SELF-CONCEPT, BEHAVIOURAL ATTRIBUTIONS AND SELF-AWARENESS IN ADOLESCENTS WITH AUTISM SPECTRUM DISORDER: A MIXED-METHODS APPROACH

by

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Abstract

Although a modest body of literature has emerged to investigate the experiences of youth with Autism Spectrum Disorder (ASD), there is a need to better understand their experiences to guide developmentally appropriate interventions and supports. This exploratory mixed-methods project included two studies aimed at gathering information about the self-perceptions and lived experiences of adolescents with ASD. In study 1, 27 adolescents (ages 13-18) completed measures to examine their self-concept and self-perceived competence, self-awareness of ASD characteristics and behaviours, and the types of behavioural attributions and stigmatizing beliefs they ascribe to their problematic behaviours. Two comparison groups (adolescents with Attention Deficit Hyperactivity Disorder and typically developing adolescents) were used for self-concept and behavioural attribution comparisons. Study 2 comprised a smaller sub-set of 13 participants who participated in interviews designed to capture how ASD is perceived and experienced by those living with this disorder. Study 1 results suggested that adolescents with ASD have some awareness of the social, behavioural and adaptive challenges associated with their diagnosis and, as a group, hold some self-perceptions of competence and behavioural attributions that are different from those of adolescents without ASD. In Study 2, interviews were analyzed thematically to capture how adolescents talk about their diagnosis and psychosocial experiences, and how this may impact their self-concept and self-image. Four
major categories emerged: (1) self-awareness and understanding of ASD; (2) psychosocial stress; (3) social-ecological factors; and (4) sources of support. Together, these results provide insights about how they perceive themselves and their diagnosis and some of the individual, family, and school factors related to their self-perceptions and self-awareness. Results from both studies converge to provide support for a systems approach to understanding the interactions between adolescents, families, peers, school, community, and greater society when undertaking individual assessments of needs and treatment planning for ASD. Findings from the studies are discussed with respect to the positive and negative effects of awareness and knowledge about one’s diagnosis on self-perceptions and psychological adaptation. This research has important implications for clinical and educational interventions that address the unique needs and strengths of adolescents with ASD to promote positive developmental outcomes.
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CHAPTER 1

INTRODUCTION

Autism Spectrum Disorders (ASDs) are neurodevelopmental disabilities characterized by impairments in social interaction and communication, as well as repetitive and stereotyped patterns of behaviours and interests (American Psychiatric Association, 2000). Autism Spectrum Disorders include diagnoses of autism, Asperger syndrome (AS), and Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS). Although usually diagnosed in early childhood, the impairments of autism are life-long and pose ongoing social and behavioural challenges (Billstedt, Gillberg & Gillberg, 2005; Eaves & Ho, 2008; Howlin, Goode, Hutton, & Rutter, 2004; Szatmari, Bartolucci, & Bremner, 1989). Recently there has been considerable attention paid to the early years (e.g., very early detection and intervention). In contrast, relatively little research has focused on the adolescent period, particularly in terms of how adolescents with ASD adapt and adjust to this critical period of transition and identity-formation.

Several studies have examined how individuals with ASD perceive and understand others, but research examining how individuals with ASD see themselves and experience their diagnosis is limited. Much of what is currently known about the behaviours and lives of individuals with ASD comes from descriptions and reports from clinicians, researchers, family members and other professionals rather than from the individuals themselves. Thus, our understanding of the self-perceptions of adolescents with ASD remains limited.
This dissertation has been written in a manuscript format. The overarching goal of this dissertation was to make a unique contribution to knowledge about the self-perceptions and lived experiences of adolescents with ASD, by working directly with them to understand their perspective and perceptions of their own strengths and weaknesses. Chapter 2 (Study 1, using quantitative methods) examines self-concept and self-perceived competence, self-awareness of ASD characteristics and behaviours, and the types of behavioural attributions youth ascribe to their ASD symptomatology. Chapter 3 (Study 2, using qualitative methods) uniquely documents the lived experiences of adolescents with ASD and how they describe and understand their diagnosis. Chapter 4 discusses general conclusions and implications by integrating the quantitative and qualitative strands of data with a focus on the implications for clinical interventions within the family, school, and therapeutic context.

The present chapter provides a brief overview of the key constructs that are studied in this dissertation including the relevant definitions and background literature. The areas reviewed include the historical and current context of Autism Spectrum Disorders (ASD), and the constructs of self-concept, self-awareness, behavioural attributions, and diagnostic acceptance and lived experiences of individuals with ASD. Taken together, this review of the literature will highlight the unique challenges that adolescents with ASD experience. This chapter concludes with a rationale for the present research, the primary objectives of the dissertation, and a general outline of the mixed-methods design that was achieved by combining the two manuscripts.

**Autism Spectrum Disorders (ASD)**

Autism was first described by Leo Kanner (Kanner, 1943) and Hans Asperger (Asperger, 1991). For almost 70 years, research and clinical practice have increased our understanding of the symptoms associated with ASD. The concept of the autism ‘spectrum’ was initially offered
by Wing (1988, 1991) to describe a continuum of disorders varying in symptoms, severity, and prognosis. Today, Autism Spectrum Disorders (ASDs) are among the most common neurodevelopmental disorders and encompass Autistic Disorder (AD; commonly referred to as Autism), Asperger’s Disorder (commonly referred to as Asperger’s syndrome, AS), and Pervasive Developmental Disorder Not Otherwise Specified (PDD- NOS). Taken together, ASDs represent a subset of the Pervasive Developmental Disorders (PDDs) as outlined by the Diagnostic and Statistical Manual of Mental Disorders, 4th ed., text revision (DSM-IV-TR; APA, 2000). While the symptoms may differ across specific diagnoses, a diagnosis of ASD currently includes a triad of impairments in the areas of social interaction, communication, and restricted and repetitive behaviours and interests (RRBIs) as defined in the DSM-IV-TR (APA, 2000) and the International Classification of Diseases, tenth ed. (ICD-10; World Health Organization, 1992).

In order to meet criteria for a diagnosis of ASD, delays or abnormal functioning must be evident in at least one of the above areas associated with autism before the age of three years (APA, 2000). There is great heterogeneity in how the symptoms of ASD are expressed and individuals on the autism spectrum vary considerably in the degree of impairment experienced in each of the core domains. Many individuals with ASD also present with related difficulties in cognitive functioning, learning, attention, sensory processing, and comorbid mental health problems (Volkmar, Lord, Bailey, Schultz, & Klin, 2004). The causes of ASD are not known, although there is strong evidence that ASD is a genetic disorder involving multiple genes involved in prenatal and postnatal brain development (DiCicco-Bloom et al., 2006). Genetic factors increase vulnerability to ASD and account for 10-20% of cases of ASD through identifiable genetic variation (Geschwind, 2011). In high-risk samples, sibling recurrence rate
may be as high as 18% (Ozonoff et al., 2011).

Because there is no reliable biological marker for ASD, the diagnosis is made through behavioural assessments and interviews. At present, there are a number of observational measures, parent interviews and rating scales used to identify symptoms of ASD (Lord & Corsello, 2005). These measures are designed to examine and evaluate the central defining characteristics of ASD, including impairment in social reciprocity, communication, and repetitive behaviours or interests. Within the social domain, characteristics include lack of eye contact, a narrow range of directed facial expressions, and difficulties initiating social overtures or engaging in reciprocal conversation. Individuals with ASD also show delay, impairment, or an absence of communication strategies that include aspects of both nonverbal (e.g., limited use of gestures) and verbal communication (e.g., late onset of phrase speech, pronoun reversal, echolalia, or stereotyped speech). The third diagnostic domain comprises symptoms associated with restricted, repetitive behaviours and interests, and includes repetitive motor mannerisms (e.g., hand flapping), unusual sensory interests, restricted or unusual topics of interest, and difficulties with changes in routine.

Canadian epidemiological studies over the last decade suggest prevalence rates for all ASDs of approximately 90 to 120 out of 10 000 (Fombonne, 2003, 2005; Fombonne, Quirke, & Hagen, 2011); however, the most current statistics from the Centers for Disease Control and Prevention (Baio, 2012) in the United States report a rate of 1 in 88. The apparent increase in prevalence rates has been reported to reflect changes in diagnostic conceptualizations and case identification methods, as well as increased public awareness, services, and policies (Saracino, Noseworthy, Steiman, Reisinger, & Fombonne, 2010), but ongoing research aims to explore the possible role of other factors.
Among this large population of children with ASD, there is subset of higher functioning individuals who meet criteria for ‘high-functioning’ ASD (HFASD), AS, or PDD-NOS. According to the current diagnostic criteria in the DSM-IV-TR, a diagnosis of autism (AD) requires all three features of ASD, while a diagnosis of AS requires only impairment in reciprocal social interaction and the presence of repetitive behaviours. A PDD-NOS diagnosis implies that an individual has features of ASD, but does not meet full diagnostic criteria for AD or AS. HFASD and AS are both characterized by impairments in social interactions and restricted, repetitive, and stereotypic patterns of behaviours and interests, but differ in regard to language development. Individuals with AS achieve typical language milestones, such as using single non-echoed words by age 2 years and using communicative phrases by 3 years (DSM-IV-TR, APA 2000). For the purpose of this dissertation, the term autism spectrum disorder (ASD) is used to describe individuals with HFASD, AS or PDD-NOS with intellectual functioning above 80. HFASD or AS will be referred to separately in the literature review if specified in the relevant research studies.

The next edition of the DSM has been drafted and the diagnostic subcategories from the DSM-IV-TR will be removed to form one-dimensional category. ASD definitions in the proposed DSM-5 and ICD-11 will contain two domains, social communication/social interaction and restricted, repetitive behaviours and interests, rather than the previous three dimensions (http://www.DSM5.org; APA, 2012). Some of these proposed changes have resulted from factor analytic studies that have shown one social-communication factor (Gotham, Risi, Pickles & Lord, 2007). Researchers believe the new DSM-5 criteria will avoid some of the existing diagnostic confusion and provide a more specific framework to guide diagnosis, estimation of prevalence, treatment planning and research (Mahjouri & Lord, 2012).
Although usually diagnosed in early childhood, the impairments of ASD are life-long and pose ongoing social and behavioural challenges (Billstedt et al., 2005; Eaves & Ho, 2008; Howlin, Goode, Hutton, & Rutter, 2004; Szatmari et al., 1989). As reviewed by Seltzer, Shattuck, Abbeduto and Greenberg (2004), individuals with ASD display heterogeneity in the extent to which they manifest core behavioural symptoms of ASD. Yet, it is important to recognize that although modest improvement is seen for all behaviours, ASD is a lifelong pervasive disorder and the difficulties can continue into adulthood (Seltzer et al., 2004; Shattuck et al., 2007).

*Developmental Considerations in Adolescence*

Adolescence can be a particularly difficult developmental stage for any individual due to hormonal and physical changes, increased demands to develop new relationships with peers, including romantic relationships, emotional independence from parents, and struggles to develop healthy individual and group identity. In addition, adolescents are faced with several developmental tasks that include self-identity formation, self-reflection, and evaluation of life experiences, as well as increased autonomy. Many of these developmental tasks are dependent on skills that are often fundamentally challenging for individuals with ASD, such as social competence, social cognition, language abilities, emotion decoding, perspective taking, cognitive flexibility, and abstract reasoning skills. This makes the transition into adolescence inherently more difficult for individuals with ASD (Brent, Rios, Happé & Charman, 2004; Capps, Yirmiya, & Sigman, 1992; Hale & Tager-Flusberg, 2005; Klinger & Renner, 2000; Ozonoff & Griffith, 2000). The importance of adolescent research in ASD is underscored by the well-documented significant adjustment problems in adolescents with ASD, such as anxiety, depression and suicidal ideation (Barnhill & Smith-Myles, 2001; Ghaziuddin, Weidmer-Mikhail & Ghaziuddin,
As adolescents transition to middle school and high school, peer networks, close friendships, and dating relationships increase in intensity and importance, and become a source of social support, contributing to adolescent self-concept and well-being (La Greca & Harrison, 2005). Acceptance by peers is a component of adolescent self-identity and influences psychosocial adjustment (Harter, 1997). Adjustment and interpersonal competence in adolescence often relies on intimate and reciprocal exchanges (Buhrmester, 1990; see review in Hartup, 1993). This can be particularly challenging for adolescents with ASD due to their pronounced social difficulties with developing and maintaining peer relationships (APA, 2000). The current knowledge on the nature and quality of social and romantic functioning among adolescents and young adults with ASD is limited. It is, however, not surprising that individuals with ASD have been shown to have fewer friendships and poorer friendship quality than typically developing peers (Chamberlain, Kasari & Rotheram-Fuller, 2007; Locke, Ishijima, Kasari & London, 2010; Mazurek & Kanne, 2010). Individuals with ASD typically desire peer approval (Williamson, Craig and Slinger, 2010) or social involvement and show some awareness when their desires are not met (Lasgaard, Neilsen, Eriken & Gossens, 2010). There have also been several studies demonstrating that they report more loneliness (Bauminger et al, 2003; Locke et al, 2010; Whitehouse, Durkin, Jaquet & Ziatas, 2009) than typically developing peers. The personal accounts of adolescents and young adults with ASD have highlighted their desire for friends and their experience of loneliness and not fitting in (Carrington & Graham, 2001;
Howard, Cohn, & Orsmond, 2006; Jackson, 2002; Jones & Meldal, 2001; Molloy & Vasil, 2004; Portway & Johnson, 2003). To add to these social difficulties, children and adolescents with ASD are also more likely to be bullied by peers (Cappadocia, Weiss & Pepler, 2012; Humphrey & Symes, 2010; Little 2002; Shtayermman 2007, 2009; Van Roekel, Scholte & Didden, 2010).

