated</b>								
<b>Specific psychiatric symptoms e.g., severe behaviour problems, depression, hallucinations</b>	Yes	62 (77%)	16 (64%)	106	.214	1.55			
	No	19 (23%)	9 (36%)						
<b>Involvement with youth justice system</b>	<b>Violated</b>								
<b>FORMAL CARE<sup>40</sup></b>									
<b>Psychiatrist</b>	No contact in the past 3 years	16 (27%)	10 (48%)	81	.077	3.13			
	Contact in the past 3 years	44 (73%)	11 (52%)						

<sup>40</sup> 25 cases missing from all formal care items, except for the item 'dietician'

<b>Social worker</b>	No contact in the past 3 years	30 (50%)	13 (62%)	81	.347	.88	
	Contact in the past 3 years	30 (50%)	8 (38%)				
<b>Psychologist, psychometric, psychological associate</b>	No contact in the past 3 years	30 (50%)	11 (52%)	81	.851	.03	
	Contact in the past 3 years	30 (50%)	10 (48%)				
<b>Occupational therapist, physiotherapist</b>	No contact in the past 3 years	18 (30%)	10 (48%)	81	.144	2.13	
	Contact in the past 3 years	42 (70%)	11 (52%)				
<b>Recreation, art, music, play therapist</b>	<b>Violated</b>						
<b>Registered nurse</b>	No contact in the past 3 years	32 (53%)	14 (67%)	81	.288	1.13	
	Contact in the past 3 years	28 (47%)	7 (33%)				
<b>Child protection</b>	No contact in the past 3 years	34 (57%)	7 (33%)	81	.066	.08	
	Contact in the past 3 years	26 (43%)	14 (67%)				
<b>Child/youth counsellor</b>	No contact in the past 3 years	47 (78%)	14 (67%)	81	.286	3.38	
	Contact in the past 3 years	13 (22%)	7 (33%)				
<b>Behaviour therapist</b>	No contact in the past 3 years	30 (50%)	10 (48%)	81	.851	.03	
	Contact in the past 3 years	30 (50%)	11 (52%)				
<b>Dietician</b>	No contact in the past 3 years	51 (63%)	17 (68%)	106	.646	.21	



	Contact in the past 3 years	30 (37%)	8 (32%)				
<b>Speech language pathologist</b>	No contact in the past 3 years	18 (30%)	7 (33%)	81	.776	.08	
	Contact in the past 3 years	42 (70%)	14 (67%)				

Table 4. 10 Overall Health Items Compared Between Low Functioning Males and Low Functioning Females, ( $df=1$ ), sample size (% sample in group)

Item	Code	Males N (%) Standardized Residuals	Females N (%) Standardized Residuals	N	P value	X <sup>2</sup>	Odds Ratios	95% Confidence Interval	Cramer's V
Intensity of highest level of pain present	<b>Violated</b>								
Repetitive health complaints	Not present	62 (77%)	19 (76%)	106	.955	.00			
	Present	19 (23%)	6 (24%)						
Difficulty falling asleep	Not present	26 (48%)	7 (28%)	106	.699	.15			
	Present	55 (52%)	18 (72%)						
Sleep problems	Not present	48 (81%)	15 (76%)	80 <sup>41</sup>	.340	.91			
	Present	11 (19%)	6 (24%)						
Frequency with which child/youth complains or shows evidence of pain	<b>Violated</b>								
Prescribed medication	<b>Violated</b>								
<b>DSM-IV</b>									
Reactive attachment disorder	<b>Violated</b>								

<sup>41</sup> 26 cases missing from item

<b>Attentional deficit hyperactivity disorder</b>	<b>Violated</b>						
<b>Disruptive behavior disorder</b>	<b>Violated</b>						
<b>Learning or communication disorder</b>	Not present	39 (48%)	15 (60%)	106	.300	1.07	
	Present	42 (52%)	10 (40%)				
<b>Substance related disorders</b>	<b>Violated</b>						
<b>Schizophrenia or other psychotic disorders</b>	<b>Violated</b>						
<b>Mood disorders</b>	<b>Violated</b>						
<b>Eating disorders</b>	<b>Violated</b>						
<b>Anxiety disorders</b>	<b>Violated</b>						
<b>Adjustment disorder</b>	<b>Violated</b>						
<b>Sleep disorders</b>	<b>Violated</b>						
<b>MEDICAL DIAGNOSIS</b>							
<b>Asthma</b>	<b>Violated</b>						
<b>Diabetes mellitus</b>	<b>Violated</b>						
	Not present	75 (93%)	20 (80%)		3.26	.071	

<b>Epilepsy or seizure disorders</b>	Present	6 (7%)	5 (20%)	81 <sup>42</sup>			
<b>Fetal alcohol effects/syndrome</b>	<b>Violated</b>						
<b>Migraine</b>	<b>Violated</b>						
<b>Traumatic brain injury</b>	<b>Violated</b>						
<b>Severe allergies</b>	<b>Violated</b>						

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<sup>42</sup> 25 cases missing from item

Table 4. 11 *Social Items Compared Between Low Functioning Males and Low Functioning Females, (df=1), sample size (% sample in group)*

Social Item	Code	Males N (%) Standardized Residuals	Females N (%) Standardized Residuals	N	P value	X <sup>2</sup>	Odds Ratio	95% Confidence Interval	Cramer's V
<b>Socially inappropriate behaviour or disruptive behaviours</b>	No	16 (20%) <b>-0.76</b>	10 (40%) <b>1.36</b>	10 6	<.05	4.2	1.37	.95-1.88	.200
	Yes	65 (80%) <b>0.43</b>	15 (60%) <b>-0.78</b>						
<b>Ability to understand others (comprehension)</b>	<b>Violated</b>								
<b>Making self understood (expression)</b>	<b>Violated</b>								
<b>Demonstrates lack of social and emotional conventions when socializing</b>	No	25 (31%)	8 (32%)	10 6	.915	.01			
	Yes	56 (69 %)	17 (68%)						
<b>Extreme shyness</b>	No	62 (77%)	20 (80%)	10 6	.718	.13			
	Yes	19 (23%)	5 (20%)						
<b>Peer group includes individuals with persistence anti-social behaviours</b>	<b>Violated</b>								
<b>Lack of interest in social interaction</b>	No	29 (36%)	11 (44%)	10 6	.447	3.71			
	Yes	52 (64%)	14 (54%)						

<b>Strong and supportive relationship with friends/peers</b>	No	61 (75%)	18 (72%)	10 6	.740	.11	
	Yes	20 (25%)	7 (28%)				
<b>Social inclusion by peers</b>	No	53 (65%)	16 (64%)	10 6	.896	.06	
	Yes	28 (35%)	9 (36%)				
<b>Has at least one friend with whom visits/plays/socializes regularly</b>	No	61 (75 %)	17 (68%)	10 6	.469	.52	
	Yes	20 (25%)	8 (32%)				
<b>Conflict or repeated criticisms of close friends</b>	<b>Violated</b>						
<b>Pervasive conflict with peers (exclude close friends)</b>	<b>Violated</b>						
<b>Friends are persistently hostile or critical of child/youth</b>	<b>Violated</b>						
<b>Reports having a confidant</b>	<b>Violated</b>						
<b>Victim of bullying</b>	<b>Violated</b>						

Table 4. 12 Motor Items Compared Between Low Functioning Males and Low Functioning Females, ( $df=1$ ), sample size (% sample in group)

Item	Code	Males N (%) Standardized Residuals	Females N (%) Standardized Residuals	N	P value	X <sup>2</sup>	Odds Ratios	95% Confidence Interval	Cramer's V
<b>Gross motor skills</b>	Adequate	33 (55%)	10 (48%)	81 <sup>43</sup>	.560	.34			
	Exhibits difficulty	27 (45%)	11 (52%)						
<b>Fine motor skills</b>	<b>Violated</b>								
<b>Hours of PA (in the last 3 days)</b>	Less than 2 hours	31 (38%)	14 (56%)	106	.117	2.46			
	More than 3 hours	50 (62%)	11 (44%)						

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<sup>43</sup> 25 cases missing from item

Table 4. 13 Scales Compared Among Low Functioning Males and Females, Sample Size (% sample in group)

Scale	Code	LF Males	LF Females	df	N	P value	X <sup>2</sup>	Cramer's V
<b>Anxiety</b>	Low to Moderate	48 (64%)	17 (68%)	1	99	.775	.081	
	High to Very High	26 (35%)	8 (32%)					
<b>Depression</b>	Low	29 (36%)	7 (28%)	2	105	.117	4.28	
	Moderate to High	40 (50%)	10 (40%)					
	Very High	11 (14%)	8 (32%)					
<b>Pain</b>	<b>Violated</b>							
<b>Peer</b>	<b>Violated</b>							
<b>Communication</b>	Low to Moderate	19 (24%)	9 (37%)	2	104	.411	1.77	
	High	37 (46%)	9 (37%)					
	Very High	24 (30%)	6 (25%)					
<b>Disruptive/ Aggressive Behaviours</b>	Low to Moderate	58 (77%)	13 (62%)	1	96	.154	2.03	
	High to Very High	17 (23%)	8 (38%)					



<b>Caregiver Distress</b>	<b>Violated</b>
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**APPENDIX 4a: Recoding of Variables***Recoding of Background Information Items*

<b>Item</b>	<b>Original Code</b>	<b>New code</b>
<b>REASON FOR REFERRAL</b>		
<b>Threat or danger to self</b>	0. No 1. Yes	N/A
<b>Threat or danger to others</b>	0. No 1. Yes	N/A
<b>Problem with addiction or dependency</b>	0. No 1. Yes	N/A
<b>Specific psychiatric symptoms- e.g., severe behaviour problems, depression, hallucinations</b>	0. No 1. Yes	N/A
<b>Involvement with youth justice system</b>	0. No 1. Yes	N/A
<b>FORMAL CARE</b>		
<b>Psychiatrist</b>	0. No contact in last 3 years 1. No contact in last 90 days, but contact in last 3 years 2. No contact in last 30 days, but contact 31–90 days ago 3. No contact in last 7 days, but contact 8–30 days ago 4. Contact in last 7 days but not daily 5. Daily contact in last 7 days	0. No contact in last 3 years (0) 1. Contact in last 3 years (1,2,3,4,5)
<b>Social worker</b>	0. No contact in last 3 years 1. No contact in last 90 days, but contact in last 3 years 2. No contact in last 30 days, but contact 31–90 days ago 3. No contact in last 7 days, but contact 8–30 days ago 4. Contact in last 7 days but not daily 5. Daily contact in last 7 days	0. No contact in last 3 years (0) 1. Contact in last 3 years (1,2,3,4,5)
<b>Psychologist, psychometric, psychological associate</b>	0. No contact in last 3 years 1. No contact in last 90 days, but contact in last 3 years 2. No contact in last 30 days, but contact 31–90 days ago 3. No contact in last 7 days, but contact 8–30 days ago 4. Contact in last 7 days but not daily 5. Daily contact in last 7 days	0. No contact in last 3 years (0) 1. Contact in last 3 years (1,2,3,4,5)

<b>Occupational therapist, Physiotherapist</b>	<ul style="list-style-type: none"> <li>0. No contact in last 3 years</li> <li>1. No contact in last 90 days, but contact in last 3 years</li> <li>2. No contact in last 30 days, but contact 31–90 days ago</li> <li>3. No contact in last 7 days, but contact 8–30 days ago</li> <li>4. Contact in last 7 days but not daily</li> <li>5. Daily contact in last 7 days</li> </ul>	<ul style="list-style-type: none"> <li>0. No contact in last 3 years (0)</li> <li>1. Contact in last 3 years (1,2,3,4,5)</li> </ul>
<b>Recreation, art, music, play therapist</b>	<ul style="list-style-type: none"> <li>0. No contact in last 3 years</li> <li>1. No contact in last 90 days, but contact in last 3 years</li> <li>2. No contact in last 30 days, but contact 31–90 days ago</li> <li>3. No contact in last 7 days, but contact 8–30 days ago</li> <li>4. Contact in last 7 days but not daily</li> <li>5. Daily contact in last 7 days</li> </ul>	<ul style="list-style-type: none"> <li>0. No contact in last 3 years (0)</li> <li>1. Contact in last 3 years (1,2,3,4,5)</li> </ul>
<b>Registered nurse</b>	<ul style="list-style-type: none"> <li>0. No contact in last 3 years</li> <li>1. No contact in last 90 days, but contact in last 3 years</li> <li>2. No contact in last 30 days, but contact 31–90 days ago</li> <li>3. No contact in last 7 days, but contact 8–30 days ago</li> <li>4. Contact in last 7 days but not daily</li> <li>5. Daily contact in last 7 days</li> </ul>	<ul style="list-style-type: none"> <li>0. No contact in last 3 years (0)</li> <li>1. Contact in last 3 years (1,2,3,4,5)</li> </ul>
<b>Child protection</b>	<ul style="list-style-type: none"> <li>0. No contact in last 3 years</li> <li>1. No contact in last 90 days, but contact in last 3 years</li> <li>2. No contact in last 30 days, but contact 31–90 days ago</li> <li>3. No contact in last 7 days, but contact 8–30 days ago</li> <li>4. Contact in last 7 days but not daily</li> <li>5. Daily contact in last 7 days</li> </ul>	<ul style="list-style-type: none"> <li>0. No contact in last 3 years (0)</li> <li>1. Contact in last 3 years (1,2,3,4,5)</li> </ul>
<b>Behaviour therapist</b>	<ul style="list-style-type: none"> <li>0. No contact in last 3 years</li> <li>1. No contact in last 90 days, but contact in last 3 years</li> <li>2. No contact in last 30 days, but contact 31–90 days ago</li> <li>3. No contact in last 7 days, but contact 8–30 days ago</li> <li>4. Contact in last 7 days but not daily</li> <li>5. Daily contact in last 7 days</li> </ul>	<ul style="list-style-type: none"> <li>0. No contact in last 3 years (0)</li> <li>1. Contact in last 3 years (1,2,3,4,5)</li> </ul>

<b>Dietician</b>	<ul style="list-style-type: none"> <li>0. No contact in last 3 years</li> <li>1. No contact in last 90 days, but contact in last 3 years</li> <li>2. No contact in last 30 days, but contact 31–90 days ago</li> <li>3. No contact in last 7 days, but contact 8–30 days ago</li> <li>4. Contact in last 7 days but not daily</li> <li>5. Daily contact in last 7 days</li> </ul>	<ul style="list-style-type: none"> <li>0. No contact in last 3 years (0)</li> <li>1. Contact in last 3 years (1,2,3,4,5)</li> </ul>
<b>Speech language pathologist</b>	<ul style="list-style-type: none"> <li>0. No contact in last 3 years</li> <li>1. No contact in last 90 days, but contact in last 3 years</li> <li>2. No contact in last 30 days, but contact 31–90 days ago</li> <li>3. No contact in last 7 days, but contact 8–30 days ago</li> <li>4. Contact in last 7 days but not daily</li> <li>5. Daily contact in last 7 days</li> </ul>	<ul style="list-style-type: none"> <li>0. No contact in last 3 years (0)</li> <li>1. Contact in last 3 years (1,2,3,4,5)</li> </ul>

*Recoding of Overall Health Items*

<b>Item</b>	<b>Original Code</b>	<b>New code</b>
<b>Intensity of highest level of pain present</b>	0. No pain 1. Mild 2. Moderate 3. Severe 4. Times when pain is horrible or excruciating	0. No pain (0) 1. Mild to excruciating pain (1,2,3,4)
<b>Repetitive health complaints- e.g., persistently seeks attention for physical symptoms such as headaches and stomach ache; incessant concern with body functions</b>	0. Not present 1. Present but not exhibited in last 3 days 2. Exhibited on 1-2 of last 3 days 3. Exhibited daily in last 3 days, 1-2 episodes 4. Exhibited daily in last 3 days, 3 or more episodes or continuously	0. Not present (0) 1. Present (1,2,3,4)
<b>Difficulty falling asleep or staying asleep</b>	0. Not present 1. Present but not exhibited in last 3 days 2. Exhibited on 1-2 of last 3 days 3. Exhibited daily in last 3 days, 1-2 episodes 4. Exhibited daily in last 3 days, 3 or more episodes or continuously	0. Not present (0) 1. Present (1,2,3,4)
<b>Sleep problems related to hypomania or mania</b>	0. Never 1. More than 1 year ago 2. 31 days- 1 year ago 3. 8-30 days ago 4. 4-7 days ago 5. In last 3 days	0. Not present (0) 1. Present (1,2,3,4,5)
<b>Frequency with which child/youth complains or shows evidence of pain</b>	0. No pain 1. Present but no exhibited in last 3 days 2. Exhibited on 1-2 of last 3 days 3. Exhibited daily in the last 3 days	0. No pain (0) 1. Pain (1,2,3)
<b>Adherent with medications prescribed by physician-&gt; Prescribed medication</b>	0. Always adherent 1. Adherent 80% of time or more 2. Adherent less than 80% of time, including failure to purchase prescribed medications 8. Not medication prescribed	0. Not prescribed medication (8) 1. Prescribed (0, 1,2)
<b>DSM-IV</b>		
<b>Reactive attachment disorders</b>	0. Not present 1. Most important	0. Not present (0,8)

	2. Second most important 3. Third most important 4. Less important 8. No provisional diagnosis	1. Present (1,2,3,4)
<b>Attentional deficit hyperactivity disorder</b>	0. Not present 1. Most important 2. Second most important 3. Third most important 4. Less important 8. No provisional diagnosis	0. Not present (0,8) 1. Present (1,2,3,4)
<b>Disruptive behavior disorders- e.g., oppositional defiant disorder, conduct disorder</b>	0. Not present 1. Most important 2. Second most important 3. Third most important 4. Less important 8. No provisional diagnosis	0. Not present (0,8) 1. Present (1,2,3,4)
<b>Learning or communication disorders</b>	0. Not present 1. Most important 2. Second most important 3. Third most important 4. Less important 8. No provisional diagnosis	0. Not present (0,8) 1. Present (1,2,3,4)
<b>Substance related disorders</b>	0. Not present 1. Most important 2. Second most important 3. Third most important 4. Less important 8. No provisional diagnosis	0. Not present (0,8) 1. Present (1,2,3,4)
<b>Schizophrenia or other psychotic disorders</b>	0. Not present 1. Most important 2. Second most important 3. Third most important 4. Less important 8. No provisional diagnosis	0. Not present (0,8) 1. Present (1,2,3,4)
<b>Mood disorders</b>	0. Not present 1. Most important 2. Second most important 3. Third most important 4. Less important 8. No provisional diagnosis	0. Not present (0,8) 1. Present (1,2,3,4)
<b>Eating disorders</b>	0. Not present 1. Most important 2. Second most important	0. Not present (0,8)