Romantic relationships have been found to be more challenging and infrequent for young adults with ASD than other social relationships (Green et al., 2000; Jennes-Coussens, Magill-Evans, & Koning 2006). Like their typically developing peers, many individuals with ASD desire intimate relationships, but they typically do not have the appropriate skills and knowledge to initiate relationships, and as such, are more likely to engage in inappropriate or intrusive social and romantic relationship behaviours (Stokes & Kuar, 2005; Stokes, Newton & Kuar, 2007; Ruble & Dalrymple, 1993). While most of these studies rely on parent or caregiver report, one notable exception was a study by Mehzabin and Stokes (2011), which drew directly on insights directly from individuals with ASD. Young adults with ASD reported fewer sexual experiences and less sex education, and expressed higher levels of concern about future relationships than typically developing young adults. Specifically, concerns were expressed regarding possible misinterpretations of their behaviour as sexual and about finding a future life partner. Overall, the literature has shown that, as a group, individuals with ASD have an interest in intimate relationships and sexual experiences, but their poor social and communication skills have a negative impact on their success with developing and maintaining appropriate intimate relationships.

Another relevant developmental task for adolescents is finding and maintaining employment. Many adolescents begin to work part-time jobs and their sense of competence in employment situations becomes a new domain of self-evaluation. While there is limited research
focusing on the vocational needs of adolescents and young adults with ASD, Gerhardt and Lainer (2011) recently reported how the needs of individuals with ASD for support in obtaining employment and for succeeding in the workplace far exceed the available resources. Current research suggests that deficits in social and communication skills interfere with job attainment and retention for adults with ASD (Higgins, Koch, Boughfman & Vierstra, 2008). A handful of studies have reported on the low rate of employment (i.e., 4-17%) among individuals with ASD during the transition to adulthood (Eaves & Ho, 2008; Howlin, 2004; Taylor & Seltzer, 2011). Taylor and Seltzer (2011) found that less than a quarter of young adults with ASD without intellectual disabilities received some employment or vocational services (e.g., supported employment, sheltered workshop) when compared to young adults with intellectual delays. The researchers commented on the inadequacy of the current service system to accommodate the needs of higher functioning individuals with ASD in order to help them develop their independence and achieve sustainable careers. Shattuck et al. (2012) reported that more than half of the youth with ASD in their study who left high school within the past two years had not participated in employment or additional educational opportunities. Their results revealed that youth with ASD had the lowest rates of participation in employment compared to youth with other disabilities. Together, these studies suggest that further research and intervention programs are needed to understand individual vocational needs and to develop better transition programs to facilitate optimal vocational and post-secondary outcomes.

Self-Concept and Perceived Competence

Self-concept is broadly defined as a person’s perceptions of oneself. Perceptions are formed through experience with and interpretations of one’s environment (Marsh & Shavelson, 1985). There is a general consensus that self-concept is a multidimensional construct (Harter,
The cognitive-developmental perspective of self-concept suggests that as children age, their self-perceptions move from global and undifferentiated to well-differentiated and hierarchically integrated (Harter, 1999). Self-concept is generally measured by self-report using individuals’ self-evaluations and descriptions to determine self-concept scores. At the point of being well differentiated, individuals may have high perceived competence in one domain while displaying low perceived competence in another (Harter, 1982). An examination of domain-specific perceived competence scores, as well as overall self-concept, provides a comprehensive picture of how an individual, or members of a group, see themselves. Supplemental to “global” self-concept, Harter (1985, 1988) identifies the following areas of perceived competence for children and adolescents: academic, appearance, athletic, behavioural, and social. Adolescent domains also include close friendship, job competence, and romantic appeal. The terms self-concept and self-perception are often used interchangeably to denote one’s perceptions in domain-specific areas, whereas self-esteem or global self-worth denote perceptions of one’s overall sense of well-being (Zeleke, 2004).

A few published studies have examined self-perceived competencies in children and adolescents with ASD using Harter’s self-perception scales. Capps, Sigman, and Yirmiya (1995) used an early version of Harter’s self-perception scale for children, the *Perceived Competence Scale for Children* (Harter, 1982), with 18 children and adolescents with ASD (9-16 years) and a typically developing group. They found that children and youth with ASD generally had low self-perceived competence of their social abilities, physical appearance, and global self-worth when compared to typically developing peers. Notably, participants with higher intellectual abilities saw themselves as less socially competent, suggesting that cognitive ability may affect how accurately individuals see themselves. Vickerstaff, Heriot, Wong, Lopes and Dossetor
(2007) investigated self-perceived social competence on the *Self Perception Profile for Children* (SPPC; Harter, 1985) in 22 children with high functioning ASD (7-13 years). They also found a significant negative association between self-perceived social competence and age and intellectual ability. Low self-perceived social competence was also found to be a significant predictor of high levels of self-reported depressive symptomatology among children with HFASD. Finally, Williamson et al. (2008) compared self-concept in 19 children and adolescents with Asperger syndrome (AS; 11-15 years) and typically developing peers. Consistent with Capps et al., Williamson et al. reported lower self-perceived competence in social and athletic domains in the participants with AS. No differences were found for self-perceived competence of physical appearance, scholastic competence, or behavioural conduct. The study also highlighted the importance of peer and parental approval as a predictor of depressive symptoms. The adolescents with AS perceived less peer approval than typically developing peers, but placed as much emphasis on the importance of peer and parental approval as their peers. In their sample, approval rather than competencies were predictive of depression among participants with AS.

Quality of life studies have also suggested similar areas of perceived difficulties in ASD. Consistent with Capps et al., Shipman, Sheldrick and Perrin (2011) found that adolescents with ASD scored lower on the social and physical functioning domains of a paediatric quality of life measure, as well as on emotional and school functioning domains. Jennes-Coussens, Magill-Evans, and Koning (2006) also found that young adults with AS reported significantly lower social and physical quality of life when compared to typically developing young adults.

Overall, self-perception studies have consistently shown that children and adolescents with ASD report significantly lower self-perceived social competency, whereas findings in other domains, such as perceptions of physical appearance, athletic abilities, and overall global self-
worth, are inconsistent. Many of these studies have used the Self-Perception Profile for Children, but no studies to date have used the *Self-Perception Profile for Adolescents* (SPPA; Harter, 1988) with the ASD population. Although there is considerable overlap across the child and adolescent versions for the six common domains, other developmentally relevant competency areas, including close friendship, romantic appeal, and job competence, can only be examined with the adolescent version. These areas are important for the transition from adolescence to young adulthood and are likely to yield additional insights into the adolescent experience for youth with ASD.

**Self-Awareness**

Many studies examining self-awareness deficits in ASD use the terms ‘self-awareness’ and ‘insight’ interchangeably. It is important, however, to recognize that awareness and insight are conceptually separable terms, and as such, require different methods of investigation (Markova & Berious, 2011). In the present study, ‘awareness’ is defined as an individual’s *knowledge* that they have a symptom or some form of impairment, whereas ‘insight’ incorporates the individual’s *understanding* of the causes and impacts of the symptom or impairment.

As children progress through to adolescence, there is a gradual shift in their focus from behavioural or physical attributes to psychological or personality attributes (Damon & Hart, 1992). Given the inherent social communication and perspective-taking deficits in individuals with ASD, the development of self-awareness and self-understanding, and the increased emphasis on social and psychological features of the self may be more difficult. In support of this view, Lee and Hobson (1998) found that adolescents with ASD had more restricted ranges of emotions when talking about themselves and were less likely to anchor their attributes in social activities and relations when compared to developmentally delayed individuals without autism.
Jackson, Skirrow and Hare (2011) found a similar pattern among a small subset of adult males with AS (19-63 years) that were compared to a neurotypical control group. These studies suggest that individuals with ASD may have selective impairments in certain aspects of self-awareness, rather than in global self-awareness, since they were equally able to describe themselves in physical, active, and psychological terms relative to controls. Both Kanner (1973) and Wing (1981) have suggested that among individuals with ASD, an ability to perceive differences and develop strategies to cope with those difficulties may be an important predictor of outcome. As individuals with ASD become more aware of differences between themselves and others, they begin to display efforts to change (Kanner, 1971). Self-awareness and understanding in individuals with ASD have been difficult to study empirically because of their theory of mind and perspective-taking difficulties (Baron-Cohen, 2000; Frith, Happe, & Siddons 1994).

Attwood (2006) suggests that the realization of being different from other children usually occurs between 6 to 8 years of age in children with ASD. Although this range has not been formally tested, these ages are consistent with Damon and Hart’s (1992) second level of self-concept development in which school age children use comparative assessments of their understanding of the self. Clinical accounts, like the one highlighted below, also shed light on how this realization may manifest in individuals with ASD.

*Here is one of my most vivid memories of school: I am standing in a corner of the playground as usual, as far away as possible from people who might bump into me or shout, gazing into the sky and absorbed in my own thoughts. I am eight or nine years old and I have begun to realize that I am different in some nameless but all-pervasive way.*
I don’t understand the children around me. They frighten me and confuse me. They don’t want to talk about things that are interesting. I used to think that they were silly, but now I am beginning to understand that I am the one who is all wrong (Sainsbury, 2009, p. 25).

Understanding the nature and extent of a disorder is an important component of accepting the disorder and experiencing more positive outcomes. The association between self-awareness or insight and outcome has been well documented among individuals with neurological and mental health disabilities (e.g., learning disabilities, schizophrenia; obsessive compulsive disorder, traumatic brain injuries) and self-awareness has been found to have an effect on treatment compliance and long-term outcome (Davidson, 2003; Davidson & Strauss, 1992; Eisen et al., 2001; Goldberg, Higgins, Raskind & Herman, 2003; Raskind, Goldberg, Higgins & Herman, 1999; Schwartz, Cohen & Grubaugh, 1997; Storch et al., 2008).

The most common method used to evaluate self-awareness in ASD studies compares adolescents’ self-ratings of their functioning with another measure considered to be more objective (i.e., parent ratings, actual performance on tasks). The general consensus of these studies is that individuals with ASD have some awareness of their difficulties and are able to participate and complete self-report measures. Despite some evidence of awareness and symptom acknowledgement, many studies report systematic differences between parent- and self-report ratings. Significant discrepancies between parent and child/adolescent report have been found on measures of social competence (Chamberlain et al., 2007; Knott, Dunlop & Mackay, 2006; Koning & Magill-Evans, 2001; Lerner, Calhoun, Mikami & De Los Reyes, 2012; Smith-Myles et al., 2007), emotional and behavioural functioning (Hurtig et al., 2009; Mazefsky, Kao & Oswald, 2011; Smith-Myles et al., 2007; Vickerstaff, Heriot, Wong, Lopes, & Dessetor, 2007), and quality of life (Shipman, Sheldrick & Perrin, 2011). Results from these investigations
suggest low levels of awareness or even denial by individuals with ASD, based on higher
behaviour or symptom ratings by parents than by the individuals themselves. Only a few studies
have demonstrated concordance between parent and adolescent reports on measures of anxiety
and behavioural problems, and more specifically among their ratings of somatic, social, and
externalizing problems (Farrugia & Hudson, 2006; Hurtig et al., 2009).