	3. Third most important 4. Less important 8. No provisional diagnosis	1. Present (1,2,3,4)
<b>Anxiety disorders- e.g., separation anxiety disorder, obsessive compulsive disorder</b>	0. Not present 1. Most important 2. Second most important 3. Third most important 4. Less important 8. No provisional diagnosis	0. Not present (0,8) 1. Present (1,2,3,4)
<b>Adjustment disorder</b>	0. Not present 1. Most important 2. Second most important 3. Third most important 4. Less important 8. No provisional diagnosis	0. Not present (0,8) 1. Present (1,2,3,4)
<b>Sleep disorders</b>	0. Not present 1. Most important 2. Second most important 3. Third most important 4. Less important 8. No provisional diagnosis	0. Not present (0,8) 1. Present (1,2,3,4)
<b>MEDICAL CONDITIONS</b>		
<b>Asthma</b>	0. Not present 1. Primary diagnosis/diagnoses for current stay 2. Diagnosis present, receiving active treatment 3. Diagnosis present, monitored but no active treatment	0. Not present (0) 1. Present (1,2,3)
<b>Diabetes mellitus</b>	0. Not present 1. Primary diagnosis/diagnoses for current stay 2. Diagnosis present, receiving active treatment 3. Diagnosis present, monitored but no active treatment	0. Not present (0) 1. Present (1,2,3)
<b>Epilepsy or seizure disorders</b>	0. Not present 1. Primary diagnosis/diagnoses for current stay 2. Diagnosis present, receiving active treatment 3. Diagnosis present, monitored but no active treatment	0. Not present (0) 1. Present (1,2,3)

<b>Fetal alcohol effects/syndrome</b>	<ul style="list-style-type: none"> <li>0. Not present</li> <li>1. Primary diagnosis/diagnoses for current stay</li> <li>2. Diagnosis present, receiving active treatment</li> <li>3. Diagnosis present, monitored but no active treatment</li> </ul>	<ul style="list-style-type: none"> <li>0. Not present (0)</li> <li>1. Present (1,2,3)</li> </ul>
<b>Migraine</b>	<ul style="list-style-type: none"> <li>0. Not present</li> <li>1. Primary diagnosis/diagnoses for current stay</li> <li>2. Diagnosis present, receiving active treatment</li> <li>3. Diagnosis present, monitored but no active treatment</li> </ul>	<ul style="list-style-type: none"> <li>0. Not present (0)</li> <li>1. Present (1,2,3)</li> </ul>
<b>Traumatic brain injury</b>	<ul style="list-style-type: none"> <li>0. Not present</li> <li>1. Primary diagnosis/diagnoses for current stay</li> <li>2. Diagnosis present, receiving active treatment</li> <li>3. Diagnosis present, monitored but no active treatment</li> </ul>	<ul style="list-style-type: none"> <li>0. Not present (0)</li> <li>1. Present (1,2,3)</li> </ul>
<b>Severe (anaphylactic) allergies- Exclude medication allergies</b>	<ul style="list-style-type: none"> <li>0. Not present</li> <li>1. Primary diagnosis/diagnoses for current stay</li> <li>2. Diagnosis present, receiving active treatment</li> <li>3. Diagnosis present, monitored but no active treatment</li> </ul>	<ul style="list-style-type: none"> <li>0. Not present (0)</li> <li>1. Present (1,2,3)</li> </ul>



*Recoding of Social Items*

<b>Item</b>	<b>Original Code</b>	<b>New Code</b>
<b>Socially inappropriate or disruptive behaviours- e.g., screamed out during class, smeared or threw food or feces</b>	0. Not present 1. Present but not exhibited in last 3 days 2. Exhibited on 1-2 of last 3 days 3. Exhibited daily in last 3 days, 1-2 episodes 4. Exhibited daily in last 3 days, 3 or more episodes or continuously	0.No (0) 1.Yes (1,2,3,4)
<b>Ability to understand others (comprehension)</b>	0. Understands- <i>Clear comprehension</i> 1. Usually understands- <i>Misses some part/intent of message BUT comprehends most conversation</i> 2. Often understands- <i>Misses some part/intent of message BUT with repetition or explanation can often comprehend conversation</i> 3. Sometimes understands- <i>Responds adequately to simple, direct communication only</i> 4. Rarely or never understands	0.Understands (0) 1. Difficulty understanding (1,2,3,4)
<b>Making self understood (expression)</b>	0. Understood- <i>Expresses ideas without difficulty</i> 1. Usually understood- <i>Difficulty finding words or finishing thoughts BUT if given time, little or no prompting required</i> 2. Often understood- <i>Difficulty finding words or finishing thoughts AND prompting usually required</i> 3. Sometimes understood- <i>Ability is limited to making concrete requests, e.g., regarding food, drink, toilet</i> 4. Rarely or never understood	0.Understood (0) 1. Difficulty being understood (1,2,3,4)
<b>Demonstrates lack of social and emotional conventions when socializing- e.g., lack of eye contact</b>	0. No 1. Yes	0. No 1. Yes
<b>Extreme shyness- e.g., severe inhibition in familiar social situations</b>	0. No 1. Yes	0. No 1. Yes

<b>Peer group includes individuals with persistence anti-social behaviours</b>	0. No 1. Yes	0. No 1. Yes
<b>Lack of interest in social interaction</b>	0. Not present 1. Present but not exhibited in last 3 days 2. Exhibited on 1-2 of last 3 days 3. Exhibited daily in last 3 days, 1-2 episodes 4. Exhibited daily in last 3 days, 3 or more episodes or continuously	0. No (0) 1. Present (1,2,3,4)
<b>Strong and supportive relationship with friends/peers</b>	0. No 1. Yes	0. No 1. Yes
<b>Social inclusion by peers- e.g., playmates at recess</b>	0. No 1. Yes	0. No 1. Yes
<b>Has at least one friend with whom visits/plays/socializes regularly</b>	0. No 1. Yes	0. No 1. Yes
<b>Conflict or repeated criticisms of close friends</b>	0. No 1. Yes 8. Not applicable	0. No 1. Yes *Excluded 8
<b>Pervasive conflict with peers (exclude close friends)</b>	0. No 1. Yes 8. Not applicable	0. No 1. Yes *Excluded 8
<b>Friends are persistently hostile or critical of child/youth</b>	0. No 1. Yes 8. Not applicable	0. No 1. Yes *Excluded 8
<b>Reports having a confidant</b>	0. No 1. Yes	0. No 1. Yes
<b>Victim of bullying</b>	0. Never 1. More than 1 year ago 2. 31 days to 1 year ago 3. 8-30 days ago 4. 4-7 days ago 5. In last 3 days	0. Never (0) 1. Has been bullied (1,2,3,4,5)

*Recoding of Motor Items*

Variable Name	Original Code	New Code
<b>Gross motor skills</b>	<p>0. Adequate- <i>Performs skill with satisfactory speed and quality of movement both indoors and outdoors (including uneven ground)</i></p> <p>1. Minimal difficulty- <i>Slight difficulty maintaining balance or controlling limb movement (e.g., appears clumsy, slower movements)</i></p> <p>2. Moderate difficulty- <i>Noticeable deficits in balance and controlling limb movements (e.g., frequently stumbles, drops objects, walks into objects)</i></p> <p>3. Severe difficulty- <i>Limitations in trunk, head, and limb control resulting in sever difficulty with coordination of own movements (e.g., unable to reach for a glass of water without knocking it over)</i></p> <p>4. <i>No ability to move body (full paralysis)</i></p>	<p>0. Adequate</p> <p>1. Exhibits difficulty (1,2,3,4)</p>
<b>Fine motor skills</b>	<p>0. Adequate- <i>Performs movements within appropriate time frame and with appropriate quality of movement</i></p> <p>1. Minimal difficulty- <i>Slight difficulty controlling movement (e.g., somewhat slow or easily fatigued)</i></p> <p>2. Moderate difficulty- <i>Noticeable deficits in fine motor skill development (e.g., unable to hold pencil properly and produce legible writing)</i></p> <p>3. Severe difficulty- <i>Severe limitation in ability to coordinate small muscle movement (e.g., significant struggle to pick up an object using thumb and forefinger)</i></p> <p>4. <i>No ability to move body (full paralysis)</i></p>	<p>0. Adequate</p> <p>1. Exhibits difficulty (1,2,3,4)</p>

<b>Total hours of exercise or physical activity in last 3 days</b>	0. None	0. 2 hours or less of PA (0,1,2)
	1. Less than 1 hour	1. 3+ hours of PA (3,4)
	2. 1-2 hours	
	3. 3-4 hours	
	4. More than 4 hours	

**APPENDIX 4b: Cut-Points used for Scales**

<b>Scale</b>	<b>Pre-determined Cut-Points</b>	<b>HF Females and Males</b>	<b>LF Females and Males</b>
<b>Disruptive/Aggressive Behaviour</b>	Low: 1-3 Moderate: 4-9 High: 10-14 Very High: 15-20	Low: 1-3 Moderate: 4-9 High to Very High: 10-20	Low to Moderate: 4-9 High to Very High: 10-20
<b>Anxiety</b>	Low: 1-3 Moderate: 4-9 High: 10-17 Very High: 18-32	Low: 1-3 Moderate: 4-9 High to Very High: 10-32	Low to Moderate: 1-9 High to Very High: 10-32).
<b>Communication</b>	Low: 1 Moderate: 2 High: 3-5 Very High: 6-8	Low: 1 Moderate: 2 High to Very High: 3-6	Low to Moderate: 1-2 High: 3-5 Very High: 6
<b>Depression Symptoms</b>	Low: 1-8 Moderate: 9-14 High: 15-18 Very High: 19-36	Low: 1-8 Moderate: 9-14 High: 15-18 Very High: 19-36	Low: 1-8 Moderate to High: 9-18 Very High: 19-36
<b>Pain</b>	Moderate: 1-2 High: 3 Very High: 4	Scale could not be collapsed to ensure cell sizes were not less than 5	
<b>Caregiver Distress</b>	Low: 1-2 Moderate: 3 High: 4 Very High: 5	Low: 1-2 Moderate to Very High: 3-5	Scale could not be collapsed to ensure cell sizes were not less than 5
<b>Peer Relationship</b>	Scale did not have pre-determined cut-points. Original scale of 0-5 to be used	Scale could not be collapsed to ensure cell sizes were not less than 5	

**Chapter 5- Study #4: Social and Motor Skills of Children and Youth with ASD from the Perspectives of Caregivers**

### **5.1. Abstract**

Social and motor deficits among individuals with autism spectrum disorder (ASD) are well documented. There is support to suggest a reciprocal relationship between social and motor deficits among individuals with ASD, in that social deficits prevent motor skill development and motor deficits prevent social skill development. The methods used to investigate motor and social impairments in children with ASD usually focus on quantitative methods and therefore do not provide the perspectives of caregivers. As such, this study explored social and motor impairments of children with ASD through the perspectives of eight caregivers of children with ASD using semi-structured interviews. Many salient findings emerged from the interviews conducted with caregivers, particularly concerning the social and motor development of their children. As well, the relationship between their children's social and motor deficits were also highlighted. Finally, the study discusses areas of concern that require attention. For instance, it is important that health care professionals educate parents about the consequences of motor impairments or delays and their associations with the development of social skills. As such, routine motor skill monitoring and assessments by caregivers and health care professionals should be encouraged. Future research exploring social and motor deficits in children with ASD through the caregiver perspective is warranted, as their perspectives can provide the framework needed to identify and minimize social and motor deficits in children with ASD.

## 5.2. Introduction

Social and motor deficits among individuals with autism spectrum disorder (ASD) are well documented. While deficits in social and communication domains are a core diagnostic criterion for diagnosing ASD, motor deficits are not, but are often referred to as ‘associated symptoms’ (American Psychiatric Association [APA], 2016; Ming, Brimacomber & Wagner, 2007). With respect to social impairments, children with ASD often have difficulty making eye contact, engaging in mature play, and initiating social interactions (Anderson, Moore, Godfrey, & Fletcher-Flinn, 2004; Fodstad, Matson, Hess & Neal, 2009; Tureck & Matson, 2012). Further, children with ASD have difficulty engaging and perceiving social and emotional experiences while interacting with peers (Bauminger, 2002). Social deficits among children with ASD are associated with loneliness, depression, social withdrawal, and a lower IQ (Bauminger, 2002; Ratcliffe, Wong, Doessetor, & Hayes, 2015; White & Roberson-Nay, 2009).

Motor impairments in children with ASD include balance issues, difficulty throwing and catching, hypotonia (i.e., low muscle tone), and apraxia (i.e., difficulty with motor planning) (Bhat, Landa, & Galloway, 2011; Ming et al., 2007; Provost, Lopez, & Heimerl, 2006). However, the influence of age on motor deficits appears to be inconsistent. Ming et al. (2007) reported motor apraxia and hypotonia were less prevalent in older children with ASD when compared to younger children with ASD and therefore suggested that impairments can be modified through the developmental aging process. It should be noted that the IQ of participants was not reported (Ming et al., 2007). Conversely Lloyd, Macdonald, and Lord (2011) found motor delays in fact worsened with age. Unfortunately, risk factors associated with motor impairments have not been widely researched. Findings from a study conducted by Kopp, Bekung, and Gillberg (2009) however did report an association between motor impairments and



IQ, age, and ASD symptom severity in females with ASD, in that younger females with lower IQs and more severe ASD symptoms exhibited greater motor impairments. Similarly, Green et al. (2009) reported school-aged children with ASD exhibited gross and fine motor impairments; however, these motor impairments were more severe in children with IQs less than 70. Green et al. (2009) proposed children with ASD and IQs less than 70 exhibited greater motor deficits because they may be more 'neurologically compromised.' Given the documented motor and social impairments in children with ASD, research investigating the relationship between these two impairments are discussed next.

There is support to suggest a reciprocal relationship between social and motor deficits among individuals with ASD. Researchers have suggested children who exhibit poor motor skills also have poor social skills (Bhat et al., 2011; MacDonald, Lord, & Ulrich, 2014; Lloyd et al., 2011). It has been proposed that motor delays in early life may contribute to social impairments in children with ASD (Bhat et al., 2011; MacDonald et al., 2014). Bhat et al. (2011) argued the development of locomotor skills allows for communication gestures and object sharing between toddlers and their caregivers, having a direct impact on social communication behaviours. Further, when children lack particular motor skills (e.g., coordination and mobility) this prevents them from engaging in free play with their peers, a shared experience which promotes friendships and social connections (Bhat et al., 2011). In a study conducted by Lloyd et al. (2011) toddlers across the spectrum exhibited significant motor delays which were exacerbated with age. Children develop motor skills, particularly gross motor skills, through active play with peers. However, interaction with peers for children with ASD is challenging and often avoided. As a result, children with ASD miss opportunities that promote the development of these motor skills. Lloyd et al. (2011) proposed there is a reciprocal relationship between social and motor

deficits in children with ASD in that social deficits prevent motor skill development and motor deficits prevent social skill development.

The methods used to investigate motor and social impairments in children with ASD usually focus on quantitative methods and therefore fails to provide the voice of caregivers. After a review of the literature, it appeared a qualitative study exploring social and motor impairments of children with ASD through the perspectives of caregivers was lacking. The caregiver voice can add further detail to these quantitative findings. For example, they can provide detailed answers to questions such as, why are their children exhibiting such deficits? What are the factors that they think contribute to their children's social and motor deficits? And caregivers can provide specific examples of such deficits, in a way that numbers cannot. The perspective of caregivers have the potential to provide unique insights pertaining to these deficits as they will be able to share their personal stories, opinions, and concerns all pertaining to their children's social and motor deficits.

As such, this study will explore social and motor impairments of children with ASD through the perspectives of their caregivers. Specifically, the study will identify specific social and motor impairments exhibited in children with ASD, as well as the effects of these deficits. It is important to note that this is the first paper to investigate, from the caregivers' perspectives, these issues.

### **5.3. Methodology**

**5.3.1. Ethics.** After ethics approval was obtained by the Wilfrid Laurier University Research Ethics Board, participant recruitment ensued.

**5.3.2. Sampling strategy.** To recruit parents of children with ASD purposeful sampling (Patton, 2002) was used. Specifically, criterion sampling and snowball sampling were employed

(Patton, 2002). Criterion sampling includes identifying participants based on pre-determined inclusion and exclusion criteria, whereas, snowball sampling includes asking participants to recommend individuals known to them who may be suitable to participate in the study (Patton, 2002). Participants were recruited through word of mouth and by emailing flyers outlining the details of the study to facilities serving individuals with developmental disabilities. Appendix 5a includes the information flyer. Facebook was also used to recruit potential participants from groups for parents of children with ASD in the Kitchener-Waterloo area. As well, the researcher elicited help from individuals who worked closely with individuals with disabilities (e.g., physical activity instructors and services providers for children with disabilities). Once individuals contacted the researcher each potential participant was screened to determine if he/she met the study criteria. Participants had to be an English-speaking parent of a child who had been formally diagnosed with ASD by a medical professional. Participants were asked if they knew any individuals who might be interested in participating in the study.

According to Patton (2002) rules regarding sample size or power in qualitative research do not exist. Patton (2002) states, “Sample size depends on what you want to know, the purpose of the inquiry, what’s at stake, what will be useful, what will have credibility, and what can be done with available time and resources” (p. 244). As such, the research team ended recruitment once saturation of the data had been reached. This was determined when replication of the themes from the participants occurred.

**5.3.4. Procedure.** Multiple forms of data collection were used to successfully address the research purpose, each of which will be discussed below.

**5.3.4.1. Background questionnaires.** Prior to the interviews, participants were asked to complete background questionnaire. The purpose of the background questionnaires was to gather

demographic information and to provide further context for the interviews. Demographic questions consisted of the following: age, date of birth, education status, marital status, and living situation. Information providing context for the interviews consisted of: background information regarding the children's disability, information regarding the children's overall health, and the children's level of social and motor skills. See Appendix 5b for the background questionnaire.

**5.3.4.2. Interviews.** Semi-structured, face-to-face interviews were conducted with each participant. Two female participants were married and preferred to complete the interviews with their husbands. For one of these female participants, English was her second language and she requested to have her husband join the interview to assist with translation. Her husband was not included as a participant because he only served as a translator and did not answer the questions directly. For the other female participant, her husband actively participated in the interview and therefore was included as an additional participant. The interviews with the eight participants ranged from 41 to 93 minutes (average time: 61 minutes). These eight participants included a father of two children with ASD and a husband and wife who participated in the interview together. All interviews were completed in person and either conducted in the ASD Lab at Wilfrid Laurier University or at the homes of the participants. Each interview consisted of 26 questions concerning the following areas: their children's social skills, concerns the parents may have for their children from a social perspective, the children's motor skills, concerns the parents may have for their children from a motor perspective, the association between their children's motor and social skills, and factors influencing the development of their children's social and motor skills. All interviews were recorded and transcribed verbatim. Pseudonyms were used to ensure the confidentiality of the participants. See Appendix 5b for the interview guide.