There are two validated self-administered scales used to measure ASD symptoms in
adults: the Autism Spectrum Quotient (AQ, Baron-Cohen et al., 2001) and the Ritvo Autism and
Asperger Diagnostic Scale (RAADS, Ritvo et al., 2008). A small number of studies have
examined the suitability of self-report symptom measures for individuals with ASD. Johnson,
Filliter and Murphy (2009) suggested a need for an appraisal of an individuals’ self-awareness
before self-report tools are considered a reliable means for measuring symptoms and level of
functioning.

A few studies have explored self-perceptions of an ASD diagnosis and symptomatology.
In a study examining psychosocial functioning in male adolescents with AS (11-19 years), a
large majority of participants were judged by an interviewer to have relatively poor insight into
their diagnosis (Green et al., 2000). One third of the sample was reported to display a complete
lack of insight, as they were unable to provide any description of their diagnosis and associated
difficulties.

In another study of self-awareness, Johnson et al. (2009) examined how children and
adolescents with ASD (9-18 years) perceive their autism-related traits and behaviours relative to
how their parents perceive them. They used three different measures to characterize traits
associated with ASD in adults: Autism Spectrum Quotient (AQ, Baron-Cohen et al., 2001),
Systemizing Quotient (SQ, Baron-Cohen et al., 2003), and the Empathy Quotient (EQ, Baron-
Cohen & Wheelwright, 2004). Youth with ASD had some awareness of their expression of autistic and empathic traits, but they rated themselves as having fewer autistic features and more empathic traits than indicated by their parents’ ratings. There were no differences between self and parent-ratings for a matched control group. Scores on the SQ, which measures the degree to which individuals are interested in constructing and analyzing systems, did not differ between adolescents and parents. Interpretations of the findings from the SQ were made with caution, due to a possible relationship with age and intellectual functioning. These measures were also originally developed with adult samples and not empirically tested on child and adolescent participants. Overall, this study supports the notion that children and adolescents have some limitations in their self-awareness of autism-related traits, but that their self-awareness is not uniformly impaired for all behaviours and traits.

Cederlund, Hagberg, and Gillberg, (2010) used several questions from a semi-structured investigator-based diagnostic interview (Asperger Syndrome Diagnostic Interview, ASDI; Gillberg, Gillberg, Rastam, & Wentz, 2001) to examine how adolescent and adult males with AS (16-36 years) regard themselves, and to what extent their parents agree with their perceptions. The results revealed some agreement between adolescents and parents on features of AS (e.g., problems making friends, socially/emotionally inappropriate behaviour, imposition of routines/rituals on self, and imposition of routines/rituals on others), whereas parents rated their children as having greater impairments in their social competence, the ability to read social cues, and narrow interests. Based on the latter findings, researchers concluded that the corresponding items might be more challenging for individuals with AS to objectively evaluate.

More recently, Bishop and Seltzer (2012) examined self-reported autism symptoms in a community sample of adults with ASD (18-52 years) using the AQ. Total self-report scores on
the AQ were found to be substantially lower than the scores reported in the original validation study, with only 17% meeting the diagnostic cut-off and 37% meeting the screening cut-off. Additional analysis revealed that scores on the Communication and Social Skill subscales were significantly lower (i.e., rated as being less impaired) than scores on the Attention Switching and Attention to Detail subscales, indicating that adults with ASD may have a particular difficulty recognizing their social and communication challenges. The researchers also included adults with below average intelligence (i.e., IQ below 85) to evaluate the effect of intellectual functioning. Adults with higher intellectual functioning tended to endorse more symptoms of ASD. Maternal reports about their child’s current and past ASD behaviours were also collected. Contrary to low scores on the self-rated adult AQ, overall maternal reports suggested significant social-communication difficulties.

It has been unclear whether discrepant self-evaluations in individuals with ASD are reflective of distortions in how they process and understand information or if they serve a self-protective function (Barnhill et al., 2000). Johnson et al. (2009) suggested that children and adolescents might be prone to a positive illusory bias with regard to autism-related symptoms, and Lerner, Mikami and Levine (2011) found partial support for the self-protective model in youth with high-functioning ASD. Positive illusory bias (PIB) is operationally defined as the difference between a person’s self-perceptions of their abilities and their actual abilities wherein the individual’s self-perceptions are more positive than their actual abilities (Hoza, Pelham, Dobbs, Owens & Pillow, 2002). Researchers working with children and adolescents with ADHD have reported robust findings of PIB as evidenced in overestimations of their competence (Evangelista, Owens, Golden & Pelham, 2008; Hoza et al., 2002, 2004; Owens, Goldfine, Evangelista, Hoza & Kaiser, 2007; Owens & Hoza, 2003). Adaptive factors (i.e., those
promoting self-esteem, motivation and task persistence) and maladaptive factors (i.e., those contributing to resistance to treatment by decreasing processing of negative feedback or recognition of the need to improve behaviour) of PIB have been reported in the literature involving individuals with ADHD (Mikami, Szwedo, Allen, Evans, & Hare, 2010; Owens et al., 2007), learning disabilities (Heath & Glen, 2005) and typically developing individuals (Taylor & Brown, 1988). The literature on PIB, however, has predominantly focused on the overestimation of competence rather than on underestimations of atypical behaviours and symptoms.

As described above, self-awareness has been shown to impact treatment compliance and long-term outcome in other populations. Very little is known, however, about the relationship between self-awareness and outcomes among individuals with ASD. Verhoeven et al. (2011) explored the relationship between self-awareness and treatment outcome in adolescents with ASD, concluding that better self-awareness prior to treatment was associated with an increase in social functioning during treatment and a decrease in parent-reported problems of daily functioning. Interestingly, while parents reported better outcomes in adolescents with improved self-awareness, the participants were more likely to report an increase in problems of daily functioning and psychological problems one year after treatment. The authors suggested that better self-awareness likely resulted in more realistic self-perceptions.

Although increased awareness can positively impact treatment outcomes, self-awareness of one’s own difficulties can also lead to distress and frustration. Several studies have highlighted a negative relationship between social self-awareness and negative mood or depressive symptomatology in individuals with ASD (Butzer & Konstantareas 2003; Capps et al., 1995; Hedley & Young, 2006; Vickerstaff et al, 2007; Wing, 1981). Age and intellectual functioning have also been reported as vulnerability factors for frustration and depressive
symptoms (Capps et al., 1995; Ghaziuddin, Ghaziuddin & Greden (2002); Lainhart, 1999; Sterling, Dawson, Estes & Greenson, 2008). More research is needed to understand these associations between self-awareness of ASD symptoms and the presence of symptoms of internalizing disorders. Other factors, such as reduced motivation, repeated rejection, negative beliefs and attributions, may contribute to poor psychosocial adjustment.

**Behavioural Attributions**

Ultimately, the sense of being different from others can lead to low self-esteem, contributing to anxiety, mood disorders, and lack of direction (Palombo, 1991). Given the high incidence of adjustment problems in adolescents with ASD, researchers have examined the relationship between how these individuals process social information about themselves and others and their psychosocial functioning (Flood, Hare & Wallis, 2011; Hedley & Young, 2006; Meyer, Mundy, van Hecke & Durocher, 2006). Studies have demonstrated that adolescents with ASD or AS are more likely to display cognitive thinking errors (Barnhill, 2001) and delusional beliefs (Abell & Hare, 2005) that may impact how they interpret social situations.

Although some studies have begun to look at cognitive thinking errors in individuals with ASD, there is a need for more research about how they understand, accept, and appreciate their differences and how that information can impact interventions addressing beliefs and thinking styles (e.g., reattribution training, cognitive restructuring). One approach to quantifying and understanding an individual’s adaptive and maladaptive ways of thinking about oneself is to examine attributions. Attribution theory suggests that individuals’ attributions (i.e., their explanations of their actions, successes, and failures) are associated with motivation, affect, performance, and expectations for future outcomes (Weiner, 1985). This theory focuses on controllability (an event is viewed as either within or outside an individual’s control), stability
(viewed as stable or unstable/variable over time), globality (viewed as occurring in all situations versus only in specific situations), and locus of causality (viewed as either internally or externally caused). According to Weiner (1994), individuals who view their negative behaviours and characteristics as uncontrollable and pervasive are unlikely to feel that they can change and therefore would not be motivated to put effort into changing. Weiner, Perry and Magnusson (1988) expanded on this attribution theory to include stigma (i.e., the view that a specific deviation in physical attributes, character, or behaviour is undesirable). Perceived causes of stigma determine affective responses (e.g., pity or anger) towards the stigmatized person (Weiner et al., 1988).

Current research on the attributions of children with ADHD and learning disorders provide insight into the importance of these constructs (Collett & Gimpel, 2004; Hoza et al., 2001; Johnston & Lee, 2005; Kaidar, Wiener & Tannock, 2003; Pelham, Waschbusch, Hoza, Pillow & Gnagy, 2001; Wiener et al., 2012). Children with ADHD have been reported to view their most problematic behaviour as less within their control and more global across situations when compared to matched controls (Kaidar et al., 2003; Wiener et al., 2012). Children with ADHD also perceive stigmatization and this perception is associated with low behavioural self-concept and self-esteem (Wiener et al., 2012). Among children with learning disabilities, those who viewed their learning disability as delimiting, malleable, and nonstigmatizing experienced fewer achievement problems, had higher self-perceptions of their abilities and academic competence, and felt more socially accepted (Rothman & Cosden, 1995).

To date, there has been one study in the ASD literature that used Weiner’s (1985) framework to examine the attributions made by mothers about their children’s ASD diagnosis (Dale, Jahoda & Knott, 2006). The findings suggested that mothers of children with ASD make a
diverse and complex range of attributions about their children’s diagnosis that are consistent with Wiener’s dimensions of locus of cause, stability, and controllability. The authors suggested that studying attributions enables better understanding and decision-making by parents. Similarly, it is important to explore the attributions of adolescents with ASD themselves, as this will provide a deeper understanding of their motivation, affect, performance, and expectations for future outcomes. Research investigating the degree to which adolescents with ASD are aware of their problematic behaviours and strengths, and the degree to which they believe their behaviours are controllable, pervasive, internally caused and stigmatizing can have important implications for clinical practice, program planning and intervention.

Very few studies have examined attributional style in individuals with ASD, and within this body of work the methodology and results have varied. Some studies have found no evidence of differences in attributional style between individuals with AS and a typically developing group (Blackshaw, Kinderman, Hare & Hatton, 2001) or a clinical control group with schizophrenia (Craig, Hatton, Craig & Bentall, 2004). These studies included some adolescents and mostly adults (15-40 years) with AS. Other studies demonstrated differences in general attributional style. Barnhill and Smith Myles (2001) used the Children’s Attributional Style Questionnaire (CASQ; Seligman et al., 1984) to measure attributional style (internal/external, stable/unstable, and global/specific), and found that one third of the adolescents with ASD (12-17 years) obtained scores on the CASQ that were suggestive of a pessimistic, failure-prone style. No comparison group was used for this study. The researchers also found a significant relationship between attributional style and depression, such that participants with more self-reported depressive symptoms were more likely to blame themselves for negative events or outcomes, to consider the cause of the event to be consistent over time, and to generalize the
cause across situations. Using the same attribution questionnaire, Flood et al. (2011) found that adolescents with AS (11-15 years) were more likely than typically developing peers to endorse global explanations for negative social situations; the other attributional domains (internal/external, stable/unstable) were not significantly different. Each of these studies has measured attributional style by having participants respond to questions about a hypothetical scenario, rather than a real-life event or situation. The current study addresses this gap by measuring attributions for self-identified problem behaviours.

Research on perceptions of stigma among individuals with ASD is also sparse. Ruiz Calzada, Pistrand and Mandy (2012) qualitatively reported that children and adolescents with ASD study described fears of peer stigmatization and being perceived as “not normal”. They highlighted the importance of countering the effects of stigma through psychoeducational programs designed to help individuals with ASD integrate their diagnosis in a positive and constructive way and to better educate peers. A high level of peer victimization has also been reported in a small sample of adolescents and young adults with AS (Shtayermman, 2007, 2009), in which ASD symptomatology was negatively correlated with victimization reports. The author concluded that higher functioning individuals are at greater risk for victimization because they receive less attention from teachers. School age children have also been found to display negative attitudes and behavioural intentions towards videos of peers with autism (Campbell, Ferguson, Herzinger, Jackson & Marino, 2004; Swaim & Morgan, 2001). Butler and Gillis (2011) examined the impact of labels and behaviours on the stigmatization of adults with Asperger syndrome. Their study revealed that it is the atypical behaviours associated with Asperger syndrome that influence stigmatizing attitudes and not the label of the disorder. More
information is needed to determine if there are certain behaviours or characteristics that lead to greater stigmatization.