**5.3.4.3. *Field notes.*** Relevant information was documented prior to, during, and after the interviews. Such information included participants' emotional expressions, changes in the participants' demeanours, description of the environment in which the interviews took place, as well as time and length of the interviews. The completion of field notes assisted with data analysis by adding further context and ensuring accuracy in the interpretation of the data (Patton, 2002).

**5.3.4.4. *Journaling.*** The researcher kept a reflective journal throughout the duration of the study (Ortlipp, 2008). In this journal, the researcher documented her thoughts, opinions, and any potential biases. This journal was referred to during data analysis to make sure the researcher's personal insights were not influencing emerging themes (Ortlipp, 2008).

**5.3.4.5. *Member checks.*** Copies of the transcribed interviews were sent to participants via email. Member checks offered participants some degree of control over what was analysed by welcoming the participants to add, omit, and elaborate on any information they provided during their own interviews (Lincoln & Guba, 1985). Member checks enhanced both the credibility and trustworthiness of the data by confirming the information was transcribed accurately and conveyed the participants' true thoughts and feelings (Lincoln & Guba, 1985).

### **5.3.5. Trustworthiness**

**5.3.5.1. *Credibility.*** To the best ability of the researcher, multiple methods were employed to assure credibility. To ensure credibility as a researcher (Patton, 2002), an extensive literature review discussing and critically analyzing past and present research in the area of social and motor skills in children with ASD was completed. Also, the researcher's experiences academically and within the community working with children with disabilities assisted in conducting this research. Specifically, the researcher has taken four graduate quantitative courses

and one graduate qualitative class and is a part of a graduate qualitative research group comprised of graduate students and faculty members. She has also conducted multiple qualitative studies, including her Master of Science thesis. With regards to applied experience, she has extensive experience working with individuals with disabilities as she currently runs a physical activity program (Movin' and Groovin') for individuals with disabilities. The researcher has also completed ethics training (TCPS-2). She was also supervised by Dr. Fletcher and Dr. Bryden. Dr. Fletcher is an experienced qualitative researcher and Dr. Bryden is a skilled quantitative researcher. Moreover, the researcher built positive rapport with her participants by maintaining open lines of communication throughout the research process, in addition to the use of consent forms and member checks, as suggested by Patton (2002).

The second method of enhancing the credibility of this study was through triangulation (Patton, 2002). Two forms of triangulation were used: data triangulation, and investigator triangulation. Data triangulation required using multiple methods to collect data (e.g., background questionnaires, interviews, field notes, and member checks), while investigator triangulation involved having more than one individual assist with data analysis (Patton, 2002). Dr. Fletcher and Dr. Bryden read over transcripts and assisted with data analyses. This reduced potential bias of having only one individual analyze the data. By doing so, the credibility of the data was strengthened (Patton, 2002). As already mentioned, field notes and member checks were also used to enhance the credibility of the research study.

**5.3.5.2. Transferability.** To allow for other researchers to determine the transferability of the findings from this study to other contexts and situations, detail regarding the participants and the research process have been reported in detail as suggested by Lincoln and Guba (1985).

**5.3.5.3. Confirmability.** Confirmability assures the accuracy of data, particularly through the use of an audit trail (Lincoln and Guba, 1985) which documents all aspects of the research study. As recommended by Lincoln and Guba (1985), the audit trail included the following: literature review, methodology, recorded interviews, transcripts, field notes, and detailed documentation of the data analysis process. Through the use of an audit trail, confirmability of this study was established.

**5.3.6. Qualitative analysis.** Thematic analysis guided the data analyses process. Thematic analysis can be defined as “A method for identifying, analysing, and reporting patterns (themes) within data” (Braun & Clarke, 2006, p.83). More specifically, the analytic process followed the researcher’s interpretation of the steps recommended by Moustakas (1994). The first step recommended by Moustakas is *époché* which required setting aside any pre-existing judgments, acknowledging any personal biases, and assuring the researcher had an open-mind throughout the entire research study process. As such, notes were taken prior, during and, after all interviews. These notes were readily available for review and to assist with analysis throughout the entire research study. Additionally, the researcher kept a reflective journal throughout the duration of the study. To refrain from pre-judgments and becoming personally involved with the participants, to the best of her ability, the researcher provided neutral responses and reactions to all participants throughout the interview process. After all interviews were completed and transcribed verbatim, the researcher read each transcript strictly for the purpose of content. After a thorough read through, transcripts were read over again; however, this time quotes addressing the research purpose were highlighted. An additional read was completed to ensure information pertaining to the research purpose was not missed. Next, similar highlighted topics were organized under themes. These topics began very broad and with further analysis

became more specific and then grouped into sub-themes. This step also involved the deletion of any non-relative quotes. The next and last step involved the deletion of repetitive quotes. This process was also undertaken by her supervisors. Data analysis was then discussed among all researchers. It is also important to note, the researcher used her field notes and journal throughout the data analysis process. Reviewing field notes ensured accuracy while interpreting data and provided further context to the quotes, such as emotion displayed by a participant. Referring to the researcher's journal minimized the likelihood of the researcher's own thoughts and opinions influencing the emerging themes (Ortlipp, 2008). Themes and subthemes were not confirmed until all members agreed they were an accurate portrayal of the information provided by the participants.

#### **5.4. Results**

The participants in the study included six females and two males. Participants ranged from 42 to 52 years of age (Note, one participant did not disclose his age) and all identified themselves as being a parent to (a) child(ren) with ASD. Seven participants had one child with ASD, while one participant had two children with ASD. Five participants reported having finished secondary education, one participant completed 'some university' and the remaining participant did not wish to disclose the highest level of education she attained. Seven participants reported being married and the remaining participant reported being separated. Four participants were employed, one was self-employed and three were stay-at-home parents. Refer to Table 5.1 for background information on the caregivers.

The children of participants received a formal diagnosis by a medical professional of ASD between the ages of two and a half and 12 years (mean= 5.5 years). Children of participants ranged in age from six to 16 years (mean=10.3 years). Three children were females and five



children were males. Two parents reported their children had medical conditions. Refer to Table 5.2 for background information on the children with ASD.

**5.4.1. Themes.** Analysis of the data revealed two major themes regarding caregivers' perspectives of their children's social and motor skills. Theme 1 was 'Our journey with ASD.' The subthemes for this theme were as follows: "We just had this feeling that something wasn't right"; and This is our reality, now what? Theme 2 was 'Ability to Engage' and the subthemes for this theme were as follows: Diversity in Functioning; Barriers and the Aftermath; Factors to success; and Putting it all together. These themes and their corresponding subthemes are outlined in Table 5.3. Each will be discussed in turn.

**5.4.1.2. *Our journey with ASD.*** During the interviews, all participants provided in-depth detail regarding the events prior to, during, and after their children's diagnoses. In doing so, they described the behaviours and developmental delays their children exhibited. These behaviours and delays were red flags for parents who feared something may be wrong. As a result, parents and their children were referred to specialists resulting in the diagnoses of ASD. Regardless of when the diagnoses were received, all parents shared strategies that helped them manage and minimize symptoms associated with their children's ASD. In describing the parents' journeys with ASD, the following subthemes emerged: (1) "We just had this feeling that something wasn't right." And; (2) This is our reality. Now what?

**5.4.1.2.1. *"We just had this feeling that something wasn't right."*** All parents recalled specific behaviours and delays their children exhibited at young ages which made them suspect something may be wrong with their children. Suspicion for Diane arose when her child was only 7 months old.

*So, we started noticing already at like 7 months old that she was startling easy and even things on TV would upset her. Noises. She would bang her head.... At 18 months she had a speech delay which was the first kind of sign that something was going on .... She was hitting herself, outbursts and anger, trouble controlling emotions. She would have temper tantrums that would go on for like an hour, nonstop screaming ... just these states where it was irrational anger, almost like a wild animal in the corner of the room and you couldn't approach her because she would fight. ~Diane, mother of Sophia*

Like Diane, many parents discussed that their children had speech delays which signaled parents to obtain advice from healthcare professionals.

*... late speech, was the first big one... she would be good at labeling things and identifying objects... it was 'that's a tree, that's a rock'... [but] it wasn't about feeling, like sad or hungry, that kind of useful language. ~Nick, father of Julia and Tessa*

*I knew something was wrong with him because he didn't talk when he was around 3 years old. So, I recognized something was wrong with him, so I took him to the doctor. ~Sabrina, mother of Ivan*

Language also played a role in Hope's suspicion; however, this only became an area of concern when her son's teachers explained Tyson was exhibiting behaviours unlike the other children in his class.

*...the teachers were very concerned. His language too was a little bit repetitive.... They were very concerned because he didn't seem to follow instructions and fit in, so the other children would be sitting, he would not be interested. He wanted to do some independent activity. ~Hope, mother of Tyson*

Matt vividly remembered his son's inconsolable meltdowns.

*I have memories where he would have complete meltdowns at night where he is crying and crying. ...And you couldn't console him. Like 'little man what's going on?' He would just scream. ~Matt, father of Lucas*

All parents also discussed the challenges associated with receiving their children's diagnoses. In three cases, children did not receive an initial diagnosis of ASD during their first assessments.

For Grace, it was suggested her son, Greg, had attention deficit disorder (ADD) rather than ASD.

*We pursued two separate psychoeducational assessments at two stages because we believed something was going on. The first time we had it done, it was at the end of grade 1 and it spilled over to grade 2 and nothing came of it. They thought that maybe, well it is listed as part of the diagnosis that he has ADD but I don't believe that's true.... We were told he was functioning on the range of normal.*

*~Grace, mother of Greg*

For Diane's daughter, ASD was not entirely ruled out but was not confirmed during her initial assessment.

*She [psychologist] said, "I really, I am not going to say I don't think she is on the spectrum, because there are some signs that she may be, but right now I am going to diagnose her with childhood anxiety, a speech language disorder and... ADHD"...it kind of put some answers to some of the stuff that was going on, but it wasn't the full thing.... So, we took her to a psychologist who spent two appointments with her and said, 'no-uh in my opinion she is absolutely on the autism spectrum.' ~Diane, mother of Sophia*

Nick and his daughter were also recommended to have an additional appointment before the psychologist could confirm his daughter, Julia, had ASD.

*[Facility A] has a pediatrician that comes in twice a year to do diagnosis and he saw her once and he said, come back to me when I come back in 6 months. And we did, and he was like 'Yah okay.' ~Nick, father of Julia and Tessa*

When Faye discussed her suspicions her son had ASD with his teacher, it was suggested he likely had attention deficit hyperactive disorder (ADHD) rather than ASD.

*I said to her [teacher] that I had been doing some research and do you think that Lucas might have autism or Asperger's? And she said, 'oh no, definitely not' she said, 'I think he has ADHD' and we said, 'but he isn't hyperactive, he is a really mellow kid.' ~Faye, mother of Lucas*

Parents discussed behaviours and delays their children exhibited making them question whether something was wrong with their children. In addressing these concerns, parents sought assessments for their children. Although in the end all children were formally diagnosed with ASD, this process was not smooth. In some cases, parents had to have more than one assessment for their children, often months between assessments which delayed diagnoses and subsequent

treatment. The difficulty in receiving ASD diagnoses may have been because their children were high functioning. Diane acknowledged this by stating:

*...Because she is high functioning now I see why it was so confusing for all the people we were working with to diagnose her with autism because they would say, 'but she's sociable like she will talk to people, so she can't be autistic.'*  
**~Diane, mother of Sophia**

Overall, this subtheme highlighted the events prior to and during the diagnostic process and the experiences they had doing so. The next subtheme will discuss events and insights after receiving their children's ASD diagnoses.

*5.4.1.2.2. This is our reality. Now what?* While discussing their experiences post diagnosis, parents shared stories illustrating their children's behaviours, as well as their strategies to manage and minimize their children's deficits. Although parents never explicitly stated they accepted their children's ASD diagnoses, their acceptance was evident in their personal stories of their children's uniqueness. For example, Nick recalled an unusual behaviour his daughter, Julia, exhibited at a very young age.

*A weird behaviour... we have uh, fridge magnet alphabet and they're all different colours, and what was it? Red and orange, and, green, were allowed to go on the fridge but purple blue and yellow had to go on the dishwasher....like we would mix them up, we swap them, we would put some in each, we would change one colour, and she would fix it....she doesn't have an aversion to them, they just need to be in the right place. ~Nick, father of Julia and Tessa*

Parents also shared how their children taught themselves skills such as handwriting and learning speech.

*He learned how to handwrite when watching my handwriting, and I never actually taught him to handwrite. ~Hope, mother of Tyson*

*When she was little she was a really voracious reader too, it was ridiculous, 'cause that was how she was learning speech. ~Nick, father of Julia and Tessa*

Grace shared a story illustrating her son's superior physical skills.

*When he was quite young, the mother rabbit and her bunnies were going between houses and a bird was coming to take the babies and the mother bird was shrieking...it distressed Greg, and he reacted, and he was so fast, he ran, and got the baby.... He brought the baby near where the mom, kind of like where the nurse was. But who catches a baby rabbit? ~Grace, mother of Greg*

Sabrina recalled the moment she realized her son, Ivan, was more capable than she assumed.

*So, when he was in elementary school, maybe grade 6 or 7, we got to track and field practice and his teacher ... said Ivan is on the bus. But I always picked him up from the bus and I was worried about how he would get from the bus stop to [home] ... I went quick to pick him up and I saw him and said, 'oh Ivan is walking home [from the bus stop] by himself.... I knew from that time on "You're okay Ivan." ~Sabrina, mother of Ivan*

In addition to sharing their personal stories, parents shared their insights and strategies they learned from their journeys with ASD which assisted in promoting skill development in their children. By doing so, they offered guidance to parents who may be experiencing similar journeys. For example, Hope found her son's behaviours improved when he was enrolled in physical activity classes for children with disabilities. She suggested parents of children with ASD should be mindful of the simple and gradual steps, particularly when enrolling them in organized physical activities.

*...be aware of the things they need and if it's a gradual process then to allow it to be a gradual process.....So if he knows how to follow a physical activity, so maybe that means that the next step is go to a class or do gymnastic and he can follow the physical instruction and plus... as those skills get better can he cope with a team? .... Mini steps and simplifying. ~Hope, mother of Tyson*

Grace found enrolling her son in organized sport with neurotypical children provided him with social and physical benefits.

*They were always engaged in activities that required them to be in a social atmosphere and I think that if we hadn't done, that I think Greg's behavior would be more rigid and I think he would have had more difficulties.... Putting him in*

*organized sports, even though we didn't realize it at the time, has had an incredible impact. ~Grace, mother of Greg*

Parents acknowledged the importance of encouraging their children to interact with others, despite the awkwardness of these interactions. Empowering their children was integral to their development.

*...with the social piece, we encourage her even though it's awkward sometimes. 'Go to the playground and approach those kids.' ~Diane, mother of Sophia*

Faye advised parents not to speak for their children regardless of how awkward the situation may be. This allowed her son to successfully communicate with others.

*[Do] not speak for your child.... They're in a spot that communication is awkward, then make your child.... He's polite, the politeness and his ability to communicate with adults has taken him a long way, whereas had he been that really grumpy, rude little kid. He wouldn't have gotten as far as he did. ~Faye, mother of Lucas*

Although Matt was unable to provide advice to parents faced with similar journeys, he supported his son and his social development as best as he could.

*I can't give anyone advice. I am as lost as they are... You just gotta keep drilling it, that's what you have to do. "Son, you have to look at people, son you have to talk to people, son you gotta say what you want, speak clearly." ~Matt, father of Lucas*

Despite the challenges often associated with caring for children with ASD, parents from this study were able to share stories highlighting their children's uniqueness. These stories were often accompanied with smiles, laughter, and pride. Throughout their journeys with ASD, parents discovered strategies which promoted specific skill development in their children, all of which they were willing to share with other parents who may be in similar situations.

**5.4.1.3. Ability to engage.** Parents discussed their children's ability to engage in activities involving motor and social skills. It was evident children exhibited different strengths and weaknesses, which ultimately affected their abilities to engage in specific tasks. In addition to

their children's strengths and weaknesses, barriers extending beyond their skill levels also played a considerable role in their ability to engage socially and/or in motor tasks. On the contrary, parents also discussed factors facilitating successful engagement. Finally, social and motor development in their children was affected by many factors, all of which will be discussed. This theme has been divided into four subthemes: (1) Diversity in functioning, (2) Barriers and the aftermath, (3) Factors to success, and (4) Putting it all together. Each subtheme will be discussed.

*5.4.1.3.1. Diversity in functioning.* Diversity in motor skills was evident within children and across children. To avoid confusion, when discussing motor skills within children 'variable' will be used. When discussing motor skills across children 'inconsistent' will be used. When parents discussed their children's motor skills, it was apparent their children exhibited variable motor skills, often dependent on their interests and the task at hand. For example, Matt and Faye, parents of Lucas, described how Lucas exhibited strong fine motor skills in some tasks, while extremely poor in others.

*At school now, he is behind with his writing... in the amount of time it takes the kids to print a paragraph, Lucas can only print one sentence. It is very, very, slow. He puts no spaces between his words, half the letters are backwards, they are big chunky letters. It's an absolute mess. ~Faye, mother of Lucas*

However, his father explained Lucas's superior fine motor skills while cutting out little characters.

*He cuts out little characters. His fine motor skills with scissors would blow your mind. ~Matt, father of Lucas*

This variability in fine motor skills was also highlighted by Hope and Lisa.

*They fluctuate a bit even as, so his writing, he can write like an adult, by grade 2 he could handwrite....So he has fantastic skills for that sort of thing but...there's some areas where the fine motor seems less and other areas where it seems really well.... Buttons used to be a challenge for him, but you would think if you could handwrite, buttons wouldn't be a big deal. ~Hope, mother of Tyson*

*Hand writing is uh not good at all, you can't really read it...drawing, he has an interest in drawing and he's actually good, like he is good at that. ~Lisa, mother of Daniel*

This variability applied not only to fine motor skills but was also evident in the children's gross motor skills, as emphasized in the following quotes.