**Diagnosis Acceptance and Lived Experiences of Individuals with ASD**

As discussed in previous sections, research has acknowledged some of the social, academic, vocational, and psychosocial difficulties associated with ASD in adolescence; however, the psychological impact of the diagnosis from the adolescents’ perspective is not well understood. Research on the impact of receiving and learning about a diagnosis in childhood and adolescence has often been limited to physical disorders and medical diseases (e.g., HIV, diabetes, cancer). Much of the current research emphasizes the benefits of open illness-related communication between patients, parents, and professionals (Wiener, Mellins, Marhefka & Battles, 2007; Young, Dixon-Woods, Windridge & Heney, 2003). In many cases, open communication has been found to improve children’s psychological adjustment (Katz & Jay, 1984). However, very little has been written about disclosure of an ASD diagnosis to children and adolescents. Clinically, there are some resources and workbooks that provide parents and professionals with information and tools to talk about ASD with them (Attwood, 2004; Gray, 1993; Faherty, 2000; Vermeulen, 2001). Additional autobiographical accounts by individuals with ASD provide insight into individual awareness of ASD, the benefits of diagnosis disclosure, and open communication in families (Grandin, 2012; Jackson, 2002). However, no empirical studies to date have examined the process of informing individuals with ASD about their diagnosis.

Children’s understanding of illness emerges from their experiences with a particular condition, their general reasoning abilities, and external influences, such as parental beliefs (McMenamy & Perrin, 2008; Sigelman, 1995). In a study of adults with learning disabilities,
McNulty (2003) concluded that how individuals come to understand and accept their disability was often dependent on the quality of explanations they received about their diagnosis. Exploration of adolescent conceptions of ASD may reveal how adolescents construct a sense of understanding about their life experiences.

The literature discusses two types of models used to explain ASD. Biomedical models of ASD view it as a neurodevelopmental disorder with neurological and genetic aetiologies. This type of explanation is the most common and is used in the current medical classification systems of ASD (e.g., DSM-IV-TR, ICD-10). The alternative conceptualization of ASD is aligned with the social model of disability (Oliver, 1990). Social theorists argue that ASD is socially constructed because society views ASD behaviours as abnormal (Molloy & Vasil, 2002, 2004). Molloy and Vasil (2002) have critiqued biomedical models of ASD because a child’s behaviour is viewed as symptoms of ASD, rather than expressions of a unique personality. Within this model, ASD is viewed as a differing cognitive style, rather than a disorder. Some researchers have discussed the stigmatizing potential of the ASD label and propose that ‘disorders’ be replaced with ‘conditions’ (i.e., Autism Spectrum Conditions or ASC; Baron-Cohen et al., 2009) or that ASD should be viewed as a ‘normal personality variant’ (Frith, 1991).

There is a growing body of research into parental experiences of having a child with ASD and perceptions of the process of diagnosis, yet the research from an individual’s perspective of their own ASD is still limited. Parents often react differently pre and post diagnosis before reaching a final stage of acceptance and adaptation (Mansell & Morris, 2004; Russell & Norwich, 2012). Parents have also been found to reconstruct ASD in a more “positive light” following a period of acceptance and adjustment to the diagnosis (Russell & Norwich, 2012). Many of these parents took proactive roles to de-stigmatize and recruit others to view ASD more
positively. Although these parents accepted and used a biomedical understanding of ASD by recognizing neurological differences in the brain, many went on to recast ASD with “different” and “valuable” narratives. Parental understandings were said to reflect both biomedical (e.g., neurological differences) and social models of disability (e.g., lessening societal disablement). Russell and Norwich concluded that parents were more likely to “adopt whatever discourse is required to secure the best outcome as they see it”. Other studies have concluded that biomedical explanations enabled parents to positively reconstruct their views of their child’s diagnosis in order to make sense of ASD and to facilitate their ability to reduce and cope with stigmatization experiences (Gray, 1993, 2002; Farrugia, 2009). The extent to which biomedical or social constructionist explanations directly impact how individuals with ASD understand, cope with, and accept their diagnosis is not entirely clear. The remaining section describes the current literature that has documented how individuals with ASD learn about their diagnosis and the implications for diagnosis acceptance and supports.

Acceptance, or the ability to adapt to the demands and limitations of a chronic health condition, has been found to play a protective role in the psychological functioning of adolescents (Casier et al., 2008) and adults (McCracken, 1998; McCracken & Eccelston, 2005) with medical conditions. More specifically, Casier et al. concluded that learning to accept a disease should be an important focus in the treatment of adolescents with cystic fibrosis. Acceptance-based interventions have been proven to be effective for some chronic health conditions in children and adolescents (Masuda, Cohen, Wicksell, Kemani & Johnson, 2011; Wicksell, Melin, Lekander & Olsson, 2009) and for parents of children with autism (Blackledge & Hayes, 2006). In addition, self-esteem and social and family support have been found to play important roles in adjustment to disability (Li & Moore, 1998).
Although much of the work on disability acceptance has focused on chronic health problems or conditions, there has been some research on acceptance among individuals with learning disabilities. Cosden, Brown and Elliot (2002) suggested that as children with learning disabilities transition into adolescence, their self-understanding and awareness of their differences leads into the process of self-acceptance. More specifically, they speculated that adolescents “are able to hold on to a self-perception that includes strengths and weaknesses without denying their disability, exaggerating their skills, or becoming overwhelmed by their academic problems” (p. 44). These researchers also suggested that, with time, adolescents become more knowledgeable about their disability because of their informal discussions with others or through personal experiences related to their disability. They also indicated that the developmental process of self-understanding among individuals with learning disabilities is guided by the individuals’ interactions with family members, school personnel, and friends. They stressed the importance of the “availability of significant others” with whom children and adolescents can discuss their disability.

The process of self-understanding and acceptance was highlighted in Higgins, Raskind, Goldberg and Herman’s (2002) five stages to acceptance of a learning disability. This study involved a 20-year longitudinal follow-up of 41 students with learning disabilities to examine how they came to terms with their diagnosis and the social or emotional impact of being labelled. Through a longitudinal design and ethnographic analysis of the interviews, the researchers developed a model of acceptance for individuals with learning disabilities. The five stages included: (a) a period of awareness of differences; (b) the labeling event; (c) a period of understanding the limiting nature of this learning disability and negotiation with service providers for assistance; (d) compartmentalization of the learning disability; and (e)
transformation or reframing of the negative attitudes towards their learning disability and an appreciation of the positive influence on their lives and character. There was no specific information in the study to indicate whether all individuals with learning disabilities pass through each stage. Further studies from this research team have suggested that self-awareness, the ability to compartmentalize the diagnosis, and acknowledge strengths and weaknesses is an important protective factor among successful individuals with learning disabilities (Goldberg et al., 2003).

In addition to learning disabilities, the literature has described a process of adjustment in individuals with ADHD. Qualitative research by Young, Bramham, Gray and Rose (2008) documented a six stage model of psychological acceptance for a diagnosis of ADHD in adults: (a) relief and elation, (b) confusion and emotional turmoil, (c) anger, (d) sadness and grief, (e) anxiety, and (f) accommodation and acceptance. This model was found to be similar to the clinical literature that describes ADHD acceptance among adults (e.g., relief and optimism, denial, anger and resentment, grief, mobilization, and accommodation; Murphy, 1995).

It is not clear if individuals with ASD have similar experiences when they learn about their diagnosis. Although clinical accounts and qualitative studies have begun to generate a better understanding of how individuals with ASD perceive and understand their diagnosis, more studies are needed to document their process of self-understanding and psychological acceptance. Most of the literature and research about ASD is from the professional or parent perspective. To date, there have been a handful of studies reporting on the perceptions and experiences of adolescents and young adults with ASD (Carrington & Graham, 2001; Howard et al, 2006; Huws & Jones, 2008; Molloy & Vasil, 2004). Several studies have also described the perceptions of adults with AS who have reflected back on their life experiences with their
diagnosis (Griffith, Totsika, Nash & Hastings, 2011; Hurlbutt & Chalmers, 2002, 2004; Muller, Schuler, Burton & Yates, 2003; Muller, Schuler & Yates, 2008; Punshon, Skirrow & Murphy, 2009). Most of these studies have included open-ended interview questions in their design. Specific details and themes of the studies will be described in more detail below.

Many of the studies document individuals’ experiences with feeling different. Some qualitative studies and clinical literature suggest that individuals with ASD develop inappropriate compensatory reactions (e.g., reactive depression, self-blame, denial, arrogance, imitation, masquerading) as a response to their realization that they are different (Attwood, 2006; Carrington & Graham, 2001). Humphrey and Lewis (2008) identified two groups from a sample of 20 students with ASD (11-17 years) in mainstream schools whose qualitative descriptions of themselves and their diagnosis were characterized by either negative narratives (e.g., ‘being different’ or ‘not normal’) or an acceptance of their diagnosis and celebration of their differences from typically developing peers. Using an interpretive phenomenological framework, the researchers used semi-structured interviews, diaries and drawings to explore the perspectives and experiences of participants in the context in which they occurred. It was also noted that some participants gave both types of responses, which may have reflected their struggles to come to terms with their diagnosis.

Molloy and Vasil (2004) examined the direct impact of a diagnosis of AS by conducting in-depth biographical interviews to create life stories. The stories were compiled into a book but were not published in a peer-reviewed journal. The authors described six key themes that emerged from their description of life stories of six adolescents with AS (12-18 years) and their families. These themes included diagnosis as a sense-making narrative, labeling and identification, socializing and establishing friendships, difficulties associated with schooling,
relationships with family, and dealing with feelings of anger and sadness. With regard to
diagnostic issues, participants in this study indicated that a formal diagnosis of AS provided an
explanation for their unusual behaviours. Initial reactions to the diagnosis included feelings of
shock and disbelief, but ultimately, each of the participants indicated that the diagnosis brought a
sense of relief and reduced feelings of confusion and failure. Most of the adolescents in this
sample believed that the diagnostic criteria accurately described their characteristics. The authors
concluded that AS became a fundamental part of their self-identity; however, there were
differences in the degree to which each of the adolescents identified with the diagnosis and
derfined themselves as a person with AS. All of the participants saw themselves as being
‘different’ and the authors concluded that they were able to incorporate their feelings of
difference into their identities and self-perceptions. Some were able to feel positive about their
diagnosis and recognize the benefits of increasing access to supports and interventions,
particularly in the school context.

Huws and Jones completed semi-structured interviews with nine college students with
ASD (16-21 years) to examine their perceptions of diagnosis, disclosure, and having autism.
Results suggested that the disclosure of a diagnosis of ASD was viewed as either beneficial (e.g.,
clarified their life experiences) or detrimental (e.g., perceived ASD as stigmatizing or viewed the
diagnosis as causing disruption to their future plans) to the individual with ASD. Some of the
participants were able to accommodate their diagnosis and seek new information, while others
disliked having ASD and avoided seeking information about ASD.

These qualitative studies are similar to Levy’s (2001) clinical perceptions of how
individuals with AS cope with their diagnosis. Based on her experiences as a clinician, she
reported three different possible outcomes: (1) some individuals display improved self-
confidence from learning about their diagnosis; (2) some individuals become consumed by the diagnosis and may withdraw from relationships with individuals unaffected by AS; or (3) some individuals do not want to be singled out as different and may come to resent learning about their diagnosis.

Several studies have also explored the adult experience of awareness and acceptance of ASD; however, there are limitations with this type of data as they rely on adult recollections of experiences and insights. Generally, these findings have tended to be more variable, with some identifying the negative impact of not having had a label in childhood (i.e., reduced awareness by the community and impoverished supports, leading to increased isolation, bullying and victimization, or mental health difficulties; Griffith et al., 2011; Hebron & Humphrey, 2012; Muller et al., 2008; Portway & Johnson, 2005; Punshon et al., 2009). Others have described the benefits (e.g., Hurlbutt & Chalmers, 2002; Rosqvist, 2012) or conversely, the challenges of learning later in life about the diagnosis. For example, Punshon et al. interviewed ten adults (22-45 years) about the impact of receiving a diagnosis of AS in adulthood (after the age of 18 years). The results highlighted the effect of negative life experiences (e.g., alienation and difference) and experiences with pre-diagnostic services on their beliefs about AS and subsequent mental health difficulties. For most of the participants, knowledge of their diagnosis provided a framework to explain their difficulties to themselves and society. All of the individuals in this study were able to recognize both positive and negative aspects of an AS diagnosis.