*He can climb really, really, well and has always been able to do that but throwing a ball, catching a ball less... less than average at catching a ball but climbing things, like a monkey. ~Hope, mother of Tyson*

*He runs ... I feel like it is a little awkward compared to how other kids run around .... He has trouble climbing, when we go to the park. He doesn't climb things the way other kids do... You know he can throw and catch a ball... His teacher told me that Lucas can catch a football better than any of the other [typically developing] kids in the class. ~Faye, mother of Lucas*

As clearly stated in the quotes above, children displayed variable fine and/or gross motor skills.

Some parents acknowledged this variability to be a result of interest and/or the nature of the task.

The inconsistency of motor skills was also evident across the children with ASD. Inconsistencies between children were illustrated in the quotes as one mother highlighted her son's superior fine motor skills, whereas the other quote was from a mother discussing her daughter's poor fine motor tasks.

*He was a rubik's cube master, like in grade 6 he could do it without even looking, like magic....I'd say that's really good fine motor skills. He's doing art in grade 10 and is going to continue it because he loves it so much. He's gotten tons of praise from his art teacher. ~Grace, mother of Greg*

*She struggled with writing. Even as a little, little kid she had no interest in coloring, drawing, anything like that. It was just scratches and scribbles and really hard, ripping paper. ~Diane, mother of Sophia*

This inconsistency was further highlighted as parents discussed their children's gross motor skills. In Diane's case, her daughter struggled with tasks such as running, whereas Lisa described her son's gross motor skills as great.



*She runs a little sloppy [laughs] I say clumsily... She tends to fall and trip a bit more.... Throwing and catching is limited; getting there, but it's limited. Hitting things with the bat or whatever, very limited. ~Diane, mother of Sophia*

*He played just...one season [of baseball] ...his gross motor skills are very well.... He's happy about that. ~Lisa, mother of Daniel*

Parents identified their children's strengths and weaknesses while discussing their fine and gross motor skills. By doing so, it was clear children displayed inconsistent fine and/or gross motor skills dependent on the task at hand. The variability in motor skills were not only present within children but also across the children. For example, while one child clearly demonstrated superior gross motor skills, another child exhibited very poor gross motor skills. In sum, the quotes illustrated the variability and inconsistencies in the children's ability to engage in tasks requiring gross and/or fine motor skills.

*5.4.1.3.2. Barriers and the aftermath.* All parents discussed the barriers their children experienced with regards to social interactions, as well as their ability to engage in physical activities. Barriers to social interaction will be discussed first. One of the barriers preventing children from playing and interacting with their peers was their preference to play alongside their peers rather than with their peers.

*He will play alongside them, but he will be doing his own thing. He has kids at school that he calls his friends who I know he interacts with, but I think they are short interactions. ~Faye, mother of Lucas*

*...she's had play dates at our house and her version of a playdate is playing beside her little friend. I will ask if they are having fun playing together and she will say, "Yah, mom I am." But they are not interacting. So, it is kind of a weird concept of you know 'Yah we're playing but not actually talking to each other.' ~Diane, mother of Sophia*

Another barrier to social interaction was their children's inability to initiate social engagement with other children. However, the children typically were amenable to peer-initiated social engagement.

*... Like I said if someone else initiates a social connection he is agreeable to it, he can manage it, but he won't seek it out on his own. ~Grace, mother of Greg*

*He is stuck to only playing outside by himself. If someone will ask him, it is no problem. ~Sabrina, mother of Ivan*

Parents conveyed their children's inability to engage in typical "back and forth conversations", which also acted as a barrier to social interaction with their peers.

*His social...is tied to his own interest.... The more you can sort of get him to listen to what you want to talk about, he's willing to do it, but it doesn't come natural to him, it's almost like you have to establish a back and forth. ~Hope, mother of Tyson*

*She tries to have conversations. She just loses the back and forth of conversation .... Sometimes you'll ask her something and she doesn't know how to answer you, but she knows socially that you are waiting for an answer, so she will blurt out the first thing that comes to mind. So she tries to be social, but I think she just doesn't understand the flow of you know, back and forth conversation. ~Diane, mother of Sophia*

*Tessa doesn't have a great small talk. She is still pretty functional in her language at times. She's got some scripts, but a natural flow of conversation still escapes her at times. ~Nick, father of Julia and Tessa*

A common barrier to social interactions parents noted was that their children did not have friends with whom they could interact.

*He wants to be social... you know full school year with no invitation to birthday parties. So, he's really not social. If you speak to him once, you're his best friend. ... and he'll tell you he has best friends and we just let it go because we don't want to hurt him, yah but there's not a strong network there. ~Lisa, mother of Daniel*

Although most parents conveyed their children did not have friends, not many explicitly stated why. Sabrina and Faye were an exception to this.

*He doesn't have friends, just at school from his classroom. I don't know if they are friends or not. Classroom friends.... But he's not around friends, I think that it's because he can't speak very well. So, I think ... that is what blocks him from the conversation with people that speak fluently. ~Sabrina, mother of Ivan*

*He doesn't go for play dates... So four years, he has been invited to three birthday parties.... But for him not to be invited, we think is it because of his lack of social skills that they just don't want him there. ~Faye, mother of Lucas*

The social barriers presented parents with many concerns for their children. Parents feared their children would be easily manipulated.

*Understanding manipulation, as he gets older I think he's been pretty sheltered from it but as he gets older understanding manipulation, motivation, things that aren't obvious.... That for sure worries me. ~Hope, mother of Tyson*

*My worry is that socially she will be taken advantage of by other kids. Talked into doing things she shouldn't do because she is getting attention. "Hey, they want to play with me, they don't think I'm weird, I'm just going to do whatever they tell me to do." I am afraid she will get swept up into that. ~Diane, mother of Sophia*

*...Greg would take everything on the surface, superficial, very literal, not understanding the deeper meaning, not understanding the context, getting into a situation where he wouldn't understand what was happening and how to deal with it. ~Grace, mother of Greg*

Lisa shared her concerns about the costs associated with her son's desire to be included.

*I fear sometimes that he wants so badly to be accepted that I hope he doesn't become a follower or to be bullied into a situation...just to be that cool kid, you know?... That's, that's my fear. That he would uh, you know so desperate to want friends and be accepted do thing things that he probably, he knows that they are not okay, but under that pressure, would do it. That's my fear. ~Lisa, mother of Daniel*

Nick, a father of two females with ASD, expressed different concerns for each of his daughters.

*Tessa, she's going to get hurt. And she, she, wears it on her sleeve and [pause] she's going to get hurt by being so vulnerable and she's going to get worn down by carrying grudges. ~Nick, father of Julia and Tessa*

*My concern is that she [Julia] stops making progress and plateaus at some point, and this is what we got. And what she's got now isn't, wouldn't be enough to function on her own. ~Nick, father of Julia and Tessa*

Other parental concerns included their children not having friends, and the ramifications for their children's futures.

*We worry about him not having friends.... And because he is an only child, too, when he becomes an adult and we're gone, we don't want him to be a hermit*

*somewhere by himself and struggling to interact with people. ~Faye, mother of Lucas*

*Our whole society is based on interactions. It's based on living. You know what I mean? If you can't interact with someone, how are you going to progress in life? How are you going to find someone like my lovely wife over here to spend the rest of your life with? How are you going to make friends? How are you going to develop friendships that are normal? ~ Matt, father of Lucas*

*If you know your child is not the same as the peers, that there is something wrong then [he is] growing up and getting older, [as] parents [we are] worried about his future.... ~Sabrina, mother of Ivan*

Parents also shared barriers to physical activity. All parents reported their children were physically active; however, barriers prevented participation in specific physical activities. Some barriers were a direct result of symptoms associated with their ASD diagnoses such as their sensory issues, anxiety, and attention.

*His sensory skills, like in the gymnasium at school, it prevents him from participating fully in phys-ed class. His hard line about his interests, so he has, one of the things on his report card was dance, he says 'I am not dancing, I hate it and they are not going to make me dance.' You cannot convince him to do it. ~Faye, mother of Lucas*

*Her anxiety for sure [affects physical activity]. Some days she just doesn't want to go maybe to the pool or to the arena because something is bothering her anxiety-wise. Anxiety definitely affects different things. Like "I can't do this as good as so-and-so, so I'm not going to do it." I would say her anxiety would definitely affect her physical activity level. ~Diane, mother of Sophia*

Other barriers included not having friends, the weather, and parental influence.

*... he's become less active...in the last 6 months.... he was always outside before, he was always with the hockey stick, with the hockey net.... He has become less active, I think part of it is because he has nobody with him, you know? He's by himself. ...the friend factor isn't there for him. ~Lisa, mother of Daniel*

*It fluctuates with weather, and my patterns will influence [Tyson and sibling]. So once the weather gets cold, I would say less physical even though I am trying to.... When the weather's nice I'd say they get a fair amount of physical activity when the weather's not nice, less. ~Hope, mother of Tyson*

Despite parents discussing the physical activity barriers their children experienced, this did not seem to concern most of the parents. An exception to this were two parents who did express concerns. Interestingly, both parent concerns had an element of safety.

*The only concern is mostly being safe, and it's why I haven't put him in soccer or basketball or anything ...even taking him skating can be a challenge because there's so much chaos and people flying at speeds and others falling over like that's a lot of sensory to navigate.... you know? Cycling on a path, his dad does that a lot with him... [it's] still a bit of a struggle because he's dealing with speed ... to, navigate chaoticness around him or a lot of stimulus around him and being physical. ~Hope, mother of Tyson*

*It's mostly the safety concerns that I have. She hasn't learned to ride a two-wheeler because I can't run fast enough behind her, because she doesn't understand the concept of brakes yet. She likes to peddle and go faster, and she doesn't necessarily understand she needs to slow down at times, she just wants to keep going. ~Nick, father of Tessa and Julia*

It was apparent these concerns were less about socializing or skill level but rather their children's safety and wellbeing, as illustrated in the quote below.

*Whether he can bounce a ball or not, I think that's a skill you can either develop and be better at or not. That's an easier thing to manage and work on than it is to perceive all the things going around you and cope and be able to integrate physically. ~Hope, mother of Tyson*

This subtheme outlined barriers perceived by parents of children with ASD.

Regardless of skill level, it was apparent barriers to social interaction and physical activity were present. Interestingly, parents expressed greater concern for their children's social deficits than their children's inability to partake in physical activity. Although not specifically asked, it was obvious parents felt their children's social deficits had greater lifelong consequences in comparison to the deficits that prohibited them from engaging in physical activities.

*5.4.1.3.3. Factors to success.* Although parents were eager to discuss factors that made social interaction and physical activity difficult for their children, they were just as

eager to discuss factors that successfully facilitated these tasks for their children. Factors allowing for successful social interaction will be outlined first. The majority of participants felt social interaction was most successful when with adults, rather than other children. Although Tyson, Hope's son, perceived engaging with other children was the 'norm', it appeared he still gravitated toward adults because they better suited his needs.

*... adults fill, they feed his questions.... He would naturally go to adults even though he wants to be part of his peers, because that's the perception that is sort of that norm, what kids do... he would like the idea of being with his peers, but I think he would engage more with adults because they ... suit ... his needs. ~Hope, mother of Tyson*

Similarly, Nick explained his daughter gravitated towards adults because they were more accommodating.

*Adults tend to be more accommodating and so it's easier.... [Tessa] gravitates towards the adults because they are willing to do what she wants to do. ~Nick, father of Julia and Tessa*

It was evident children felt more comfortable and less nervous to initiate a social interaction with an adult, as opposed to a peer.

*Kids- she tends to be really nervous to approach them.... Where with adults it is almost the opposite [laughs].... But we find she has no fear approaching men or women and even talking to them. But with kids she hangs back and then observes a little bit and then might try to reach out a little bit.... She definitely feels more comfortable with adults. ~Diane, mother of Sophia*

Adults also seemed to accommodate the intelligence level of children, more than children their own age.

*...he talks above a peer. You know he's intelligent. He's smart.... we did an educational assessment on him .... he was grade [higher grade] level for oral communication. So, he's extremely smart, so he can speak with an adult and they would get it, as opposed to a peer his own age, they're not getting that yet. Whereas there are other parts where he has a huge deficit, so an adult would be tolerant of that deficit, a peer wouldn't so much. ~Lisa, mother of Daniel*

*.... the level of his conversation is more than what kids do.... It's almost like he brings himself down ...He is not sure how to get to their level to be able to communicate with them. ~Faye, mother of Lucas*

In addition to adults, Tessa's social interactions were also successful when it was with children younger than her, as well as children from different cultures.

*I've noticed she gravitates towards kids younger than her and... kids from different cultures and language because they already don't understand the social aspect or she's able to control them more, basically, right? She can be the one in charge with a kid two years younger or a kid that doesn't understand social nuances because they're from Syria. ~Nick, father of Julia and Tessa*

In addition to factors promoting successful social interactions, factors leading to successful engagement in physical activities were also discussed by parents. For Greg, the sport could be competitive, in a team, or an independent sport. As long as he was interested in the given sport, he was able to successfully engage in the sport.

*I think it has everything to do with his interests. He is his very best self at climbing because that's his passion. ~Grace, mother of Greg*

Hope and Diane both felt individual sports were most ideal for their children, as opposed to team sports; however, the reasons for this differed.

*His ideal physical scenario would be first structured so that he can follow it... and ... I'm leaning more on independent.... The more you get more people, more interaction, more movement, that would be less ideal. ~Hope, mother of Tyson*

*No competition, single sport.... We found when we put her in swimming at first in class settings, she was not doing well at all because I think she felt insecure compared to the other kids swimming. When we put her in swimming privately, she completely came out of her shell, she learned the basics to the point where we were able to put her back into a classroom setting.... Competition, she doesn't do well under pressure at all... She really does better when she is left to do it on her own .... She just doesn't want to do the team thing. ~Diane, mother of Sophia*

While independent sport led to greater success for Diane and Hope's children, Lisa felt team sport led to greater success for her son.

*... team sport... I believe I feel it's better for him. He would prefer team sport um, competition [pause] I would have to say he's competitive... as a team.... That is good for him because then the deficits don't necessarily show, you know, if he's struggling... because it's a team. ~Lisa, mother of Daniel*

Parents clearly identified factors promoting successful engagement for their children. With regards to social interaction, successful factors were very similar, as most parents felt their children engaged mostly in successful social interactions with adults. As for factors leading to successful physical activity engagement, there were fewer similarities. Some parents felt individual sport was more successful for their children, while others felt team sport was most successful.

*5.4.1.3.4. Putting it all together.* Interviews with parents focused primarily on the abilities of their children with ASD. Despite the diversity among these abilities, it was apparent the main factors influencing their motor and social skills were similar, namely, the association between their social and motor abilities, the school influence, and finally, family influence. First, the association between their children's social and motor abilities will be discussed. For most parents, they felt their children's social abilities and physical abilities interacted negatively.

*If he has to dribble a ball and do the next few steps which is either move forward with it, pass it, have somebody, you know, the more layers you put on to those elements, then I think it will affect his physical ability but then I think it will also affect his frustration, his social... his reaction to people which will be social, you know, he reacts... if it's a specific goal, and all those layers and socially it will be negative, it will come out...with possibly even negative comments of frustration. ~Hope, mother of Tyson*

*I think that because she is just a little clumsier and a little more awkward, not sure of herself... I think it definitely affects her socially. She is not one to want to join kids in the play yard playing soccer, she tends to shy away and just thinks she can't do it. Or she will try and be clumsy and trip over herself and is embarrassed and doesn't want to do it again. She is really, she has got a lot of anxiety about*



*that.... I find her physical and social, they don't go well together at all. ~Diane, mother of Sophia*

*Social abilities prevent him from being active. ~Sabrina, mother of Ivan*

Nick's daughter, Tessa, had trouble in softball because of the social challenges she encountered with her teammates. He expressed if the social challenges were absent, this would have opened a door for Tessa, in terms of participation in team sport.

*I think it could open doors.... So, if she would, if she had ended up being really good at ball... she wants to be in charge, if she was the star of the team and everyone else gravitated to her and did what she wanted, that would help. But just being able to do the games in groups and having those motor skills to be able do, yah it opens doors. ~Nick, father of Julia and Tessa*

On the contrary, two parents felt their children's motor skills enhanced their social abilities.

*Daniel's gross motor skills promote extra-curricular activities, which he enjoys which promotes social activity in team sport. ~Lisa, mother of Daniel*

*Because he is really physically capable, it is probably enhancing his social skills... When he is doing something he is comfortable with, physically, then it helps him engage socially, which he wouldn't otherwise have done. People wouldn't have said 'Wow, you're a really great climber, can I climb with you?' ~Grace, mother of Greg*

Similarly, school played an influential role in their children's social and motor skill development. In most cases, parents felt this role was negative. Hope and Faye discussed when their children would react negatively to a specific task at school this prevented other children from wanting to engage with them.

*Well when he is frustrated and stressed out and overwhelmed at school then you know he isn't able to communicate properly, right? His behaviour will stand out more, so laughing unstoppable, not being able to stop laughing in class, getting up and touching things...if he's getting up and touching things because he's had enough and is gravitating towards that and it's hard to socialize and be more the social norm. ~Hope, mother of Tyson*

*If they are making him do something that he doesn't want to do, or he feels he's not skilled enough to do like printing. He tells us he hates printing, he can't do it, that his printing doesn't look like the other kid's printing. And if they are forcing*

*him at school, their job is to teach him, he sees it as forcing it on him, and it affects his social skills. He starts to cry, the other kids see that, they don't want to be around him, and as soon as the meltdown starts, and he starts crying they scatter. How he reacts to school and what activity they are making him do directly affects his social aspects of school, too. ~Faye, mother of Lucas*

For Diane, her daughter felt inferior when she compared herself to other students causing her to withdraw socially.

*I know that she is really aware that she is different in some ways. Like she will say things like 'I can't read as good as so and so, I am not picking up French as good as so and so.' So, she tends to withdraw more and become a little bit more isolated. I think she realizes she is a little different and that kids treat her a little different. ~Diane, mother of Sophia*

Diane further discussed how school negatively affected her daughter's motor abilities.

Due to her daughter's difficulty with writing, the school suggested she use an iPad instead.

*I know they are working really hard with the writing, but it is almost like now, the teacher at the last appointment was saying to do an IEP where she is on an iPad instead of writing at all.... I want her to keep using that writing skill, I am afraid if she uses the iPad she will lose it. In some ways they are encouraging her and in others I am like 'ugh' .... They are like... 'let's just kind of throw in the towel and teach her to type.' ~Diane, mother of Sophia*

Matt felt his son's motor and social skills were negatively affected by school, mainly because his son did not enjoy being there.