Despite some of the negative experiences associated with their diagnosis, many of the participants in these adult studies spoke highly of support systems (Griffith et al., 2011; Hurlbutt & Chalmers, 2002; Muller et al., 2008) or the internet (Jones & Meldal, 2001), as a means to
receive social or emotional support and to better understand or cope with their diagnosis. Some of these individuals expressed pride in their ASD culture and conveyed strong opinions about the types of services and supports that could benefit individuals with ASD. The importance of including individuals with ASD as active consultants or experts was also highlighted.

Overall, the research on how individuals with ASD come to understand and accept their diagnosis is limited. The process of diagnosis acceptance has not been formally evaluated with this population; however, qualitative studies have begun to document differing feelings and reactions to the ASD diagnosis (e.g., alienation, isolation, bullying, feelings of difference, rejection, pride). More research is needed to better understand these experiences in adolescence in order to help guide developmentally appropriate interventions and supports to decrease the significant potential for long-term psychological consequences.

**Rationale and Objectives of the Current Paper**

The above literature review highlights the multi-factorial approach that is needed in order to understand the complexity of the adolescent experience for youth with ASD. Insights from caregivers, clinicians and educators offer some understanding, but there remains a significant gap in the literature with respect to the ‘insider’ accounts and real-life experiences of individuals with ASD (Billington, 2006). Although there is a modest body of literature suggesting that adolescents with ASD have some awareness of their strengths and weaknesses, more information is needed to better understand how they perceive themselves and interpret their ASD diagnosis. Such findings have important implications for self-concept and adjustment, treatment compliance, transition services, and long-term outcomes. By exploring in-depth the self-perceptions and self-awareness of individuals with ASD, this study will fill a void in the current adolescent literature. The aim of this research program is to gain a first-hand understanding of
individuals’ understanding and awareness of their strengths and weaknesses, what they attribute their difficulties to, and how that information impacts outcomes and adjustment. This type of research has significant clinical benefits that can inform programming and help to educate families and professionals about working with individuals with ASD.

To address these gaps in the literature, the aims of this dissertation were (1) to examine self-concept and self-perceived competence, self-awareness of ASD characteristic and behaviours, and the types of behavioural attributions youth ascribe to their ASD behaviours, and (2) to explore how adolescents with ASD understand their diagnosis, perceive their strengths and weaknesses, and cope with their diagnosis. To address these objectives, a mixed-methods convergent parallel design was used. This type of design consists of collecting and analyzing two independent strands of qualitative and quantitative data in a single phase, merging the results of the two strands, and searching for the relationships between the two databases (Creswell & Plano Clarke, 2011; Greene, 2007). Study 1 presents the broad quantitative results about self-concept, self-awareness, and behavioural attributions among 27 adolescents with ASD and comparison groups of adolescents. The goal of the second study was to extend and add depth to these quantitative findings by providing qualitative examples of the lived experiences of adolescents with ASD among a sub-set of 13 participants. A semi-structured interview protocol grounded in some of the questions addressed in Study 1 allowed participants to offer their observations and insights about their diagnosis and how they have come to understand and cope with their diagnosis. The dissertation concludes with a brief discussion about how results across the two data sets provide a complementary and multi-faceted understanding of self-perceptions and self-awareness among adolescents with ASD.
These goals are particularly important as more adolescents and young adults with ASD partake in inclusive educational, vocational, and community settings in Canada, thus creating a need for more research that will enhance our understanding of their developmental strengths, needs and challenges. The information gathered from this research program can be used to educate professionals and families about which characteristics of their disorder individuals with ASD may find most concerning as they enter adolescence and early adulthood. Furthermore, information collected in this research program has the potential to assist families, schools, and mental health professionals in developing positive self-concept and social skills curricula that are meaningful across home, academic, and community settings for youth with ASD.
CHAPTER 2

STUDY 1

Autism Spectrum Disorders (ASDs) are neurodevelopmental disorders characterized by impairments in social interaction and communication, as well as repetitive and stereotyped patterns of behaviours and interests (APA, 2000). ASDs include diagnoses of autism, Asperger syndrome (AS), and Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS). Although usually diagnosed in early childhood, the impairments of autism are life-long and pose ongoing social and behavioural challenges (Billstedt et al., 2005; Eaves & Ho, 2008; Howlin et al., 2004; Szatmari et al., 1989). There has been considerable attention paid to the early years (e.g., very early detection and intervention). In contrast, relatively little research has focused on the adolescent period, particularly in terms of how adolescents with ASD adapt and adjust to this critical period of transition and identity-formation.

Several studies have examined how individuals with ASD perceive and understand others, but research examining how individuals with ASD see themselves and experience their diagnosis is limited. Much of what is currently known about the behaviours and lives of individuals with ASD comes from descriptions and reports from family members, researchers, clinicians, and other professionals rather than from the individuals themselves. Thus, our understanding of the self-perceptions of adolescents with ASD remains limited.

Self-Concept and Perceived Competence

Self-concept is broadly defined as one’s perceptions of oneself. Perceptions are formed through experience with and interpretations of one’s environment (Marsh & Shavelson, 1985). There is a general consensus that self-concept is a multidimensional construct (Harter, 1996, 2012; Marsh & Hattie, 1996). The cognitive-developmental perspective of self-concept suggests
that as children age, their self-perceptions move from global and undifferentiated to well-differentiated and hierarchically integrated (Harter, 1999). Self-concept is usually measured by self-report using individuals’ self-evaluations and descriptions. At the point of being well differentiated, individuals may have high perceived competence in one domain while displaying low perceived competence in another (Harter, 1982).

Self-perception studies in ASD have consistently shown that children and adolescents with ASD report significantly lower self-perceived social competency, whereas findings in other domains, such as perceptions of physical appearance, athletic abilities, and overall global self-worth, are inconsistent (Capps et al., 1995; Vickerstaff et al., 2007; Williamson et al., 2008). Many of these studies have used the Self-Perception Profile for Children, but no studies to date have used the Self-Perception Profile for Adolescents (SPPA; Harter, 1988) with the ASD population. Although there is considerable overlap across the child and adolescent versions for the six common domains, other developmentally relevant competency areas, including close friendship, romantic appeal, and job competence, can only be examined with the adolescent version. These areas are important for the transition from adolescence to young adulthood and are likely to yield additional insights into the adolescent experience for youth with ASD.

**Self-Awareness**

In the present study, ‘awareness’ is defined as an individual’s knowledge that they have a symptom or some form of impairment, whereas ‘insight’ incorporates the individual’s understanding of the causes and impacts of the symptom or impairment. The most common method used to evaluate self-awareness in ASD compares adolescents’ self-ratings of their functioning with another measure considered to be more objective (i.e., parent ratings, actual performance on tasks). The general consensus of these studies is that individuals with ASD have
some awareness of their difficulties and are able to participate and complete self-report measures (Bishop & Seltzer, 2012; Cederlund et al., 2010; Jackson et al., 2011; Johnson et al., 2009; Lee & Hobson, 1998). Despite some evidence of awareness and symptom acknowledgement, many studies report systematic differences between parent- and self-report ratings. Significant discrepancies between parent and child/adolescent report have been found on measures of social competence (Chamberlain et al., 2007; Knott et al., 2006; Koning & Magill-Evans, 2001; Lerner et al., 2012; Smith-Myles et al., 2007), emotional and behavioural functioning (Hurtig et al., 2009; Mazefsky, Kao & Oswald, 2011; Smith-Myles et al., 2007; Vickerstaff et al., 2007), and quality of life (Shipman et al., 2011). Results from these investigations suggest low levels of awareness or even denial by individuals with ASD, based on higher behaviour or symptom ratings by parents than by the individuals themselves. Only a few studies have demonstrated concordance between parent and adolescent reports on measures of anxiety and behavioural problems, and more specifically among their ratings of somatic, social, and externalizing problems (Farrugia & Hudson, 2006, Hurtig et al., 2009).

Self-awareness has been shown to impact treatment compliance and long-term outcome in other populations (Davidson, 2003; Davidson & Strauss, 1992; Eisen et al., 2000; Goldberg et al., 2003; Hauser et al., 2006; Raskind et al., 1999; Schwartz et al., 2006; Storch et al., 2008). Very little is known, however, about the relationship between self-awareness and outcomes among individuals with ASD. Verhoeven et al. (2011) demonstrated that better self-awareness prior to treatment was associated with an increase in social functioning during treatment and a decrease in parent-reported problems of daily functioning in adolescents with ASD.

Although increased awareness can positively impact treatment outcomes, self-awareness of one’s own difficulties can also lead to distress and frustration. Several studies have
highlighted a relationship between increased social self-awareness and negative mood or depressive symptomatology in individuals with ASD (Butzer & Konstantareas 2003; Capps et al., 1995; Hedley & Young, 2006; Vickerstaff et al., 2007; Wing, 1981). Age and intellectual functioning have also been reported as vulnerability factors for frustration and depressive symptoms (Capps et al., 1995; Ghaziuddin et al., 2002; Lainhart, 1999; Sterling et al., 2008).

More research is needed to understand these associations between self-awareness of ASD symptoms and the presence of symptoms of internalizing disorders. Other factors, such as reduced motivation, repeated rejection, negative beliefs and attributions, may contribute to poor psychosocial adjustment.

**Behavioural Attributions**

Although some studies have begun to look at cognitive thinking errors in individuals with ASD, there is a need for more research about how they understand, accept, and appreciate their differences and how that information can impact interventions addressing beliefs and thinking styles (e.g., reattribution training, cognitive restructuring). One approach to quantifying and understanding an individual’s adaptive and maladaptive ways of thinking about oneself is to examine attributions. Attribution theory suggests that individuals’ attributions (i.e., their explanations of their actions, successes, and failures) are associated with motivation, affect, performance, and expectations for future outcomes (Weiner, 1985). This theory focuses on controllability (an event is viewed as either within or outside an individual’s control), stability (viewed as stable or unstable/variable over time), globality (viewed as occurring in all situations versus only in specific situations), and locus of causality (viewed as either internally or externally caused). According to Weiner (1994), individuals who view their negative behaviours and characteristics as uncontrollable and pervasive are unlikely to feel that they can change and
therefore would not be motivated to put effort into changing. Weiner et al., (1988) expanded on the original attribution theory to include stigma (i.e., the view that a specific deviation in physical attributes, character, or behaviour is undesirable). Perceived causes of stigma determine affective responses (e.g., pity or anger) towards the stigmatized person (Weiner et al., 1988).

Attributions of children and adolescents with ADHD and learning disorders have been reported in the literature (Collett & Gimpel, 2004; Hoza, Pelham, Waschbusch, Kipp & Owens, 2001; Johnston & Lee, 2005; Kaidar et al., 2003; Pelham et al., 2001; Wiener et al., 2012). Children with ADHD have been reported to view their most problematic behaviour as less within their control and more global across situations when compared to matched controls (Kaider et al., 2003; Wiener et al., 2012). Children with ADHD also perceive stigmatization and this perception is associated with low behavioural self-concept and self-esteem (Wiener et al., 2012). Among children with learning disabilities, those who viewed their learning disability as delimiting, malleable, and nonstigmatizing experienced fewer achievement problems, had higher self-perceptions of their abilities and academic competence, and felt more socially accepted (Rothman & Cosden, 1995).

Very few studies have examined attributional style in individuals with ASD, and within this body of work the methodology and results have varied. Some studies have found no evidence of differences in attributional style between individuals with AS and comparison groups (Blackshaw et al., 2001; Craig et al., 2004). Other studies have demonstrated differences in general attributional style, including a pessimistic, failure-prone style (Barnhill and Smith Myles, 2001) or evidence of more global explanations for negative social situations (Flood, Hare & Willis, 2011). Each of these studies has measured attributional style by having participants
respond to questions about a hypothetical scenario, rather than a real-life event or situation. The current study addresses this gap by measuring attributions for self-identified problem behaviours.