*We never understood why he wasn't doing well in school. It's because he hated the place. Do you want to go somewhere you hate every day? If you hate where you are every day, you are going to be miserable, you aren't going to want to socialize with people.... I would even say it affects his motor skills as well because if he hates being there, he isn't going to want to do anything. That's where you're learning your fine motor skills like how to print, and scissors. If he is miserable, again he doesn't want to do anything. ~Matt, father of Lucas*

Conversely, not all parents felt school played a negative role in their children's motor abilities.

For example, Nick felt school encouraged motor development for both his daughters.

*... there's the free play at recess where you got monkey bars and soccer fields, so you strictly go out and burn energy ...they are at least able to explore different motor activities whether they want to do monkey bars or play tag or whatever. And then there's the completely organized stuff in phys-ed class where they're given rules and activities to preform, and practice doing it. And because Julia thrives off routines, that's good for her, so if it's dodgeball or whatever, it's getting to learn new things that we wouldn't have really thought to do at home.  
~Nick, father of Julia and Tessa*

Finally, family also played a major role in the motor and social skills of children. In all cases parents discussed how they promoted physical activity and social interaction for their children. This was often a result of their lifestyles or through constant encouragement.

*I think our lifestyle has been very active... I think that it is something comfortable and familiar to Greg.... We have a social lifestyle too, so I think we have contributed to where he is at now. ~Grace, mother of Greg*

*We encourage her as much as possible to be social, we encourage play dates a lot. We encourage physical, absolutely. In our family we try to put a big role on that.... I want to encourage healthy eating, healthy lifestyle for her as much as possible. ~Diane, mother of Sophia*

In Hope's case, physical activity offered the opportunity for her son to bond with his father.

*He loves going for bike rides and thankfully his dad does too, so he does that activity with his dad. So, the physical offers...an activity that can bond. And then help the social interaction. Right? And, that's very much the case with his dad because there's more difficulty on that side of the family, to interact, the relationship is more strained. But having some physical activity facilitates it, it does help to, to do that. ~Hope, mother of Tyson*

This subtheme emphasized the development of social and motor skills were influenced by many factors, namely school and family. Most parents felt school played a negative role in their children's social and motor development; however, one parent did feel the school played a positive role. All parents felt family positively influenced the social and motor development of their children. The reciprocal relationship between their children's social and motor skills was also discussed by all participants; however, the nature of this

relationship differed among children. For example, while some parents felt their children's social deficits affected their motor skills negatively, other parents felt their children's ability to excel in physical activities enhanced their social skills. Overall, this subtheme highlights the social and motor development in children with ASD are influenced by many factors.

## **5.5. Discussion**

The current study explored social and motor deficits of children with ASD through the perspectives of their caregivers. Many salient findings emerged from the interviews conducted with caregivers. Findings mostly concerned the social and motor development of their children. The caregivers' perspectives of the social and motor abilities of their children will be discussed in further detail.

**5.5.1. Motor deficits.** It was evident diversity existed within and across children's motor impairments. Variability within children will first be discussed. Parents conveyed their children displayed age appropriate motor skills in one task but poor motor skills in another task. This was true for both fine and gross motor skills. Children most often exhibited age appropriate motor skills when performing tasks they enjoyed. The opposite was often true when they were required to complete tasks they did not enjoy. One explanation for such findings is that if a child enjoys a specific activity, he or she will likely practice the activity more than if he or she did not enjoy the activity. An additional explanation may be the requirements of the motor task. For example, Tyson was able to handwrite well but had difficulty doing up buttons on a shirt. The requirements of these tasks are different; handwriting requires manipulating a small object using only one hand, whereas doing up buttons on a shirt requires bilateral coordination. Determining

the requirements of the task from a motor perspective may provide more insight into the cause of specific motor impairments exhibited by children with ASD.

The diversity in motor skills across children can be a core aspect of the variability among children with ASD. It is evident children with ASD exhibit different strengths and weaknesses, particularly with regards to their motor skills. Inconsistency in motor skill ability across children with ASD has been attributed to multiple factors. For example, children with lower IQs and greater autistic symptoms display greater motor deficits (Green et al., 2009; Kopp et al., 2009). The diversity in motor skills between and within individuals with ASD must be measured. It is important that in experimental studies how individuals perform at a task level is assessed, rather than collapsing across items to obtain an overall score. As such, future research investigating variability in motor skills among children with ASD is warranted.

**5.5.2. Social deficits.** Parents from this study confirmed their children interacted more successfully with adults opposed to peers their own age. This finding is supported by previous research. For instance, in an observation study conducted by Anderson et al. (2004) children with ASD had considerably more interactions with adults, which most often were their teachers, compared to their peers. However, Anderson et al. (2004) noted this interaction was mostly assistance-seeking or assistance-giving. Researchers proposed this adult interaction may lead to increased dependence on adult assistance and further act as a barrier between children with ASD and their peers. Researchers hypothesized neurotypical children may avoid children with ASD to keep their distance from the teachers. Further, the presence of a teacher constantly around the child with ASD may suggest to the other children the child is “unusual” (Anderson et al., 2004, p. 382). The current study further adds to this body literature by providing reasons as to why children with ASD may gravitate towards adults rather than their peers. Caregivers explained

adults were more tolerant of their children's deficits, whereas their peers would find these deficits as "weird." Given most children in the current study had high functioning ASD and had a greater IQ than their typically developing peers, children often spoke at an intellectual level that was above their peers. For example, Lisa stated that her son, Daniel, was at a higher grade-level grade (in comparison to his current grade) for oral communication, as confirmed by an educational assessment. As a result, this did not facilitate smooth peer to peer interaction. Children from the current study felt more comfortable and less nervous to initiate social interactions with adults, as opposed to peers. Currently, there is a body of research investigating promising strategies to teach social skills to children with ASD. A review conducted by William White, Keonig and Scahill (2007) explored social skill training programs for children with ASD. In this review, the researchers provided a table listing frequently cited and effective social training techniques including teaching simple social scripts, involving parents, and modeling age-specific social initiation strategies (William White et al., 2007). Further, research has found that pairing children with ASD, with typically developing children increased the overall social interactions among children with ASD (Kohler, Greteman, Raschke, & Hignman, 2007; Laushey & Juane Heflin, 2000; Morrier & Ziegler, 2018). Although research has explored the effectiveness of adult-delivered social interventions for children with ASD (e.g., Boyd et al., 2007; Gena, 2006; Hancock & Kaiser, 2002), a study investigating interventions in which children with ASD are paired with adults is lacking. Given that the findings from this study confirm children with ASD are more comfortable with adults, it may be worthwhile to explore the effectiveness of pairing children with ASD with adults when teaching specific skills, such as motor skills.

Furthermore, parents conveyed their children played alongside their peers, rather than interacting with them directly, regardless of age. This again is supported by previous research. For example, in a study exploring the social networks of children with ASD at school, researchers reported children with ASD appeared to be socially unengaged while on the playground characterizing the friendships of school-aged children with ASD (6 to 11) as ‘unilateral’ rather than ‘reciprocal’ (Kasari, Locke, Gulsrud, & Rotherman-Fuller, 2011). It is important future research continues to investigate social interaction among children with ASD. There is a body of research that has investigated effective social skill interventions for children with ASD (e.g., Godin, Freeman, Rigby, 2017; William White et al., 2007). Such interventions include the peer buddy system, role play, and the use of social scripts. However, research fails to provide the perspective of individuals with ASD. It remains unknown whether individuals with ASD want to engage directly with their peers or if they instead prefer to be in the presence of peers but have minimal interaction. As such, it is important social intervention studies first explore the social goals of the individuals with ASD. In doing so, a qualitative study investigating the social preferences of individuals with ASD from the perspective of individuals with ASD is warranted.

**5.5.3. The Social and motor relationship.** All parents discussed the various social and motor deficits their children with ASD exhibited. A novel finding from the current study was the level of concern parents had for their children’s motor and social deficits. Although motor deficits were just as common as social deficits, parents had greater concerns regarding their children’s social deficits. It was evident parents felt their children’s social deficits had greater consequences than their children’s motor deficits in terms of navigating or functioning in their environments. These concerns stemmed from parents fears of their children being manipulated

and not having friends. However, given the associations between social and motor deficits, it is important parents provide similar attention to their children's motor deficits as they do their social deficits. Research suggests social and motor deficits may have a reciprocal relationship, in that children who exhibit social deficits are more likely to exhibit motor deficits, and children who exhibit motor deficits are more likely to exhibit social deficits (Bhat et al., 2011; MacDonald et al., 2014; Lloyd et al., 2011). Motor impairments can significantly influence the ability to partake in a variety of activities such as sports, engagement with peers, and activities of daily living etc.) (Thomas, Sciberra, Lycett, Papadopoulos, & Rinehart, 2015) and therefore such impairments need to be addressed. Health care professionals need to educate parents of the potential consequences related to motor deficits, in addition to monitoring and assessing such deficits in children with ASD.

Despite the lack of concern regarding their children's motor deficits, caregivers did acknowledge the association between their children's social and motor abilities. In most cases, caregivers conveyed their children's social deficits prevented them from successfully engaging in physical activities, whereas the reverse was also true. Children who exhibited poor motor skills were less accepted by their teammates, and as a result their social deficits acted as barriers to motor development. As mentioned above, this relationship supports previous research (e.g., Bhat et al., 2011; MacDonald et al., 2014; Lloyd et al., 2011). The current study also provides the caregivers' perception of this relationship, in addition to examples in which this relationship is evident in their children with ASD.

**5.5.4. Influences on social and motor development.** Another novel finding from this study revealed the school influence on the social and motor development of the children with ASD, as perceived by caregivers. Children spend most of their waking hours at school, therefore



educators have the responsibility to foster positive development in all domains among children, whether typically developing or not. However, this did not appear to be the case for social and motor development, as perceived by the caregivers. Most caregivers felt school negatively influenced their children's social and motor development. This was especially true for Diane who conveyed her daughter's teacher suggested her daughter use an iPad due to her difficulty with writing. Diane felt the teacher was "throwing in the towel" rather than working with her daughter to improve her writing skills. Parents felt their children's social deficits were particularly evident in the classroom and as a result this deterred other children from wanting to be their friends. This is the first qualitative study to identify the influence of the school environment on social and motor development in children with ASD, as perceived by caregivers. An exception to this is a qualitative study exploring the physical education experiences of boys with disabilities (age and disabilities unknown [Fitzgerald, 2005]). The participants reported they were ignored by their gym teacher, as the gym teacher focused more on students who played for 'high status' school sport teams. The participants also felt because they were not on 'high status' school sport teams, this prevented them from having high social capital among their peers. One participant perceived the gym teacher looked down on him and only considered the things he could not do because he was in a wheelchair. When the boys compared themselves to the typically developing males in their gym class, they felt they were not as physically talented as them. In cases where the physical education class focused on rugby, the boys had to participate in a different activity as directed by the teacher. Some of the participants felt this was unfair and they were being treated differently than their classmates. Finally, participants expressed frustration as they felt their typically developing peers left them out while playing sports during the physical education class. For example, participants conveyed their peers never passed them

the basketball because they were perceived as not being very good at basketball due to their disabilities (Fitzgerald, 2005).

It is crucial school is a safe environment fostering social and motor development for children with ASD. There may be difficulties associated with working with children on the spectrum to develop skills such as writing and physical skills. As such, it is important needs-based individual plans are developed for children who may be struggling in these areas. It is important these plans are developed with supporting evidence and the rationale of implementing such plans are explained, understood, and approved by the parents of these children. It is also important schools increase the awareness and acceptance of ASD to ensure other children are more tolerant and understanding of the deficits children with ASD exhibit. It should be highlighted that the issues children on the spectrum experience in the school setting may in fact relate to lack of support and resources provided to teachers.

**5.5.5. Limitations.** Despite the novel findings within this research, this study is not without limitations. A total of eight caregivers were interviewed, six of which were females. Therefore, the perspectives from this study may be more applicable to mothers as opposed to fathers. It is also important to note all but one caregiver described their children as high functioning. The social and motor deficits discussed may be more prominent among individuals with high functioning ASD rather than low functioning ASD. Finally, all caregivers resided in southern Ontario and as a result, such perspectives may not be similar to caregivers residing outside of Ontario.

## **5.6. Conclusion**

The current study has provided a unique perspective on social and motor impairments in children with ASD. The study provided insights of caregivers pertaining to social and motor deficits exhibited by their children with ASD. The study also highlights areas of concern

requiring attention. Motor deficits appeared to be less of a concern for parents of children with ASD. Given the consequences motor deficits can have for children, it is important these deficits are provided similar attention as social deficits. In doing so, health care professionals should educate parents about the consequences of motor impairments or delays and their associations with the development of social skills. As such, routine motor skill monitoring and assessments by caregivers and health care professionals should be encouraged. Further, in order to further elucidate the variability of motor skills among children with ASD future research should assess how individuals perform at a task level, rather than collapsing items to get an overall score. In discussing the influences of social and motor development, it was disappointing to report parents perceived the school environment had a negative influence on their children's development. This needs to be researched further to develop strategies designed to promote social and motor development of children with ASD in the school environment. Given the increase of ASD, perhaps educators should be required to complete formal training regarding ASD. Such training needs to include how to foster successful development in children with ASD, especially in areas concerning social and motor development. Based on the review of the literature, this is the only study exploring social and motor deficits in children with ASD from the perspective of caregivers. The caregiver perspective needs to be further explored as their insights have the potential to provide the framework needed to identify and minimize social and motor deficits in children with ASD.

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Table 5. 1 *Background Information on Caregivers*

<b>Pseudonym</b>	<b>Age</b>	<b>Highest level of Education</b>	<b>Employment</b>	<b>Marital Status</b>	<b># of Children</b>
Lisa	52	College	Employed	Married or common law	3
Faye	44	College	Employed	Married or common law	1
Matt	NA	University	Employed	Married or common law	1
Sabrina	46	NA	Unemployed	Married or common law	2
Grace	42	College	Unemployed	Married or common law	3
Diane	45	College	Employed	Married or common law	1
Nick	42	Some university	Unemployed	Married or common law	2
Hope	42	University	Self-employed	Separated	2

Table 5. 2 *Background Information on Children with ASD*

<b>Pseudonym</b>	<b>Age</b>	<b>Medical Health Conditions</b>	<b>Age of Diagnosis</b>
Daniel	11	ASD, generalized anxiety disorder	6
Lucas	7	ASD	6
Ivan	16	ASD	4
Greg	15	ASD	12
Sophia	7	ASD, ADHD, childhood anxiety, language disorder	6
Julia	6	ASD	2.5
Tessa	10	ASD	3.75
Tyson	11	ASD	4

Table 5. 3 *Themes and Subthemes*

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Themes	Subthemes
1. Our journey with ASD	1.1 “We just had this feeling that something wasn’t right” 1.2 This is our reality, now what?
2. Ability to Engage	2.1 Diversity in functioning 2.2 Barriers and the aftermath 2.3 Factors to success 2.4 Putting it all together

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## APPENDIX 5a: Information Flyer

### YOU ARE INVITED TO PARTICIPATE IN RESEARCH REGARDING THE ASSOCIATION AMONG IMITATION, SOCIAL, AND MOTOR DEFICITS IN INDIVIDUALS WITH ASD

#### Purpose

Individuals with autism spectrum disorder (ASD) experience both social and motor deficits, including a difficulty in imitating others. Research has found that imitation plays a role in both social and motor development. The purpose of this research is to investigate the association among imitation, social, and motor deficits in individuals with ASD and explore how the results may differ between male participants and female participants.

#### About the Researcher

The principal researcher is a PhD candidate at Wilfrid Laurier University who is conducting this research for her PhD dissertation. The research advisors, Dr. P. Fletcher and Dr. P. Bryden are professors in the Department of Kinesiology and Physical Education.

#### Participants

Females and males ages 4 to 18 years that have been formally diagnosed with ASD by a medical professional along with their primary caregivers of these individuals will be recruited for this study.

#### Procedure

First, the individual with ASD will be asked to complete three tasks:

1. The first will require that the youth tap a target on a tablet [**15 minutes**].
2. The second will ask the youth to complete a series of motor tasks associated with balance, manual dexterity, and catching and aiming [**20 to 40 minutes**].
3. The third and final task is a motor imitation task, in which the youth will be asked to imitate the researcher in a series of movements [**10 to 15 minutes**].

While the youth is completing the tools discussed above, the primary caregiver will be asked to complete the following:

1. A background questionnaire [**10 minutes**].
2. Social Reciprocity Scale (SRS-2). The purpose of this questionnaire is to assess social awareness, social cognition, social communication, social motivation, and restricted interests and repetitive behaviours in youth with ASD. SRS-2 consists of 65 items [**15 to 20 minutes**].

On a different date, the caregiver will be asked to complete the following:

1. A one-on-one semi structured interview. The purpose of this interview is to explore the caregiver's perceptions regarding his/her child's social and motor skills [**60-90 minutes**].

#### Interested in Participating?

If you feel that you are suitable participant for this study, please contact Brianne Redquest at [redq9570@mylaurier.ca](mailto:redq9570@mylaurier.ca).

**APPENDIX 5b: Data Collection Tools****BACKGROUND QUESTIONNAIRE FOR CAREGIVER PARTICIPANT****WILFRID LAURIER UNIVERSITY**

Researcher: Bri Redquest (MSc)

Advisor: Dr. Pam Bryden &amp; Dr. Paula Fletcher

*Please complete all the questions by either filling in the blank spaces provided or checking the box with the most appropriate answer.*

*The following questions are about you:*

**1. Please list your gender:** \_\_\_\_\_

**2. Date of birth (mm/year):** \_\_\_\_\_

**3. Highest level of education attained:**

- Elementary School
- High School
- College
- University
- Post-Graduate Degree
- Other, *please specify:* \_\_\_\_\_

**4. For the purpose of background information, what is your marital status?**

- Divorced
- Married or common-law
- Separated
- Single
- Widowed
- Other, *please specify:* \_\_\_\_\_

5. Please list the gender and age of all your children:

Gender	Date of Birth (mm/year)	Medical Health Conditions

*The following questions are about your child/adolescent with ASD:*

1. **When did your child receive a formal ASD diagnosis [age]?** \_\_\_\_\_
2. **Please list some current signs and symptoms of ASD that your child currently exhibits?**

---

*The following questions will focus on your child's social abilities.*

3. **Does your child prefer to interact with (check all that apply):**
  - Adults
  - Siblings
  - Peers
4. **Does your child have friends outside of the family?**
  - Yes
  - No
5. **Would you define your child as social?**

- Yes
  - No, please explain:
- 

*The following questions will focus on your child's physical activity and motor abilities.*

**6. Does your child enjoy physical activity?**

- No
- Yes

**7. Is your child enrolled in any structured physical activities/sport?**

- No
  - Yes, please list:
- 

**8. How many times per week does your child engage in more than 30 minutes of physical activity?**

---

**9. Was your child able to walk without assistance by 18 months?**

- Yes
- No

**10. Was your child able to run easily by age 3?**

- Yes
- No

**11. How would you describe your child's fine motor skills (e.g., writing) for his/her age?**

- Above average
- Average
- Below average

**12. How would you describe your child's gross motor skills (running, hopping) for his/her age?**

- Above average
- Average
- Below average

*Thank you very much for your participation in this study!*

### Interview for Caregiver of Child with ASD

*My name is Bri. I am a third year PhD Student at WLU. My research area focuses on disabilities. For the current study I am looking at the association between imitation, social and motor deficits.*

1. Please tell me a little about yourself.
  - Education, occupation
  - Family composition (number of children etc..)
  - Interests, hobbies
  
2. Please tell me about your child with ASD
  - Process of diagnosis, age, signs and symptoms of ASD (at time of diagnosis vs. now) etc.
  - Typical behaviours of your child currently
  - Other conditions (co-morbid AND health)
  - Hobbies, interests
  
- 3. Social**
  - a. Would you consider you child social? Why or why not?
    - Friends?
    - Siblings?
    - Play dates?
  
  - b. How would you describe your child's social interaction with others?
    - Does he/she have a peer group? Close friends?
    - Does he/she tend to isolate themselves or try to include themselves?
    - Play with or beside?
  
  - c. How does your child react to unfamiliar/familiar social settings?
    - Home vs public?
  
  - d. Can you talk about your child's social skills and how they may have changed throughout his/her life?
    - What factors influenced these changes?
    - Progressed? Regressed?
    - Why?
  
  - e. What is your child's ideal social situation?
    - What are factors that affect your child's social abilities?
    - With adults? Family? Friends?
    - Structured play vs unstructured play?



- f. Do you have any concerns about your child's social abilities?
  - If so, what are these?
  - How can these concerns be addressed?
- g. After talking about your child and social situations, would you consider your child social?
  - Why or why not?
- h. What is one word to describe your child from a social perspective?

#### **4. Motor**

- b. Did your child reach all of his/her developmental milestones?
  - For example, was your child able to:
    - o Roll from front to back by 3 months?
    - o To sit on their own by 8 months?
    - o Walk without help by 18 months?
    - o Run with ease by 3 years?
- c. Can you tell me about your child's fine motor skills?
  - Handwriting, drawing, beading etc.
  - Are there any factors that influence your child's fine motor skills?
  - Does this affect him/her (emotionally, socially, mentally, avoidance of particular activities, adopt different ways of completing tasks etc...)
- d. Can you tell me about your child's gross motor skills?
  - Jumping, hopping, running
  - What influences this? See above
  - How does this affect him/her (emotionally, socially, mentally, avoidance of particular activities, adopt different ways of completing tasks etc..)?
- e. Do motor skills play a role in what activities your child decides to participate in?
  - If yes, how?
- f. Can you describe your child's typical PA in a week?
  - Weekdays
  - Weekend
  - Home vs school
  - Activities
  - Community

- g. How would you describe your child's physical activity level?
  - Would you say he's/she's active for his age?
  - As active, more active, less active than individuals his/her age
- h. How would you define being physically fit?
  - Based on this definition would you say that your child is "physically fit"?
  - Why or why not?
- i. What is your child's ideal physical activity?
  - Team vs individual sport
  - Competition no competition
- j. Are there any factors that affect your child's physical activity levels?
  - Barriers/facilitators
  - Motor skills: fine vs gross
  - School days vs days off
  - Age
  - Sibling/ family/ peer involvement
  - Weather
  - Costs
- i. Do you have any concerns about your child's physical abilities?
  - If so, what are these?
  - Do you feel these concerns should be addressed?
- k. Can you provide one word to describe your child/s motor abilities?

## **5. Social and Motor**

- a. Do you feel that there is any association between your child's social and motor skills?
  - If so, what is this association?
- b. Does your child's school experience affect his/her social and/or motor abilities?
  - Gym class?
  - Teacher feedback
  - Report card --- would you be willing to share teacher's comments from report card?
- c. Does your family have a role with regards to your child's motor and social skills?
  - Sibling
  - Involvement in activities together/ separately

**6. Ending questions**

- a. Do you have any advice for parents of children with ASD, particularly from social or motor perspective?
- b. Do you have anything to add?
- Questions for me?

**Chapter 6-Study #5: The Association Among Imitation, Social, and Motor Deficits in  
Individuals with ASD**

### **6.1. Abstract**

Individuals across the spectrum experience a myriad of challenges that compromise their wellbeing. Challenges include social impairments (e.g., difficulties in peer relationships) and motor impairments (e.g., difficulty with running and writing). In addition to these challenges, they also exhibit an imitation deficit. Imitation plays a role in the development of specific domains (e.g., social and motor), therefore it may be likely that imitation deficits are associated with social and motor impairments. As such, the purpose of this study was to examine imitation, social and motor impairments among individuals with ASD. It was hypothesized individuals with greater imitation deficits would also have greater social and motor deficits. The imitation, social, and motor abilities of 21 children (10 children with ASD and 11 typically developing children ages 7 to 15) were assessed using the Social Reciprocity Scale 2nd Edition, Target Accuracy iPad task, Motor Assessment Battery for Children-2, and the Motor Imitation Task tool. The study revealed a significant relationship in motor functioning and imitation among individuals with ASD; children who exhibited greater motor difficulties also exhibited greater difficulty in imitation. The study provides recommendations for healthcare professionals, educators, family members, and researchers. For example, it is recommended that healthcare professionals assess imitation and motor skills in children suspected to have ASD. It is crucial the relationship between imitation, social, and motor functioning continues to be examined so deficits in these domains can be addressed, thus improving the quality of life of individuals across the spectrum.

## 6.2. Introduction

As highlighted in Studies #1 through 4, individuals across the spectrum experience a myriad of challenges that compromise their wellbeing. For example, in Studies #1, 2, and 3 it was revealed individuals with ASD are often diagnosed with anxiety and attention deficit hyperactivity disorder (ADHD), and experience many social challenges such as difficulties in peer relationships. Motor impairments such as difficulty with running, climbing, writing, and doing up buttons are also common among individuals with ASD, as revealed in Study #4. In addition to these challenges, it has been well documented that individuals with ASD exhibit an imitation deficit (e.g., Bernier, Daweson, Webb & Murias, 2007; Martineau, Cochin, Barthelemy & Magne, 2008; Oberman et al., 2005). This imitation deficit is thought to be the result of a disruption in the mirror neuron system (MNS), this is referred to as the “broken mirror theory of autism” (Hamilton et al., 2013).

Imitation is defined as an individual's ability to replicate an observed motor act (Prinz, 2002). Imitation plays a role in the development of social and motor skills (Zachor, Iiant, Itzchak, & Dzuik, 2007; Jones, 2009). For instance, social interaction between infants and their caregivers are characterized by a back and forth imitation of sounds and facial expressions (Ingersoll, 2008). Further, Dzuik (2007) and Jones (2009) have suggested that it is through imitative behaviour that infants acquire motor skills. Developmental psychologists suggest imitation is the foundation of cognitive development, social-emotion communicative functions, social abilities, and the ability to identify others' mental states, which is commonly referred to as the theory of mind (Lakin & Chartrand, 2003; Meltzoff & Williamson, 2013). Theory of mind allows individuals to assess the behaviours of others based on their own actions (Perkins, Stokes,

McGillivray, and Bittar, 2010). Such behaviours can include emotions, desires, goals and opinions (Perkins et al., 2010).

Considering imitation plays a role in the development of specific domains (e.g., social and motor [Zachor et al., 2010; Dzuik et al., 2007; Jones, 2009]), one would assume imitation deficits are associated with social and motor impairments experienced by individuals with ASD (Lakin & Chartrand, 2003; Meltzoff & Williamson, 2013; Rogers & Pennington, 1991).

Therefore, with evidence suggesting individuals with ASD exhibit imitation, social, and motor deficits, as well as the notion that social and motor skills are learned through imitation, it can be hypothesized that there is an association between imitation deficits and consequently social and motor impairments in children with ASD. Specifically, if an individual exhibits an imitation deficit he/she will also experience a social and/or motor deficit.

Generally, a strong link has been shown between imitation deficits and impairments in social and motor domains in individuals with ASD. Results from a study conducted by Zachor, Ilanit, and Itzhak (2010) indicated imitation abilities were significantly correlated ( $p < .01$ ) with autism severity, specifically with respect to the socio-communication domain (i.e., children with ASD who exhibited higher social reciprocal interaction and responsiveness deficits). Although it appeared motor skills did not correlate with imitation, it was found children with autism who exhibited better fine motor skills were more successful in the imitation of object manipulation as opposed to body movements (Zachor et al., 2010). Green et al. (2002) found imitation performance was strongly related to general motor performance in individuals with autism. Similarly, Vanvuchelen, Roeyers, and De Weerd (2007) revealed imitation of both meaningful and non-meaningful tasks were correlated with motor abilities among individuals with low functioning (LF) autism; however, only imitation of non-meaningful tasks was correlated with

the motor ability of high functioning (HF) group. Finally, Biscaldi et al. (2014) revealed imitation was correlated with motor performance ( $p < 0.01$ ), specifically time performance, coordination, and execution in autistic participants. These results suggested individuals with ASD who exhibited an imitation deficit, also had impaired social functioning (Zachor et al., 2010) and impaired motor performance (Biscaldi et al., 2014; Green et al., 2002; Venvuchelen et al., 2007).

There is room for improvement in the literature examining imitation, motor, and social deficits. First, most studies include only a male population and therefore, further research including both sexes is warranted. Secondly, research examining all three deficits (social, motor, and imitation) is lacking. Not only will such research be able to shed light on the imitation deficit exhibited by those with ASD but will also provide further insight into the nature of social and motor deficits exhibited by this population. Social and motor deficits are associated with many consequential challenges such as mental health difficulties (Ratcliffe, Wong, Dossetor, & Hayes, 2015) and an inability to complete daily life skills (Kopp, Beckung, & Gillberg, 2009). As such, identifying the nature of these deficits may improve the wellbeing of individuals with ASD as this will ultimately contribute to the development and implementation of the most appropriate interventions in minimizing these deficits.

The purpose of this study was to examine imitation, social, and motor deficits among individuals with ASD. It was hypothesized individuals with greater imitation deficits would also have greater social and motor deficits. It was also anticipated that individuals with ASD would have greater deficits in imitation, social, and motor functioning, when compared to their typically developing counterparts.



### 6.3. Methods

**6.3.1. Ethics.** Prior to the study, all tools and procedures were approved by the Wilfrid Laurier University Research Ethics Board. Upon receiving ethics approval, participants were recruited. Consent was obtained from each participant or his/her proxy prior to partaking in the study.

**6.3.2. Participants.** Twenty-one participants between the ages of 7 and 15 ( $M_{\text{age}}=9.5$  years,  $SD=2.94$ ) were included in this study. Ten participants, with a mean age of 10.5 years ( $SD=3.41$ ), had been formally diagnosed with ASD by a medical professional. Six were males and four were females (Table 6.1). Eleven typically developing participants had a mean age of 9.2 years ( $SD=2.44$ ), five were males and six were females (Table 6. 2).

Inclusion criteria for the ASD group were as follows: must be between ages 5 and 16 years, have received a formal diagnosis of ASD from a healthcare professional, has an IQ greater than 70 as determined by the assessor, must be English speaking, must be verbal, and able to understand basic instruction. Inclusion criteria for the typically developing group were as follows: must be between ages 5 and 16 years, has an IQ greater than 70 and no obvious medical condition(s) as determined by the assessor, must be English speaking, and able to understand basic instruction. Participant were recruited through community agencies/ organizations services to individuals with disabilities (e.g., KidsAbility, Autism Services Waterloo) and by word of mouth from individuals within the community.

**6.3.3. Procedure and research tools.** Four different assessments were used for this study. The Social Reciprocity Scale, Second Edition [(SRS-2) Constantino & Gruber, 2005] was used to assess social deficits. A Target Accuracy iPad task (Baker, Boyczuk, Cinelli, & Bryden, 2015) and Motor Assessment Battery for Children-2 (MABC-2) (Henderson, Sugden, Barnett, 2007) were used to assess motor functioning. The Motor Imitation Tasks (MITs) tool, adapted from Zachor et

al. (2015) was utilized to assess imitation deficits. There was no specific order in which assessments were administered. After explaining the tasks to participants, the researcher would ask which task the participant would like to complete first. This kept participants engaged and interested in the given tasks. In some cases, participants preferred to begin with a more active assessment (MABC-2), while others preferred to begin with a less demanding assessment (Target Accuracy iPad task). All assessments were completed on the same day and took each participant roughly one hour to complete, although all participants were told if they were not able to complete all tasks, they could come back the following day. Caregivers of all children were required to complete the Social Reciprocity Scale, Second Edition (SRS-2). In most cases, caregivers completed the SRS-2 while their children participated in the research study, however, some caregivers preferred to complete it at a different time. They then returned the form at a later date. Each of the tools utilized will be described in turn.

**6.3.2.1. *The social reciprocity scale, second edition ([SRS-2] Constantino & Gruber, 2005).*** The SRS-2 was completed by the primary caregiver of the child. The purpose of this questionnaire was to assess social awareness, social cognition, social communication, social motivation, and restricted interests and repetitive behaviours in children with ASD (Constantino & Gruber, 2005). To allow for comparison, the SRS-2 was also administered to caregivers of the typically developing children. Four forms of the SRS-2 are available, each of which pertains to a specific age group. For this study, the school-age form was used (Constantino & Gruber, 2005). The SRS-2 consisted of 65 items and took parents roughly 15 to 20 minutes to complete. A higher SRS-2 score indicated greater social deficits. The SRS-2 has been used in many studies that have assessed social abilities among individuals with ASD (Wilkinson, 2013). The tool has

been shown to have high internal consistency, validity, and interrater reliability (e.g., Constantino & Gruber, 2012).

**6.3.2.2. Target and accuracy iPad task.** Participants were asked to press down on a 1 cm diameter target on the bottom of the iPad screen. After a short period of time (500ms, 1000ms, or 1500ms), the target then appeared in a random location on the screen (Baker et al., 2015). The participant was expected to tap on the target as quickly and as accurately as possible. By doing so, the individual's reaction time was recorded (Baker et al., 2015). The participant was expected to complete 20 trials (each roughly five seconds). The duration of the task was approximately five minutes. A higher target and accuracy score indicated a greater delay in reaction time (Baker et al., 2015). Although the assessment has been used in ASD population, the reliability and validity of the task has not yet been assessed.

**6.3.2.3. Movement assessment battery for children-2.** The MABC-2 (Henderson et al., 2007) was used to assess the motor functioning of all participants. The MABC-2 was comprised of eight tasks that assess manual dexterity, aiming and catching, and balance. These eight tasks were designed for three separate age groups: 3 to 6, 7 to 10, and 11 to 16 (Henderson et al., 2007). The duration of this assessment took between 20 to 40 minutes. A lower score on the MABC-2 indicated greater movement difficulties (Henderson et al., 2007). Although the MABC-2 has not yet been validated with ASD populations, it has been for individuals diagnosed with developmental coordination disorder (DCD). For instance, Wang, Su, and Su (2012) examined the internal consistency, test-retest reliability, and responsiveness of MABC-2 with 141 children diagnosed with DCD (ages 6 to 12). Wang et al. (2012) confirmed the test was a reliable and valid measure in assessing motor abilities in children with DCD.

*Experiences of administering the tool.* In administering the tool to each group (ASD group and control group), the time it took for the ASD participants to complete the MABC-2 was longer than it took for the neurotypical participants to complete the MABC-2. The researcher provided simple concise instructions to each of the participants, both with ASD and without ASD. From here, further instruction was provided if requested from the participant. Unlike the neurotypical participants, the ASD participants would often ask the researcher to further explain the instructions for each of the tasks. They would also ask the researcher the purpose for each of the tasks (e.g., what is this measuring? Why are we doing this? What is this for?). It is important to note that the researcher did not have difficulty administering the tool to the ASD participants. This may be because the researcher knew most of the participants because they had participated in a physical activity class she co-instructed, and therefore she had already developed a strong rapport with the ASD participants. Also, most of the participants were high functioning which likely reduced potential challenges that may have been present if the participants were low functioning (e.g., low comprehension, minimal verbal ability etc.).

**6.3.2.4. Imitation deficits.** To assess imitation deficits in children with ASD, the Motor Imitation Tasks (MITs) tool was used. This tool was adapted from Zachor et al. (2015) who developed the MITs by comprising several imitation assessments used in previous research studies (Charman et al., 1997; Roeyers, Van Oost, & Bothuyne, 1998; Rogers, Hepburn, Stackhouse & Wehner, 2003; Stone, Oously, & Litleford, 1997). The assessment is divided into two components, namely imitation of meaningful actions and imitation of non-meaningful actions (see Table 6.3 for more detail). Zachor et al. (2015) suggested dividing the actions into meaningful and non-meaningful actions, and actions requiring the use of body movements and

those requiring objects, prevented differences at the level of difficulty that may influence the imitation performance.

All sessions were video recorded for quantitative scoring. The researcher and participant were seated across from one another at a table and the researcher asked the participant to “do what I do” and then proceeded to perform an action. The researcher would then wait for the participant to imitate the action. If needed, the researcher would repeat the action for the child. After the completion of the MITs, the researcher and a research assistant analyzed the recordings. Each recording was roughly 3 minutes. Analysis of all recordings took the researcher and research assistant roughly 5 hours. The researchers looked for both temporal and spatial errors. Temporal errors involved sequencing errors (including addition or deletion of movements), timing errors (increased, decreased or irregular speed of movement), and occurrence errors (multiplication of single movements) (Bedard, Agid, Chouinard, Fahn, & Korczyn, 2003). Spatial errors included multiple types of errors; however, only the following were considered, as they are applicable to this assessment: amplitude (amplification, reduction, or, irregular movement), internal configuration (improper position of fingers and hand in relation to target/ object being used), external configuration orientation (error in position objects or hands/fingers in space), and movement (improper movement of all limbs involved in motion) (Bedard et al., 2003). For each type of error present, the participant received a score of one. A higher temporal and spatial imitation score indicated a greater imitation deficit. See Appendix 6a for the evaluation sheets used to code errors.