Research on perceptions of stigma among individuals with ASD is also sparse. Calzada, Pistrand and Mandy (2012) reported that children and adolescents with ASD described fears of peer stigmatization and being perceived as “not normal”. A high level of peer victimization has also been reported in adolescents and young adults with AS (Shtayermman, 2007, 2009), in which ASD symptomatology was negatively correlated with victimization reports. Although this would appear to contradict the findings of Butler and Gillis (2011) that it is the atypical behaviours associated with AS that influence stigmatizing attitudes rather than the label of the disorder. More information is needed to determine if there are certain behaviours or characteristics that lead to greater stigmatization. School age children have also been found to display negative attitudes and behavioural intentions towards videos of peers with autism (Campbell et al., 2004; Swaim & Morgan, 2001).

**Current Study**

Although a modest body of literature has emerged to investigate the experience of youth with ASD during the adolescent years, significant gaps remain regarding how adolescents with ASD perceive themselves and interpret their ASD symptomatology, both of which are likely to have a significant impact on their ability to adapt and adjust during this period of identity-formation. Findings from this research can help to expand our understanding of the needs of youth with ASD, and may be informative in the development of programs and supports for these individuals during this critical period of transition into adulthood.

This study was guided by three objectives. The first objective was to compare the self-perceptions of competence and global self-worth of adolescents with ASD, Attention-Deficit
Hyperactivity Disorder (ADHD) and typically developing (TD) adolescents. It was predicted that adolescents with ASD would report more negative perceptions in peer-salient domains (i.e., Social Acceptance, Athletic Competence, Physical Appearance, Romantic Appeal, and Close Friendship) and job competence than the ADHD and TD adolescents.

The second objective was to identify the behaviours and characteristics that adolescents with ASD view as most or least problematic for them and the degree to which their self-reports resemble their parents’ reports. Given the limited research in this area, it was difficult to predict the extent of adolescents’ awareness of their behaviours and characteristics. However, based on previous cross-informant research between parents and children or adolescents with ASD, and evidence of limitations with respect to theory of mind and social insight in these adolescents, it was anticipated that adolescents with ASD would underestimate their social communication and behavioural difficulties when compared to their parents. Further analyses were completed to determine whether there is an association between adolescents’ awareness of their ASD behaviours and characteristics and their self-perceptions of competence. Based on clinical accounts and previous quantitative studies linking self-awareness with psychosocial difficulties, it was anticipated that adolescents with more awareness of their ASD behaviours and characteristics would display lower self-perceptions of Social Acceptance, Close Friendship and Romantic Appeal.

The third objective was to compare the behavioural attributions of adolescents with ASD, adolescents with ADHD, and TD adolescents for the behaviour or characteristic they identify as most concerning for them. It was hypothesized that, compared to TD adolescents, adolescents with ASD would report that their self-identified most problematic behaviour or characteristic is internally caused, uncontrollable, pervasive (global and stable), and stigmatizing, with
stigmatization in relation to peers being the most salient. No hypotheses were advanced in relation to comparison with adolescents with ADHD.

**Method**

**Participants**

**Adolescents with ASD.** Data were collected from a sample of 27 adolescents with ASD. Inclusion criteria were (1) chronological age between 13 years, 0 months and 18 years, 11 months; (2) verbal IQ of 80 or greater; (3) a clinical diagnosis of an ASD, including Autistic Disorder (i.e., autism), Asperger syndrome, or Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS); (4) an awareness of their ASD diagnosis (i.e., adolescent discussed their diagnosis with a parent and/or professional); (5) ability to fluently speak, understand, and read in English as the assessment questionnaires and tasks were validated and completed in English; and (6) agreement that at least one parent/caregiver would complete an interview and some questionnaires related to the adolescent’s past and current functioning. Exclusion criteria included significant neurological, psychiatric, sensory, or motor impairment (e.g., traumatic brain injury, blindness) that would preclude the completion of the standard assessment battery.

A total of 31 participants initially consented to participate in the study. Three of the consenting participants were excluded due to verbal IQ below 80 ($n = 2$) or failure to meet criteria for a best estimate clinical diagnosis of an ASD ($n = 1$). One participant failed to arrive for the assessment and did not return follow-up calls. This left a total sample of 27 adolescents with ASD.

Eleven of the adolescents (41%) were recruited through families participating in recent or ongoing research studies affiliated with the Autism Research Unit at the Hospital for Sick Children (SickKids) who had consented to be re-contacted for future research. Sixteen
participants (59%) responded to community recruitment strategies in the Greater Toronto Area, which included sending flyers to local autism service agencies and professionals (e.g., developmental pediatrician, psychologist, psychiatrist), posting advertisements on relevant agency websites, and making presentations to ASD resource centres and social groups. Eighty-five percent of the participants were from the Greater Toronto Area \((n = 23)\); the remaining 4 were from central-eastern areas of Ontario. There were no significant differences in age, IQ, age of diagnosis, age of ASD disclosure, or maternal education between recruitment sources or geographic location of participants.

Mean chronological age was 14 years, 11 months \((SD = 1.3)\). Mean verbal IQ was 101.56 \((SD = 14.0); range 79^1 \text{ to } 135\) and nonverbal IQ was 99.81 \((SD = 16.8); range 62 \text{ to } 131\). Three females participated in the study \((11\% \text{ of the sample})\). An additional 2 females contacted the researcher but, due to scheduling conflicts, they were unable to commit to the study. Two of the male participants were fraternal twins both with a diagnosis of ASD.

Mothers most often accompanied their adolescent to the session and completed the parent interview and questionnaires \((81\%)\). In three cases, both parents accompanied their adolescent and chose to participate in the parent interview together \((11\%)\). Of the two remaining cases, one involved the father and one the grandmother who was the adolescent’s legal guardian. In the latter case, the mother was still involved in her child’s care and completed the early history for

\(^1\) One participant was included in the sample even though his Verbal IQ score of 79 fell just below the exclusionary cut-off of 80. His Non-verbal IQ was 102 and Full-Scale IQ was 88. An analysis of his subtest scores across the verbal composite performances in the broadly average range for verbal reasoning and in the borderline range for word definitions. Relative weaknesses on the Vocabulary subtest were likely due to word-finding errors and difficulties with elaboration because of a rigid and inflexible problem-solving style. In addition, previous psychological testing (one year prior) revealed above average performance on a multiple-choice type of his expressive vocabulary.
the Autism Diagnostic Interview – Revised while the grandmother completed the current history section.

Ethnicity of the sample included 78% European Canadian, 7% Asian Canadian, 7% African Caribbean-Canadian, and one person (4%) each from the South Asian-Canadian and Latin American-Canadian categories. All but two of the participants were living at home with one or both biological parents; of the other two participants, one was adopted in early infancy and the other lived with his grandmother. Sixty-eight percent of the adolescents’ parents were married; 32% were divorced or separated. Although no direct measure of family socioeconomic status (SES) was collected, maternal education level\(^2\) was obtained as a broad estimate of SES. Maternal education included 19% with graduate education, 38% who had completed a Bachelor’s degree, 19% with a college degree, 13% with some college, and 13% with either a high school degree or some high school. With regards to employment status, 60% of the mothers worked full-time, 5% worked part-time, 20% were stay-at-home mothers, 10% were on leave from work, and 5% were retired. Although some families did speak additional languages in the home, participating parents and adolescents were proficient in reading, speaking, and writing in English.

In terms of adolescent education, 33% were currently in middle school (3 in grade 7, and 6 in grade 8) and 67% were in high school (6 adolescents in grade 9, 7 in grade 10, 3 in grade 11, and 2 in grade 12). The levels of school support that each adolescent received varied: 4 were in a special program for adolescents with special needs, 14 were integrated into a regular program but received some specialized support, 4 adolescents attended a regular school program with no

\(^{2}\) Maternal educational level was used instead of parent educational level because this data was readily available and there were several participants who had no contact with their father.
specialized support, 3 were homeschooled, and 2 attended an alternative academic program for behaviour or complex learning needs. Within these specialized groups, 31% were placed in an ASD program or class for part of the day.

At the time of data collection, 25% of the adolescents were taking medication for ADHD-related symptoms and two adolescents were taking medication for each of anxiety or mood symptoms. As typically found in samples of adolescents with ASD, 83% had at least one comorbid diagnosis from a professional (60% Learning Disabilities, 58% Attention Deficit Hyperactivity Disorder, 20% Anxiety Disorder, 12% Mood Disorder, 4% Gifted).

The age of initial ASD diagnosis ranged from 1 to 16 years of age, with a mean age of 6 years, 8 months ($SD = 4.07$). All adolescents had been aware of their diagnosis for at least one year at the time of the study, and had discussed their diagnosis with a parent and/or professional.

Best estimate clinical diagnoses of ASD were confirmed for each participant, based on DSM-IV criteria informed by expert clinical judgment informed by the Autism Diagnostic Observation Schedule (ADOS; Lord et al., 2000; see below for a description) and the Autism Diagnostic Interview – Revised (ADI-R; Lord, Rutter & Le Couteur, 1994). Measures for the best estimate clinical decision-making protocol are included below. All but one of the adolescents met diagnostic criteria on the ADI-R based on early history. Currently, 21 (78%) of the adolescents met criteria for an ASD on the ADOS ($n = 10$ for ASD, $n = 11$ for Autism). Based on the available clinical information, all participants in the study received a best estimate clinical diagnosis of an ASD and all of them continued to have significant social-emotional challenges and restricted and repetitive interests that met clinical criteria for an ASD diagnosis. Specifically, 17 (63%) were assigned to the High-Functioning Autism diagnostic category (i.e., significant language delay included no single word use by age 2 years and no communicative
phrases used by age 3 years) and 10 (37%) had Asperger’s syndrome (i.e., no language delay). For this study, the ASD group will be examined as one diagnostic group along a continuous dimension of severity. This decision is largely based on the current proposal by the American Psychiatric Association to eliminate the distinction among different ASD sub-types in the upcoming revision of the Diagnostic and Statistical Manual (DSM-5). This decision is based on the rationale that these sub-categories have proven to be “inconsistent over time, variable across sites and often associated with severity, language level or intelligence rather than features of the disorder” (www.dsm5.org). Additional studies have supported the notion of a single, distinct ASD category (Lord, Rutter, DiLavore & Rasi, 2008; Van Daalen et al., 2009). Furthermore, the investigation of subtypes would lead to small subgroups, precluding some of the planned statistical analyses.

**Comparison Groups.** Two comparison groups participated in the study: (1) adolescents with attention deficit hyperactivity disorder (ADHD) and (2) typically developing (TD) adolescents. An ADHD comparison group was used because ADHD and ASD are both described as early-onset, neurodevelopmental disorders that have considerable negative psychosocial and psychiatric outcomes across the lifespan (APA, 2000).

Data for the comparison groups were collected as part of a study, conducted at the Ontario Institute for Studies in Education of the University of Toronto (OISE/UT) by Dr. Judith Wiener, to evaluate the self-perceptions of adolescents with ADHD for their problem behaviours. Similar to the current study, participants in Wiener’s study were between the ages of 13 and 18 years of age and scored above 80 on a standardized abbreviated measure of intellectual functioning. They were also not suspected of having severe behavioural or mental health problems (i.e., ASD, intellectual disabilities, psychotic disorders, bipolar disorder, Tourette’s
disorder). Specifically, any adolescents presenting with ASD symptoms were removed from the ADHD group. The participants were recruited in the community through advertisements and flyers or because of their involvement in previous studies in the ADHD Laboratory at OISE/UT. For inclusion in the ADHD sample, participants had a previous diagnosis of ADHD from a physician or mental health professional. ADHD symptomatology was confirmed if the participant’s behaviour was rated as falling within the clinically significant range (T ≥ 70) by one informant (parent or teacher) and within the borderline (T ≥ 61) or clinical range by the second informant on the ADHD core subscales (DSM-IV Inattentive, DSM-IV Hyperactive-Impulsive) of the Conners 3-P and Conners 3-T (Conners, 2008). For inclusion in the TD comparison group, participating adolescents had no previous or current diagnosis of ADHD or other behavioural disorder (including ASD) and had T-scores of 65 or below on both the DSM-IV ADHD subscales of the Conners 3-P and the Conners 3-T.

A matched-pairs approach was initially taken to ensure that participants were closely matched for age, gender, and IQ; however, given the limited sample size (ADHD n = 40, TD n = 38), a matched-pairs approach was not entirely possible. The final comparison groups consisted of 24 adolescents with ADHD (21 male, 3 female) and 21 TD adolescents (18 male, 3 female). There were no differences in age and IQ between the three groups (see Table 2.1).

**Measures**

*Self-Perception Profile for Adolescents (SPPA; Harter, 1988).* The SPPA is a 45-item scale used to assess self-esteem (Global Self-Worth) and eight domain-specific self-concepts (Scholastic Competence, Social Acceptance, Athletic Competence, Physical Appearance, Behavioral Conduct, Romantic Appeal, Job Competence, and Close Friendship). Adolescents respond by selecting one of two statements that they believe most resemble them, and then
indicate whether the selected statement is “really true” or “sort of true”. This format was designed to reduce the likelihood of socially desirable responding and to match the cognitive development of children and adolescents (Harter, 1982). The Self-Perception Profile for Children (Harter, 1985), which comprises five of the eight domain-specific subscales from the SPPA, has been used successfully in studies with children and adolescents with ASD (Bauminger, Shulman & Agam, 2004; Capps et al., 1995; Vickerstaff et al., 2007; Williamson et al., 2008). Close Friendships, Romantic Appeal and Job Competence are the added subscales in the adolescent version.

The SPPA has good psychometric properties in typically developing children and adolescents (Harter, 1988) with adequate internal consistency (Cronbach’s α: .74 - 0.93) and a stable factor structure. The internal consistencies in the current study were acceptable, with the exception of the job competence scale. Cronbach’s alpha for each SPPA scale was as follows: Social Acceptance (α = .75), Romantic Appeal (α = .73), Behavioural Conduct (α = .81), Close Friendship (α = .81), Scholastic Competence (α = 0.85), Athletic Competence (α = .92), Physical Appearance (α = .74), Job Competence (α = 0.66), and Global Self-Worth (α = .88).

**Alex-ASD.** Adolescents completed a structured picture-based interview, called the Alex-ASD, that had been adapted from existing measures (the Dominic-R; Valla, Bergeron, Bidaut-Russell, St-Georges & Gaudet, 1997, and the Alex; Varma, 2007) and developed for the purpose of this study to assess adolescents’ self-identification of their own ASD characteristics and what they perceived to be their most problematic behaviour. The Dominic-R (Valla, Bergeron, Bidaut-Russell, St-George & Gaudet, 1997) was originally developed for pre-pubertal children (6-11 years) to assess for anxiety disorders, mood disorders, and disruptive behaviour disorders. An adolescent version, the Alex (Varma, 2007), was designed for use with adolescents with
Attention Deficit Hyperactivity Disorder (ADHD). For the purposes of the current project, adaptations were made to render the Alex scale appropriate for individuals with ASD, and the scale was piloted with a small sample of adolescents with ASD prior to inclusion in the full study, in order to examine its usefulness and appropriateness for the current sample, including picture content and wording.

The Alex-ASD involves a structured interview with pictures and a projective component. This format was used in order to reduce working memory and language demands (Wiener et al., 2012). Visual depictions are effective as a means of enhancing the processing of information and understanding of the environment of individuals with ASD (Hagiwara & Myles, 1999; Kuttler, Myles, & Carlson, 1998; Rogers & Myles, 2001). In addition, a picture-based presentation method normalizes the difficulties depicted in the pictures as adolescents are asked whether they are “like Alex” (i.e., rather than being asked whether they have difficulties in a particular area), which may make them more willing to acknowledge their difficulties. There has also been some suggestion that using pictorial interviews for self-reports of symptomatology (such as the Dominic-R) may be useful for children with ASD (Goodlin-Jones & Solomon, 2003); however, no empirical studies have used this type of picture-based interview method with the ASD population to date.

The original adolescent instrument (the Alex) developed by Varma (2007) consisted of 77 hand-drawn pictures of a male adolescent, Alex, appearing to be approximately 15 years of age and displaying behavioural characteristics of ADHD (10 hyperactivity patterns, 9 inattentive patterns) and of disorders that commonly co-occur with ADHD (i.e., 6 Oppositional Defiant Disorder, 6 Conduct Disorder, 19 Learning Disability, and internalizing symptomatology (3 anxiety and 2 depression). The behaviours were based on DSM-IV symptoms. In addition,
several pictures depicted Alex displaying social difficulties (5 peer relationship, 2 social
perception, 6 communication) and engaging in risk-taking situations (2 driving, 3
dangerousness), as well as 4 substance use pictures.

The Alex-ASD includes a series of 39 hand-drawn pictures of a male or female youth
(depending on the gender of the participant) engaging in various activities and behaviours that
are characteristic of ASD. The behaviours represented in the pictures were based on DSM-IV-TR
symptoms of ASD adapted from the ADI-R algorithm (thus allowing for a cross-informant
comparison between parent and self-report). The Alex-ASD images depict qualitative
impairments in social interaction (10 pictures), communication impairments (7 pictures),
restricted repetitive and stereotyped patterns of behaviour (8 pictures), and other ASD
behaviours (9 pictures, 6 of which addressed strengths/isolated skills often associated with ASD
such as visuospatial, memory, musical, drawing, reading, and computational abilities). There
were 5 additional questions addressing general positive attributes or skills in order to introduce
some positively-oriented questions to the scale. See Appendix A for a complete list of ASD
behaviours used in this scale and Appendix B for a sample of male and female versions of the
pictures.

The Alex-ASD is administered in two parts. First, adolescents are shown pictures of Alex
behaving in various ways and are asked whether they are like Alex (e.g., “Do you have trouble
making and keeping friends like Alex?”). The examiner then sorts the pictures into two piles: a
“yes” pile consisting of the pictures the adolescent endorsed as being like themselves, and a “no”
pile consisting of pictures the adolescent did not endorse. Second, the examiner selects and
presents the pictures depicting the ASD symptoms that the adolescents endorse and asks them to
select the picture that is the “biggest problem” for them.
The reliability of the ASD Total Score (34 items), and items assessing Social Interaction, Communication and Language, and Restricted Repetitive Behaviours and Interests was assessed with Cronbach’s alpha coefficient (Cronbach, 1951). The internal consistency for the Total ASD score was satisfactory ($\alpha = .77$) but the internal consistency for the domain scores was weak: Social Interaction ($\alpha = .51$), Communication and Language ($\alpha = .24$), and Repetitive Behaviours and Interests ($\alpha = .59$). Reorganization of the items using a two-factor model, consistent with the current literature (Gotham, 2006), generated more consistent domains. Fixated Interests & Repetitive Behaviours ($\alpha = .72$) now achieved a satisfactory internal consistency. The Social Communication scale ($\alpha = .49$) still fell below satisfactory levels suggesting that items in the Social Communication domain still did not intercorrelate well.

*Adolescent Attribution for Problem Behaviour Questionnaire (AAPBQ; Varma, 2007), modified for ASD behaviours.* The AAPBQ is a 16-item questionnaire, originally adapted from the Children’s Attributions for Problem Behaviours Questionnaire (APBQ; Kaider, Wiener & Tannock, 2003). The questionnaire assesses adolescents’ attributions of Controllability, Pervasiveness, Locus of Causality, and Stigmatization (see Appendix C). With the exception of locus of causality, each item is rated on a three-point scale: (a) never, (b) a little, and (c) a lot. Questions are read aloud to the participants to ensure comprehension of the questions. Adolescents are given a choice of whether they would like to record their own responses or have the examiner record their responses to alleviate any writing frustrations. Items on this questionnaire were initially assigned to scales based on the factor analysis of the Attributions for ADHD Questionnaire (AAQ; Kaider, Wiener, & Tannock, 2003; Wiener et al., 2012). Adolescents complete the questionnaire for the behaviour they self-identified as being most problematic to them on the Alex-ASD. The same attribution questionnaire was used with the
comparison groups; however, their identified problem behaviour was taken from the Alex, the original adolescent instrument developed by Varma.

Internal consistencies, as measured by Chronbach’s alpha ($\alpha$), were calculated to assess the Stigmatization, Controllability, and Pervasiveness scales. Items that reduced the internal consistency of the scale were removed. The subscales and internal consistency ratings are described below.

**Stigmatization.** Stigmatization was assessed by examining adolescents’ perceptions of being stigmatized by their parents, teachers, and peers for their most problematic behaviour. Each item was rated on a three-point scale: (a) never, (b) a little, and (c) a lot. The Parent Stigmatization subscale originally consisted of four questions ($\alpha = .63$). Three of the four questions were used to form the Parent Stigmatization subscale: “Do your parents get bothered/embarrassed/disappointed by your [behaviour]?” ($\alpha = .83$). The Teacher Stigmatization subscale used all three questions: “Do your teachers get bothered/sometimes don’t like you/treat your differently from other students because of your [behaviour]?” ($\alpha = .82$). The Peer Stigmatization subscale used all four questions: “Do your friends or classmates get bothered/embarrassed/don’t like you/treat you differently from your other peers and classmates because of your [behaviour]?” ($\alpha = .78$). A Total Stigmatization score was also computed with all the questions from the parent, teacher, and peer subscales, as well as two additional questions that focused on perceived embarrassment to themselves because of their behaviour and whether they saw themselves as getting into trouble because of their behaviour. The internal consistency of the Total Stigmatization scale was .79.

**Controllability.** This scale comprised three questions that examined how much control adolescents felt they had over their most problematic behaviour. These three questions were used
based on the factor analyses by Wiener et al. (2012). The questions were based on a 3-point scale using the following questions: “If you try really hard, do you think you can stop your [behaviour]?”, “Do you think your [behaviour] is there even when you don’t want it to be?”, and “Can you control your [behaviour]?”. Compared to the other attribution scales, the internal consistency of this scale was very low ($\alpha = .11$), which raises questions about the utility of this scale with the ASD population.

**Pervasiveness.** Adolescents’ perception of how pervasive they felt their most concerning behaviour was across situations and time was assessed by three questions. These questions focused on the stability and globality of the behaviour. One of the pervasiveness questions focused on the past, “Have you always had [behaviour]? (a) only a short time, (b) a few years, (c) as long as you can remember.” A second question focused on the present: “Do you have difficulty with [behaviour]? (a) almost never, (b) only some of the time, (c) all the time.” The third question pertained to the future: “Do you think that your difficulty with [behaviour] is going to: (a) disappear soon, (b) last only a few years, (c) last forever (even when you are an adult)?” The internal consistency of the Pervasiveness scale was acceptable ($\alpha = .75$).

**Locus of Causality.** This scale was assessed by a single question asking adolescents if they perceived their most problematic behaviour as being caused by something around them (e.g., other people), or by something inside them (“What causes your [behaviour]? Is it something around you, like people, that makes you [behaviour] or is it something inside you that makes you [behaviour]?”). Unlike the other subscales, Locus of Causality was based on a two-point scale.

**The Autism Diagnostic Observation Schedule (ADOS; Lord et al., 2000).** The ADOS is a semi-structured play/interview schedule consisting of several activities designed to elicit the behaviours diagnostic of autism/ASD. The schedule provides a well-operationalized
administration and coding system for a wide range of social-communication and repetitive behaviours. Items are divided into four main areas: Communication, Social Interaction, Play/Creativity, and Restricted/Repetitive Behaviors or Interests. Cut-off scores in the domains of Communication, Social Interaction, and Combined (Communication + Social Interaction) allow an individual to be placed in one of three possible diagnostic categories related to ASD: Autism, ASD, or Non-spectrum. The authors report good to excellent reliability of the items, domains, and classification categories (Lord et al., 2000). Recommended cut-off scores reliably distinguish children with ASD from typical and developmentally disabled non-autistic controls (Lord et al., 2000). The ADOS consists of four modules appropriate for individuals of differing developmental and language levels, ranging from non-verbal toddlers to verbally fluent adults. Modules 3 and 4 were used for the purpose of this study. Additional follow-up studies on module 4 also report good reliability and predictability among adults (Bastiaansen et al., 2010). Scores on the ADOS, in conjunction with the ADI-R (see below), were used to inform a best estimate diagnosis based on DSM-IV-TR criteria (i.e., as an inclusion criterion), as well as to assess specific ASD characteristics.

The Autism Diagnostic Interview – Revised (ADI-R; Lord et al., 1994). The ADI-R is an investigator-directed interview that elicits the information about developmental history and current functioning necessary to make a DSM-IV diagnosis of autism. The ADI-R was administered to the parent/caregiver by the investigator to verify diagnosis and to provide additional information about current ASD characteristics. The ADI-R is validated for use with children over 24 months of age. It yields a total score for autistic symptoms and sub-scores for social impairments, communicative impairment, and repetitive behaviours and interests. The primary investigator was formally trained, and had obtained site-specific research reliability in
the administration, scoring, and interpretation of the ADI-R. Inter-rater reliability of the ADI-R is excellent (.94-.97, Lord et al., 1994).