## **6.4. Results**

**6.4.1. Data analysis.** First, descriptive statistics for the ASD group and control group were examined. Mean scores for each scale item and total scores pertaining to the MABC-2,

SRS-2, scores for temporal imitation error, spatial imitation error, and the iPad Target Accuracy Task can be found in Table 6.4. Through visual inspection of this table, it is clear the ASD group performed worse on all social, motor, and imitation tasks. The task in which the two groups performed most alike (i.e., had the minimal difference between mean scores) was the Target Accuracy iPad task. As indicated by the standard deviation (SD), it appears there was more variability in the ASD group than in the typically developing group, as the SD was greater in in the ASD group for 10 of the 13 scores.

To determine which correlational analysis was most appropriate in assessing the relationship between imitation, social, and motor functioning, all variables for both groups were examined for linearity, normal distribution, and outliers using SPSS 24. Note, for this analysis total scores (MABC-2 Total Standard Score, SRS-2 Total T score) and SRS-2 raw scores were not examined. SRS-2 T-scores were used rather than raw scores because T-scores consider gender whereas the raw scores do not. Linearity of the variables was confirmed for the ASD group and control group by visually examining a scatterplot matrix. For the ASD group, social motivation (T-score) was not normally distributed as assessed by the Shapiro-Wilk test ( $p > .05$ ). For the control group, the following variables were not normally distributed as assessed by the Shapiro-Wilk test ( $p > .05$ ): social cognition (T-score), social communication (T-score), social motivation (T-score), restricted and repetitive behaviours (T-score), and target accuracy score. Based on an examination of box-and-whisker plots, outliers were present in the ASD group for scores on aiming and catching; social cognition (T-score); and spatial imitation error. For the control group, outliers were present in scores on manual dexterity, aiming and catching, social cognition (T-score), social communication (T-score), social motivation (T-score), target accuracy and age. Based on this information, it was determined Spearman's rho was the most appropriate

statistical test to assess the relationships among these variables because it is less sensitive to outliers and does not require normality (Lehmann, 2006). Because Spearman's rho is less sensitive to outliers, outliers were left in the for data analysis.

The differences in imitation, social, and motor functioning between individuals with ASD and typically developing individuals, were examined using ANOVA. The SRS-2 total T-score, MABC-2 Total Standard Score, temporal and spatial imitation error, and the target accuracy total score were examined for normality, outliers, and homogeneity of variance. The total SRS-2 scores for both the ASD and control group were not normally distributed, as assessed by Shapiro-Wilk test ( $p < .05$ ). The target accuracy score pertaining to the control group was also not normally distributed, as assessed by the Shapiro-Wilk test ( $p < .05$ ), however, given that ANOVA is considered a robust test and not susceptible to non-normality, one-way ANOVAs were still conducted (See Maxwell & Delaney, 2000). Outliers were present in the total SRS-2 T-score for the control group, and spatial imitation error for the ASD group, and the target accuracy score for both the ASD and control group. The one-way ANOVAs were conducted with outliers included. Finally, there was homogeneity of variances for each of the variables, as assessed by Levene's test for equality. A one-way ANOVA was therefore deemed suitable to analyze the data.

#### **6.4.2. Correlation of imitation, social, and motor functioning in the ASD group.**

Spearman's rho correlations were conducted on all variables with the exception of total scores (MABC-2 Total Standard Score, SRS-2 Total T score) and SRS-2 raw scores. To maximise all data, 'pairwise deletion' was selected for all analyses. A strong negative correlation was revealed between manual dexterity and spatial imitation error ( $r = -.766$ ,  $p < .05$ ). Manual dexterity statistically explained 59% of the variability in spatial imitation error. A strong negative correlation was also found between balance and temporal imitation error ( $r = -.837$ ,  $p < .01$ ).

Balance explained 69% of the variability in temporal imitation error. The negative sign is due to the scoring system of the MABC-2, with lower scores indicating greater movement difficulties. A strong positive relationship between target accuracy and social cognition was also revealed ( $r=.795$ ,  $p<.05$ ), in that target accuracy explained 63% of the variability in social cognition. There was a strong positive relationship in social communication and restricted and repetitive behaviours ( $r=.819$ ,  $p<.05$ ). Social communication statistically explained 68% of the variability in restricted and repetitive behaviours. Finally, spatial and temporal imitation error had a strong significant association ( $r=.743$ ,  $p<.05$ ). Spatial imitation error explained 55% of the variability in temporal imitation error. Refer to Table 6.5 for results of this analysis.

**6.4.3. Correlation of imitation, social, and motor functioning in the typically developing group.** Spearman's rho correlations were conducted among all variables, all variables with the exception of total scores (MABC-2 Total Standard Score, SRS-2 Total T score) and SRS-2 raw scores. To maximise all data, 'pairwise deletion' was selected for all analyses. A strong positive relationship was found between social cognition and social awareness ( $r=.787$ ,  $p<.05$ ), where social cognition explained 62% of the variability in social awareness. Results further indicated a strong positive relationship between social cognition and social motivation ( $r=.674$ ,  $p<.05$ ). Specifically, social cognition explained 45% of the variability in social motivation. Social cognition and repetitive and restricted behaviours had a strong positive significant association ( $r=.609$ ,  $p<.05$ ), social cognition explained 37% of the variability in repetitive and restricted behaviours. Spatial imitation error had a negative, strong association with repetitive and restricted behaviours ( $r=-.800$ ,  $p<.05$ ). Spatial imitation explained 64% of the variability in repetitive and restricted behaviours. Finally, spatial and temporal imitation error



had a strong significant association ( $r=.805$ ,  $p<.05$ ). Spatial imitation error explained 65% of the variability in temporal imitation error. Refer to Table 6.6 for results from this analysis.

**6.4.4. Differences between groups.** A one-way ANOVA was conducted to determine if overall scores pertaining to imitation, social, and motor functioning differed between the ASD and typically developing group. Results from the one-way ANOVA indicated means pertaining to total MABC-2 standard score and the total SRS-2 T-score were significantly different between groups. Specifically, the MABC-2 total score was significantly lower in the ASD group when compared to the control group ( $F_{(1,18)}=25.09$ ,  $p<.0005$ ). The total SRS-2 T-Score was also significantly lower in the ASD group when compared to the control group ( $F_{(1,17)}=106.76$ ,  $p<.005$ ). Mean differences between groups were not significant for temporal imitation error, spatial imitation error, and target accuracy scores. See Table 6.7 for results from this analysis.

## 6.5. Discussion

The purpose of this study was to examine imitation, social, and motor deficits. It was hypothesized individuals who had greater imitation deficits would also have greater social and motor deficits. It was also anticipated that individuals with ASD would have greater deficits in imitation, social, and motor functioning, when compared to their typically developing counterparts. The findings from this study will be discussed by first describing the relationship between imitation, social, and motor functioning for both groups. This will then be followed by a discussion of the differences among these variables in individuals with ASD and typically developing individuals.

Results indicated there was an association between imitation and motor deficits, but not imitation and social deficits among individuals with ASD. However, it is possible a relationship between imitation and social deficits exists but was not revealed in this study due to the small

sample size. Individuals who had greater manual dexterity deficits, also had greater spatial imitation deficits and individuals who had greater balance issues (static and dynamic) had greater temporal imitation deficits. These findings support the notion that motor and imitation deficits are associated in children with ASD, but social and imitation deficits are not. This is in sharp contrast to findings from a study conducted by Zachor et al. (2010) which revealed imitation deficits were associated with social deficits in children with ASD, but not motor deficits. However, the results from this study support findings from Vanvuchelen et al. (2007) who explored the relationships between imitation performance and competence on general motor tests (MABC-2 and Peabody Developmental Motor Scales) in children with ASD. Similar to this study, Vanvuchelen and colleagues concluded imitation and motor performance were correlated in children with ASD; specifically, children who performed poorer on imitation tasks also performed worse on motor tasks.

In contrast, the current study found no relationship between age, motor performance and imitation performance, whereas, Vanvuchelen et al. (2007) found the motor and imitation relationship was stronger in younger children with a lower developmental level. Similarly, Biscaldi et al. (2014) concluded imitation deficits improved with age among individuals with ASD. Unlike participants from Vanvulcheelen et al. (2007), participants included in this study were mostly high functioning, with the exception of one participant, while participants from the Vanculchelen et al. (2007) study were divided into two groups, a high functioning group and low functioning group. Also, the study conducted by Biscaldi et al. (2014) included participants ranging in age from 6 to 29 years old, whereas the age range for this study was much smaller (7 to 16 years). Perhaps to detect age differences, level of functioning must be considered and participants with a wider age range must be included. Although the current study confirms a

relationship between motor and imitation performance, it does not suggest causation. By understanding the relationship between these variables, it does encourage further research to investigate whether one deficit (i.e., imitation) is the result of the other deficit (i.e., motor deficit). As such, an observational study assessing and monitoring imitation and motor performance in infants and adults with ASD over time is warranted.

The relationship between motor and imitation performance revealed also sheds light on the specific difficulties individuals with ASD experience with regards to imitation. For manual dexterity, the type of imitation error was spatial, whereas for balance the type of imitation error was temporal. Prior studies investigating imitation and motor abilities have not assessed imitation performance by assessing temporal and spatial errors. Rather, imitation performance is often assessed using a scoring system. For example, Zachor et al. (2010) provided scores ranging from zero to three, where zero indicated failure to imitate and three indicated appropriate imitation. The current study adds insight into the specific difficulties individuals with ASD experience when attempting to imitate, and therefore provides valuable information for professionals who are working with children to improve motor skills. For example, when a child is being taught fine motor skills, spatial errors may be more prominent and therefore should be assessed and corrected. Similarly, when a child is developing gross motor skills such as balance, temporal errors may be more prominent and therefore should be assessed and corrected.

A significant association between social deficits and imitation in individuals with ASD was not revealed, but there was an association between social cognition and target accuracy scores. Individuals who had greater social cognition difficulties also had a longer reaction time. Social cognition accounted for 63% of the target accuracy score. Social cognition refers to the perception and understanding of social interactions (Suchy & Holdnack, 2013), whereas reaction

time is the time between the presentation of a stimulus and the time it takes for the individual to respond to the stimulus (Ghuntla, Mehta, Gokhale, & Shah., 2014). Individual studies have confirmed those on the spectrum do indeed have social cognition deficits (see, Miranda, Berenhuer, Rosello, Baixauli, & Colomer, 2017) and a have a delayed reaction time (see, Schmitz, Daly, & Murphy, 2002) when compared to typically developing individuals. However, a study confirming these deficits are correlated has not yet been published. Further research is needed to investigate if social cognition and reaction time are correlated in individuals with ASD.

Against expectations, the subscales from the SRS-2 and MABC-2 were not significantly correlated. However, this is likely the result of the small sample size as there is a body of research confirming children with ASD who exhibit poor motor skills also have poor social skills (Bhat, Landa, & Galloway, 2009; MacDonald, Lord, & Ulrich, 2014; Lloyd, MacDonald, & Lord, 2011). Researchers proposed social deficits in children with ASD prevent opportunities for motor development, and motor deficits act as barriers to social engagement with peers and therefore limit social development (Lloyd et al., 2011). This was also revealed in Chapter 4, as caregivers revealed their children's social deficits prevented them from being included in sport and therefore limited their opportunity for motor development. It was also conveyed by caregivers their children's motor deficits led to negative reactions by peers, thus limiting opportunity for social engagement. As mentioned, it is very likely a significant relationship between the SRS-2 subscales and MABC-2 standards scores for manual dexterity, balance, and aiming and catching was not revealed due to low sample size. As such, future research examining the association between the SRS-2 and MABC-2 among individuals with ASD

consisting of a large sample size as well as individuals from across the entire spectrum, rather than just individuals on the high end of the spectrum, is encouraged.

The association among imitation, social, and motor functioning was further explored in typically developing individuals. Unlike the individuals with ASD, motor and imitation were not significantly associated in this group, suggesting this relationship is specific to individuals with ASD. It is also possible that age could have also played a factor in this non-significant relationship. Researchers have suggested that the imitation and motor relationship is stronger in younger children (Biscaldi et al., 2014; Vanculchelen et al., 2007). Perhaps if the average age of the typically developing group younger than 9 years old, a significant relationship between imitation and motor would have been revealed. Similar findings have also been reported by Vanvuchelen et al. (2007) who concluded motor performance and imitation were not significantly associated in typically developing controls.

Interestingly, repetitive and restricted behaviours (a subscale of the SRS-2) and spatial imitation error had a significant negative relationship; as spatial imitation error increased, repetitive and restricted behaviours decreased. It should be noted although the SRS-2 has been validated for ASD populations, it has not been validated in typically developing populations. This highlights the importance of collecting data from multiple sources and using a variety of assessments to enhance the findings. Future studies comparing the functioning of typically developing individuals and ASD groups should consider using tools that have been validated for each specific group, and therefore using different tools for each group.

Against expectations, the two groups did not differ in spatial or temporal imitation error. Although significant differences were not evident, it is worth noting individuals with ASD did have a higher mean of spatial and temporal imitation errors. Specifically, the individuals with

ASD exhibited a greater number of spatial and temporal errors when asked to imitate the researcher. This contradicts findings from studies which revealed individuals with ASD performed significantly worse on imitation tasks when compared to their typically developing counterparts (See, Rogers et al., 2003; Vanvuvchelen et al., 2007; William, Whiten, & Singh, 2004).

As predicated, the two groups differed significantly with regards to their total SRS-2 T-scores and total MABC-2 standard scores. Children with ASD performed significantly worse on the MABC-2 and had significantly greater SRS-2 scores, indicating a greater social deficit. Although significant differences on the MABC-2 were revealed, the two groups did not differ significantly on their target accuracy scores. While not significant, children with ASD did have a higher mean target accuracy score, suggesting they had a greater delay in reaction time compared to typically developing children. As revealed in previous studies (Fodstad, Matson, Hess, & Neal, 2009; Ming, Brimacombe, & Wagner, 2007; Tureck & Matson, 2012), these results indicate social and motor impairments are associated with ASD.

### **6.5.1. Limitations**

Although the current study revealed important findings, it is important to highlight the limitations. Unfortunately, due to difficulty with recruitment, the sample size was small which lowers the statistical power of the study. Specifically, a sample size of 22 participants per group would be required to detect significant differences at the 0.05 level, as determined by a sample size calculation. The ASD group and typically developing group could not be aged and gender matched and therefore is an additional limitation of this study. The study included primarily HF individuals and therefore the findings may be more applicable to individuals on the high end of the spectrum rather than on the low end of the spectrum. Given the low sample size, sex

differences within groups could not be investigated. Future research investigating potential sex differences among the relationship between imitation, social, and motor functioning is needed.

## **6.6. Conclusion**

The purpose of the current study was to examine imitation and social, and motor deficits. The study revealed there was a significant relationship in motor functioning and imitation among individuals with ASD. As such, health care professionals should consider assessing imitation and motor skills in children suspected to have ASD. It is also recommended when addressing motor deficits, imitation must also be considered and when addressing imitation deficits, motor deficits should also be considered. Given the relationship between these two deficits, it is important one is not neglected in therapies. By neglecting one of these deficits and only focusing on the other, the potential for maximum improvement is reduced. Secondly, teaching motor skills through imitation is not encouraged, as this will likely reduce the success of the child. As such, the success of alternate instructional strategies, such as interactive instruction (engaging with peers to learn to concepts) or indirect instruction (learn by doing) must be explored. Future research must determine if imitation and motor deficits have a causal relationship. This will allow for the development of therapies aimed to prevent or minimize the underlying cause therefore preventing consequential deficits from arising. The study was not able to confirm a relationship between social and imitation deficits, likely due to the small sample size; however, it is important this relationship is further investigated, particularly because there is research supporting social development is learned through imitation (Lakin & Chartrand, 2003; Meltzoff & Williamson, 2013; Zachor et al., 2010). This may be addressed in future studies by asking children with ASD to imitate social actions, such as shaking hands, waving, and facial expressions. It is crucial the relationship between imitation, social, and motor functioning

continues to be examined so deficits in these domains can be addressed thus improving the quality of life of individuals across the spectrum.



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Table 6. 1 *Background Information of Individuals with ASD*

<b>ASD Participants</b>	<b>Sex</b>	<b>Age</b>	<b>Medical Health Conditions</b>
1	Male	11	ASD, generalized anxiety disorder
2	Male	7	ASD
3	Male	16	ASD
4	Male	15	ASD
5	Female	7	ASD, ADHD, childhood anxiety, language disorder
6	Female	6	ASD
7	Female	10	ASD
8	Male	11	ASD
9	Female	9	ASD
10	Male	13	ASD, Asthma, Allergies

Table 6. 2 *Background Information of Typically Developing Individuals*

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<b>Typical Developing Participants</b>	<b>Sex</b>	<b>Age</b>
1	Female	9
2	Male	7
3	Female	9
4	Female	11
5	Female	15
6	Male	10
7	Female	8
8	Male	6
9	Male	10
10	Female	7
11	Male	9

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Table 6. 3 *Items on Motor Imitation Tasks*

	<b>Meaningful Actions</b>	<b>Non-Meaningful Actions</b>
Action on objects	Drinking from a cup	Rolling a cup on the table
Body movements	Drinking action without a cup	Scratching face with 4 fingers
Action on objects	Brushing hair with a brush	Pushing a brush on the table
Body movements	Stroking own head	Rolling the hand on own head
Action on objects	Opening and closing a box	Rubbing abdomen with a box
Body movements	Clapping hands	Two handed rolling
Action on objects	Kissing a doll	Turning a doll on her back
Body movements	Blowing a kiss	Pulling two earlobes

Table 6. 4 *Descriptive Statistics for ASD Group*

Variable	N	<u>ASD Group</u>		<u>Typically Developing Group</u>		
		Mean	SD	N	Mean	SD
Manual Dexterity (percentile)	10	5.70 (23.86)	4.35 (29.54)	11	10.90 (49.45)	2.43 (31.50)
Aiming and Catching (percentile)	9	7.11 (19.11)	1.76 (15.53)	11	10.54 (57.36)	2.50 (26.11)
Balance (percentile)	10	8.33 (33.5)	2.98 (29.56)	11	12.00 (70.18)	2.09 (19.12)
Total MABC score	9	5.67 (16.05)	3.16 (20.68)	11	11.54 (67.54)	2.06 (20.20)
Social Awareness T-Score (Raw score)	9	74.89 (13.44)	9.93 (3.20)	11	43.18 (3.27)	8.47 (2.57)
Social Cognition T-Score (Raw score)	9	76.33 (19.78)	9.38 (5.04)	11	42.63 (1.90)	4.90 (2.26)

Social Communication T-Score (Raw score)	9	74.89 (32.56)	11.85 (9.66)	11	39.45 (3.73)	12.33 (3.10)
Social Motivation T-Score (Raw score)	9	71.33 (15.89)	9.58 (4.17)	11	39.18 (2.18)	14.10 (3.40)
Restricted interests and repetitive behaviours T-Score (Raw score)	9	78.89 (20.00)	10.14 (5.17)	11	43.27 (.90)	2.93 (1.45)
Total SRS score T-Score (Raw score)	9	78.89 (100.56)	10.58 (22.97)	11	39.36 (12.09)	10.71 (11.40)
Target Accuracy Score	10	948.94	322.32	10	869.42	181.20
Temporal Imitation Error	8	10.37	4.24	8	7.75	2.96
Spatial Imitation Error	9	22.37	7.29	8	15.50	6.30

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Table 6. 5 Spearman's Rho Analysis for ASD Group

Variable	Manual Dexterity	Aiming and Catching	Balance	Social Awareness	Social Cognition	Social Communication	Social Motivation	Restricted Interests and Repetitive Behaviours	Temporal Imitation Error	Spatial Imitation Error	Target Accuracy Score	Age
Manual Dexterity		.004	.046	-.504	-.177	-.527	.140	-.085	-.584	-.766*	-.037	.181
Aiming and Catching			.098	.349	.115	.349	-.242	.293	-.036	-.018	-.397	.017
Balance				.395	.118	-.114	-.237	-.436	-.837**	-.635	-.245	.532
Social Awareness					.594	.527	-.017	.126	-.234	-.214	.033	.251
Social Cognition						.643	.316	.641	-.100	-.487	.795*	.151
Social Communication							.316	.819**	.373	.144	.318	-.412
Social Motivation								.436	-.355	-.342	.303	-.080
Restricted Interests and Repetitive Behaviours									.382	.018	.563	-.544
Temporal Imitation Error										.743*	.479	-.542
Spatial Imitation Error											-.143	-.599
Target Accuracy Score												.055
Age												

\*correlation is significant at the 0.05 level (2-tailed), \*\*correlation is significant at the 0.01 level (2-tailed)

Table 6. 6 Spearman's Rho Analysis for Control Group

Variable	Manual Dexterity	Aiming and Catching	Balance	Social Awareness	Social Cognition	Social Communication	Social Motivation	Restricted Interests and Repetitive Behaviours	Temporal Imitation Error	Spatial Imitation Error	Target Accuracy Score	Age
Manual Dexterity		.072	.555	.313	.581	-.369	.235	.232	-.185	-.217	.506	-.356
Aiming and Catching			-.123	.219	.283	.186	.370	-.191	.074	.240	-.111	.870
Balance				.209	.495	.088	.229	-.029	.100	-.244	.491	-.116
Social Awareness					.787**	.159	.674*	.608*	-.270	-.551	-.340	.530
Social Cognition						.186	.713*	.326	-.052	-.457	-.037	.035
Social Communication							.571	.298	-.100	-.342	-.098	.210
Social Motivation								.434	-.277	-.577	.043	.362
Restricted Interests and Repetitive Behaviours									-.522	-.800*	-.216	.360
Temporal Imitation Error										.805*	.000	-.425
Spatial Imitation Error											.214	-.683
Target Accuracy Score												-.543
Age												

\*correlation is significant at the 0.05 level (2-tailed), \*\*correlation is significant at the 0.01 level (2-tailed)

Table 6. 7 *One-Way ANOVA Results Pertaining to Mean Differences Between the ASD and Control Group*

		<b>Sum of Squares</b>	<b>df</b>	<b>Mean Square</b>	<b>F</b>	<b>Sig.</b>
<b>MABC-2 Total</b>	<b>Between Groups</b>	171.07	1	171.07	25.09	<.0005
<b>Standard Score</b>	<b>Within Groups</b>	122.73	18	6.82		
	<b>Total</b>	293.80	19			
<b>Total SRS-2 T- Score</b>	<b>Between Groups</b>	7733.15	1	7733.15	67.52	<.0005
	<b>Within Groups</b>	2061.43	18	114.52		
	<b>Total</b>	9794.55	19			
<b>Temporal Imitation Error</b>	<b>Between Groups</b>	27.56	1	27.56	2.06	.173
	<b>Within Groups</b>	187.37	14	13.38		
	<b>Total</b>	214.94	15			
<b>Spatial Imitation Error</b>	<b>Between Groups</b>	189.06	1	189.06	1.96	.183
	<b>Within Groups</b>	1347.87	14	96.28		
	<b>Total</b>	1536.94	16			
<b>Target Accuracy Score</b>	<b>Between Groups</b>	31618.742	1	31619.74	.463	.505
	<b>Within Groups</b>	120532.56	18	68368.92		
	<b>Total</b>	1262151.31	19			



## Chapter 7- General Discussion

### 7.1. Summary of Main Findings

The purpose of this dissertation was to investigate the overall wellbeing of individuals across the spectrum, in order to ameliorate their quality of life. In addressing this purpose, a total of five studies were conducted. The results from this dissertation allowed for the development of well-informed, credible suggestions. A brief review of major findings will be followed by a series of suggestions developed from this dissertation.

All studies revealed that individuals with ASD experience a myriad of issues. Social difficulties, such as social isolation and difficulty engaging with peers, appeared to be the most common challenges among the participants from each of the studies. Issues affecting the overall health of individuals with ASD were also reported. Study #1 indicated that sleep issues were very common among HF and LF participants, with 64% of HF individuals and 72% of LF individuals triggering the sleep CAPs. Results from Study #1 further indicated aggression was prevalent among individuals with ASD, particularly LF ASD (91%). It was also highlighted in Study #3 HF males were twice as likely to be diagnosed with attention deficit hyperactivity disorder (ADHD) when compared to their female counterparts. Although HF males were more likely to be diagnosed with ADHD, a large percentage of HF females were also diagnosed with ADHD (40%). Additionally, Study #3 showed that more than half of HF males (53%) and HF 50% females were diagnosed with anxiety. Gross and fine motor impairments among children with ASD were also prevalent, as highlighted in Study #4 and Study #5. In addition to motor impairments, Study #5 further demonstrated that individuals with ASD also exhibited an imitation deficit. It is clear individuals with ASD are at risk for numerous challenges and it is essential they are addressed in addition to the core symptoms of ASD.



Unlike their social difficulties, it appeared the motor functioning of children with ASD was more inconsistent (Study #4) among participants. For example, while one caregiver described his/her child's superior fine motor skills, another described his/her child as having very poor fine motor skills. Not only was this discrepancy present between children, but also within the individual child. While a child demonstrated typical fine motor skills in one task, he/she often exhibited poor fine motor skills in another. This was also true for gross motor skills. As such, it can be hypothesized children with ASD will exhibit social deficits, and this deficit will be similar among the children. While children with ASD will likely exhibit a motor deficit, the deficit in which they exhibit may differ among children. It was further illustrated in Study #4 that there is a reciprocal relationship between social and motor functioning; social development influences motor development and vice versa. Despite the acknowledgement of this reciprocal relationship by caregivers, they expressed very little concern for their children's motor deficits in comparison to social deficits. Motor deficits among individuals with ASD warrant further attention, particularly given the association between social and motor functioning.

Another finding worth highlighting, is the lack of physical activity among individuals with ASD, regardless of their sex and where they were situated on the spectrum. Study #2 showed that of the HF sample 59% of males and 65% of females, and of the LF sample 38% of males and 56% of females were participating in less than two hours of physical activity in the last three days. Study #1 also indicated 94% of LF individuals were triggering the play and leisure CAP. This CAP was triggered by individuals who could benefit from play and leisure. This is an area of significant concern because the benefits of physical activity will help mitigate many of the current issues they experience (e.g., anxiety, social deficits, motor deficits) and help

to prevent further issues from developing. It is therefore important physical activity among individuals with ASD is encouraged and PA programs are barrier-free.

Although not directly explored in any of the studies, it appeared the school system played a sizable role in the social and motor development of children with ASD. Caregivers, from Study #4, perceived schools most often functioned as barriers. This was especially evident with Diane's experience. One teacher suggested Diane's daughter should use an iPad for writing, rather than continuing to work on her writing with a pencil, a task which was difficult for her. Diane felt the teacher was 'throwing in the towel'. Caregivers explained social functioning was also negatively affected because their children's atypical behaviours prevented other children from wanting to be their friends. The school environment also provided children with ASD the opportunity to compare themselves to others, causing them to feel inferior and withdraw socially. Study #2 further showed that children with HF ASD are bullied. HF individuals were almost six times more likely to be bullied than their LF counterparts. Of the HF sample, almost half of the individuals were bullied. Although it was not specified that this bullying took place at school, children typically spend most of their days at school. Evidently, further supports and resources are needed in educational system to foster successful development of children with ASD and to ensure they are not being bullied. are bullying is prevented among all children.

Studies #1 through 5 all demonstrated children with ASD experience issues that compromise their overall wellbeing. In order to enhance their quality of life, the concerns described above must be addressed. Suggestions pertaining to four areas: additional challenges, social and motor deficits, the school system, and physical activity will be proposed.

**7.1.2. Additional challenges.** As previously mentioned, individuals experience many challenges including social deficits, sleep issues, aggression, motor deficits, and difficulties with

imitation. It is also common for individuals with ASD to be diagnosed with ADHD and anxiety. Caregivers of children with ASD and health care practitioners must be educated about these issues, so they can be monitored and assessed. Study #1 revealed that children and youth, who triggered one concern, were also triggering concerns in other domains. For instance, the majority of children who had communication issues also had aggression issues. Additionally, many children who had difficulties in the social domain also had reduced educational success.

To determine if one of these concerns is the result of the other, a longitudinal study needs to be conducted so that a temporal order between factors could be established. Presently this type of data is not possible with the data set utilized. However, as multiple time points are collected for individuals with ASD, this type of analysis would be possible. This analysis should also consider the level of functioning and sex of the individuals. Monitoring these concerns will not only assist in early detection but will hopefully allow for these issues to be resolved before further concerns develop. In assuring that this happens it is important to first begin with health care professionals, particularly front-line health care workers routinely working with families with ASD.

Information regarding ASD and these additional challenges should be implemented in the curriculum for medical students. In addition to this, workshops focusing on the health of individuals with ASD should be offered and made mandatory for current health care professionals. A similar approach to this was investigated by Moroz and colleagues (2010). Researchers provided a daylong disability training to physical medicine and rehabilitation trainees. The training covered topics such as disability facts, medical evaluation of disabilities, and the lived experiences of people with disabilities. After attending the training, trainees reported a significant increase in disability knowledge and significantly higher scores in attitudes towards disability (Moroz et al., 2010). It is hopeful that if healthcare professionals are educated

on the challenges that are beyond the core symptoms of ASD, they will prioritize these concerns during health care visits.

Given the high prevalence of anxiety and ADHD among children with ASD, it is recommended routine screening and monitoring for these conditions is conducted annually. This will allow for the implementation of immediate intervention, if necessary, thus preventing the symptoms of these conditions to worsen and/or result in further concerns. If health care professionals are aware of these concerns, they can then educate caregivers of children with ASD. Such information should be provided to caregivers at the time of their children's diagnosis. Providing parents with checklists of symptoms associated with these co-morbid conditions may also assist in encouraging parents to monitor such concerns and therefore promote earlier detection. Finally, further research is warranted to determine means by which to manage or prevent these issues from compromising the wellbeing of individuals with ASD. To improve the quality of life among individuals with ASD, the additional challenges exposed from this dissertation must be addressed through the execution of the described suggestions.

**7.1.3. Social, motor, and imitation deficits.** Social and motor deficits among individuals with ASD were extremely common. While participants exhibited similar social deficits, they exhibited different motor deficits from one another. Although motor deficits seemed to be just as common as social deficits, caregivers expressed very little concern for their children's motor deficits. A relationship between their social and motor development was highlighted. A relationship also existed between imitation and motor deficits; when participants exhibited greater movement difficulty, they also exhibited greater difficulty while performing imitation tasks. Based on these findings, a number of recommendations are being proposed. Currently, the criteria for diagnosing ASD focuses primarily on social deficits, even though motor and imitation

deficits also appear to be core symptoms of the disorder. As such, it is suggested the DSM considers adding motor and imitation deficits as a criterion for diagnosing ASD. This may not only lead to earlier detection of ASD but will encourage parents and medical care professionals to be more cognisant of these deficits thus increasing the likelihood that these deficits are addressed. It is further suggested social skill therapies for children with ASD, include a motor component and therapies focusing on motor development, such as occupational and physical therapy, include a social component. To see maximum improvement in either of these domains, it is crucial both domains are considered. It is further recommended that within these therapies, imitation is avoided as an instructional effort. A study conducted by Iovannone, Dunlap, Huber, and Kincaid (2003) reported effective evidence-based educational practices for students with ASD. In order to facilitate success in children with ASD, authors indicated that instructional efforts should include structured and individualized supports, systematic instruction, and family involvement. Attention beyond social deficits is required to promote maximum improvement in impaired domains, as this will ultimately enhance the overall wellbeing of individuals with ASD.

**7.1.4. Physical activity.** Studies #1 through 3 demonstrated that regardless of sex and the level of functioning, children with ASD are not participating in nearly enough physical activity. This is an area of great concern because individuals with ASD are not reaping the benefits of physical activity that could potentially mitigate the additional challenges they experience. Additionally, there are many potential negative consequences associated with living a sedentary lifestyle that will not only exacerbate their current issues, but can present them with further issues (e.g., diabetes, obesity). To address the lack of physical activity among children with ASD, physical activity first must be encouraged among this population. In doing so, the guidelines for individuals triggering the play and leisure CAP suggest determining the barriers

that are preventing the child or youth from engaging in play and leisure (Stewart & Theall, 2016). Once barriers have been determined, it is important these barriers are addressed. For example, if communication is preventing the child or youth from engaging in physical activity, it is important parents, peers, teachers are trained in the child's or youth's preferred method of communication. The guidelines further suggest educating peers who will also be engaging in the physical activity about the individual's disability and their capabilities (Stewart & Theall, 2016). In Study #4, caregivers conveyed their children were most comfortable when engaging with an adult. As such, during physical activity classes partnering the children with an adult volunteer may foster greater success. As previously mentioned, it is recommended that instructors avoid using imitation while teaching children physical activities, given the findings from Study #5. Instead, instructional efforts should be specialized to each individual, include systematic instruction, and involve the family (Iovannone et al., 2003). Finally, given the relationship between social and motor development, physical activity programs for children with ASD should consist of a social component as well. This approach has been supported and recommended by previous research (e.g., Pan, 2010; Shields, Synnot, & Barr, 2012; Zhao & Chen, 2018). A specific way in which a social element can be included in a physical activity program is to have the instructor give children five minutes to ask a total of two questions to the other children. To further promote social engagement among children with ASD, it may be worthwhile to partner the child with ASD with another child (typically developing or not) for a few minutes each class. Throughout the program, the amount of time the child with ASD spends with their adult volunteer should become less, and the amount of the time they spend with their peer partner should become more. The number of questions they are required to ask could increase as the program progresses. Through increased physical activity current issues experienced by

individuals with ASD can be minimized and future issues can be prevented, thus improving the wellbeing of individuals with ASD.

**7.1.5. The school system.** Typically, children spend most of their days at school, and therefore the school system can have a strong influence in many aspects of their lives. Unfortunately, in Study #4 it was suggested that this influence was not always positive. It is so important for the educational system to encourage social and motor development among all children, particularly those with ASD considering these domains are often compromised in children with ASD. The guidelines provided to individuals who trigger the education support CAP on the ChYMH-DD propose creating an individualized education plan (Stewart & Theall, 2016). This plan should be developed in collaboration with teachers, caregivers, educational support workers, and if applicable, the child's therapists (e.g., speech and language pathologists, physical therapists etc.). The guidelines further suggest modifications within the classroom. For example, this may require the child to wear earplugs if he/she is sensitive to loud noises (Stewart & Theall, 2016). It is important that teachers are well supported and resources to assist them in teaching children with ASD are readily available. As such, it is recommended that teachers receive education on ASD, particularly given the high prevalence of ASD, it is very likely a teacher will have one or more children with ASD in the classroom at some point in their career. To do this, lessons concerning ASD can be implemented in the curriculum taught in teachers' college. It is further suggested that workshops about ASD and strategies to foster success in children with ASD are offered throughout the school year. These workshops can be strongly recommended to teachers, particularly if teachers are teaching a student on the spectrum. Leblanc, Richardson, and Burns (2009) examined the influence of an ASD training program on teachers. The training aimed to educate the teachers of the characteristics of ASD and effective

evidence-based teaching strategies that are successful while working with children with ASD. Results indicated that after teachers completed the ASD training program, they reported improved knowledge and perceptions of ASD. Authors concluded teachers who complete such training will be able to better meet the needs of students with ASD. As well, it may be beneficial for each school board to have an ASD expert that teachers and principals can contact should they have any questions concerning children with ASD, if one is not already affiliated with the school board. Not only will these recommendations allow for teachers to be well-informed of the social differences of individuals on the spectrum, but this will allow for teachers have open discussions about differences between students and accepting these differences. It is hopeful that through the increased awareness of ASD, the other children will be more compassionate and accepting of their peers who may have this diagnosis. This will hopefully translate into less bullying among children with ASD as it was revealed in this dissertation, children with HF ASD are at high risk for being bullied. To further prevent bullying among children with ASD, bullying prevention techniques as recommended by PREVNet (2018) can be implemented. Such techniques include identifying bullying early and to support all parties involved, including the child who is doing the bullying, the child being bullied, and anyone who may have witnessed the bullying. It is also important for teachers to encourage “healthy and productive relationships” among students (PREVNet, 2018). Teachers can also encourage other students to report bullying and explain to them the different ways they can do this. Students who witness bullying can be encouraged to stand up for the individual being bullied and diffuse the situation. To do so, it is important children are taught different strategies that will allow them to stop the bullying by being assertive but without escalating the situation. This may be a difficult task for some children and therefore teachers can do ‘bullying role play’ where these strategies can be practiced (PREVNet, 2018).



By promoting successful social and motor development and implementing efforts to minimize bullying among children with ASD within the school system, it is anticipated the overall wellbeing of individuals will be improved.

## **7.2. Conclusion**

A total of five studies were conducted to investigate the overall wellbeing of individuals across the spectrum. By doing so, it has allowed for the discovery of areas in which their lives are compromised. In highlighting these areas, well-informed suggestions in how these concerns can be addressed and therefore minimized, or better yet resolved, were described. These suggestions warrant the attention of caregivers of children with ASD, medical health professionals, educators, and researchers. Through these suggestions, it is hopeful the quality of life among individuals with ASD and by extension, their family members, can be enhanced.

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