*Wechsler Abbreviated Scale of Intelligence (WASI; Wechsler, 1999).* The WASI is a standardized abbreviated test of intelligence providing scores for verbal intellectual functioning, nonverbal intellectual functioning, and overall intellectual functioning. The WASI has good internal consistency (.93) and test-retest reliability coefficients across IQ scales (.88 -.93). All four subtests were administered to obtain an estimate of the adolescents’ cognitive functioning. Inclusion criteria for the study required verbal cognitive abilities in the average to above average range (VIQ ≥ 80).

*Other Measures of Cognitive Ability.* Thirty-three percent of participants had already received a recent cognitive assessment because of participation in another study at the Autism Research Unit or through an outside clinical assessment. In those instances, cognitive testing from either the Wechsler Intelligence Scale for Children, Fourth Edition (WISC-IV; n = 3) or the Stanford-Binet Intelligence Scales, Fifth Edition (SB5; n = 6) was accepted to demonstrate verbal cognitive abilities. The Full-Scale IQ scores on the WASI and WISC typically correlate highly (Wechsler, 1999), although there are not large-scale studies comparing these two editions. Standardized Full-Scale IQ scores from the intelligence measures were used for descriptive purposes of this study and to ensure that all adolescents in the sample had a Verbal IQ above 80. The WISC-IV, WASI, and SB-5 are widely used and well-standardized measures of intelligence for children and youth; research on the psychometric properties shows high reliability, test-retest stability, and concurrent and construct validity for these tests (Roid, 2003; Sattler, 2001; Wechsler, 2003).
Procedure

All data were obtained in accordance with study protocols approved by the SickKids Research Ethics Board and University of Toronto Offices of Research Ethics. Participants with ASD were screened in two stages. Parents or caregivers were first asked to provide a copy of the diagnostic report or letter from a licensed professional (e.g., developmental paediatrician, psychologist, psychiatrist) to ensure the participating adolescents had a previous diagnosis of ASD. After informed consent was obtained, background information was collected in a brief screening interview to verify the diagnosis and to ensure the inclusion criteria were met. If both stages of screening confirmed eligibility, individuals were invited to participate in the study. Most of the adolescents completed the measures at the Autism Research Unit at SickKids in Toronto, Ontario. Two of the participants, one of whom did not meet the inclusion criteria (i.e., VIQ < 80) completed the measures in their homes.

Adolescents completed a three- to four-hour study protocol that included a picture-based and semi-structured interview to assess their understanding and behavioural attributions of ASD characteristics and their diagnosis, one paper-and-pencil questionnaire to assess self-concept, and two formal measures to assess cognitive functioning and social-communication abilities associated with ASD. Each adolescent’s verbal performance on the cognitive measure and general conversational skills were used to make decisions about whether the participant was considered capable of completing the questionnaires and participating in the study protocol. Parents participated in a 90-minute to two-hour session including an in-depth structured clinical interview to confirm diagnosis and identify symptoms of ASD and completion of several questionnaires.
Some measures (e.g., ADOS, ADI-R) used to confirm ASD diagnoses were not re-administered for those participants who had received an ASD diagnosis through the Autism Research Unit or associated developmental clinic or who were already participating in a research study at the Autism Research Unit at SickKids. Each adolescent received a $20 gift card and had the option of receiving a certificate outlining the number of participation hours of community service they accrued for high school credits. Participants also had the option of receiving a brief report outlining the assessment results.

Most of the data were collected by the primary investigator (K. Drummond), a clinical child psychology doctoral student, with more than 8 years of experience assessing and working with individuals with ASD and making autism spectrum diagnoses. Research assistants at the ARU at SickKids helped collect some of the data when possible. Both the author and research assistants had all obtained extensive training and achieved reliability on the Autism Diagnostic Observation Schedule (ADOS; Lord et al., 2000) and the Autism Diagnostic Interview – Revised (ADI-R; Rutter, LeCouteur & Lord, 2003).

Data Analyses

Given that two of the measures used to operationalize self-awareness and attributions (i.e., the Alex-ASD and the AAPBQ) were newly created/adapted for use with the ASD population, Cronbach’s alpha coefficient was used to test their internal consistency. Cronbach’s alpha was also calculated for the SPPA. Correlations were calculated between adolescent demographics (age, age of diagnosis, age of diagnosis disclosure, verbal IQ) and the SPPA, the number of behaviours and characteristics endorsed on the Alex-ASD, self-awareness, attributions, and stigmatization. As the correlations between adolescent demographics and the
variables of interest were typically modest, demographic variables were not part of the main analyses.

The adolescent self-awareness score was calculated by computing adolescent-parent agreement on each of the ASD behaviours. Adolescent ratings were taken from their responses on the Alex-ASD, and parent ratings were calculated from scores on the ADI-R. As part of the ADI-R semi-structured interview, the clinician rated the parents’ description of their adolescent’s current behaviour using a 0 (behaviour is not atypical), 1 (behaviour is present in an abnormal form or the lack of a particular behaviour), or 2 and 3 (definite abnormality of the behaviour type specified). Scores were collapsed into a dichotomous scale with 0 indicating ‘no’ (the behaviour is not atypical) and a score of 1, 2, or 3 indicating ‘yes’ (the behaviour is present in an abnormal form). It was necessary to create a dichotomous scale on the ADI-R ratings because adolescents gave yes/no responses on the Alex-ASD. An agreement score was given for each item; that is, if both the adolescent and parent agreed on a particular item in either direction (i.e., the agreed upon behaviour could be either present or absent), this was coded as an agreement.

Descriptive statistics were used to explore the dependent and independent variables in the study sample. Analyses of self-identified problem behaviours and attributional style involve frequency distributions. A correlation matrix including each of the dependent variables, demographic characteristics (e.g., gender, age, age of diagnosis, grade level, cognitive functioning, ASD severity), and other variables of interest was completed. Cohen’s (1988) criteria were used to evaluate the magnitude of correlations: small ($r = .10 - .29$), medium ($r = .30 - .49$) or large ($r \geq .50$). Variables were evaluated for evidence of multicollinearity (intercorrelations among the predictors in a regression analyses) and the presence of suppressor variables that could negatively impact results and interpretation.
Five types of data analysis strategies were used. To address the first objective, a multivariate analysis of variance (MANOVA) with diagnostic group (ASD, ADHD, TD) as a factor was performed on self-competence variables on the SPPA to investigate differences between adolescents with and without ASD in their ratings of self-competence. This was followed by univariate analyses, when the multivariate analysis was significant. Post hoc analyses for each of the significant self-competence variables involved conducting pairwise comparisons to differentiate the ASD, ADHD, and TD group.

For the second objective, paired t-tests were used to compare differences between adolescents and parents in the number of ASD behaviours and characteristics they each endorsed on the Alex-ASD or ADI-R. Pearson correlations between adolescent and parent reports were calculated. McNemar tests were also used to compare the proportions of endorsement between parents and adolescents for each individual item on the Alex-ASD. The alpha level was adjusted to account for multiple comparisons using a family-wise error correction of \( \frac{.05}{2} = .025 \). Correlational analyses were also used to examine relations between self-awareness of ASD behaviours and self-perceptions of competence. A linear regression analysis was conducted to evaluate whether self-awareness predicted a significant proportion of the variance in self-perception of social acceptance.

To address the third objective, an ANOVA with diagnosis (ASD, ADHD or TD) as the grouping factor was performed on the pervasiveness variable. This was followed by pairwise post hocs comparing adolescents with ASD with each of the ADHD and TD adolescent groups. A 2 x 3 Chi-square test of independence was computed on the Locus of Causality scale. Due to the low internal consistency of the Controllability scale, individual item analyses using 2 x 3 chi-square tests of independence for specific questions, instead of the total scale, were performed.
Given the low frequency of “never” responses across all three groups, “never” and “a little” were collapsed into one scale and compared with the number of participants that endorsed the “a lot” response. Finally, a MANOVA with diagnosis (ASD, ADHD, TD) as a factor was performed on stigmatization variables to investigate differences between adolescents with and without ASD in their ratings of parent, teacher, and peer stigmatization. This was followed by univariate analyses, when the multivariate analysis was significant. Post hoc analyses for each of the significant self-competence variables involved conducting pairwise comparisons to differentiate the ASD, ADHD, and TD group.

Results

Objective 1: Self-Concept and Perceived Competence

Results of the MANOVA showed that there was a significant effect of diagnosis on self-perceptions of competence (Wilks’ Λ = .54, F(18,120) = 2.41, p = .002, η² = .27). Table 2.2 contains the means and standard deviations on the dependent variables for the three groups. Univariate analysis of each individual dependent variable showed that the three groups differed in self-perceptions of Social Acceptance, Close Friendship, Romantic Appeal, Athletic Competence, Job Competence and Global Self-Worth. There were no significant group differences in Scholastic Competence, Physical Appearance, and Behavioural Conduct.

Pairwise post hoc comparisons showed that the ASD group reported significantly lower ratings of Social Acceptance (p ≤ .001) and Athletic Competence (p ≤ .002) than either the ADHD or TD group, which did not differ from each other. The ASD group also reported lower Close Friendship competencies compared to the ADHD (p = .01) and TD (p = .004) group. Job Competence was lower among adolescents with ASD than the TD group (p = .007). Finally,
adolescents with ASD reported lower Romantic Appeal and Global Self-Worth ratings when compared to the ADHD group ($p = .022$ and $p = .023$, respectively).

**Objective 2: Self-Awareness of ASD Behaviours and Characteristics**

The frequency of ASD behaviours endorsed by adolescents is presented in Table 2.3. The most frequently endorsed symptoms included an equal number of items from the Social Communication scale (i.e., lack of eye contact, lack of social smiling, limited use of facial expressions, and difficulty with reciprocal conversation) and the Fixated Interests and Repetitive Behaviours scale (i.e., circumscribed interests, negative responses to sensory stimuli, hand/finger mannerisms, and sensory interests), as well as the presence of atypical speech or voice quality. Of the 28 items on the Alex-ASD, more than half (15) were endorsed by less than a third of the total sample.

Thirteen behaviours from the Alex-ASD were selected as most problematic to the participants (Table 2.4). The most frequently endorsed items included lack of friendships, circumscribed interests, and difficulties with changes in routine or environment. More than half (55.6%) of the identified problem behaviours were from the Fixated Interests and Repetitive Behaviours domain, while 37% were from the Social Communication domain. Two (7.4%) of the problem behaviours were related to voice quality or differences in intonation, pitch, rhythm or volume.

Adolescents with ASD endorsed fewer ASD behaviours and characteristics than their parents. The adolescents also reported fewer challenges in the Social Communication domain and the Repetitive Behaviour and Fixated Interests domain; however, the FI/RB domain score differences only approached conventional levels of significance (Table 2.5). Adolescent and parent scores were not significantly correlated for Total number of ASD behaviours ($r = .30$, $p =$
.08) or for the Fixated Interests and Repetitive Behaviours domain \((r = .27, p = .111)\). However, a moderate correlation \((r = .41, p = .025)\) was found between adolescent and parent ratings on the Social-Communication scale. Overall, the magnitudes of the correlations between adolescents and parent scores ranged from low to moderate (see Appendix D for complete correlation matrix).

To determine the proportion of adolescents who reported more ASD behaviours than their parents and those who reported fewer ASD behaviours than their parents, discrepancy scores were calculated (parent scores from the ADI-R minus adolescent scores on the Alex-ASD). The majority of adolescents reported fewer Total ASD behaviours (59%), Social-Communication Behaviours (67%), and Fixated Interests and Repetitive Behaviours (56%) than their parents. Relatively few adolescents reported more ASD behaviours than their parents (19%, 7%, and 19%), and perfect agreement was rare (11%, 11%, and 7%), for Total, Social-Communication, and Fixated Interests and Repetitive Behaviours, respectively.

Results of McNemar tests revealed that the proportion of adolescents who endorsed a specific behaviour on the Alex-ASD and the proportion of parents who endorsed the same behaviour on the ADI-R only differed significantly for 5/28 items (Table 2.6). Three items were in the Social Communication domain and 2 were from the Fixated Interests and Repetitive Behaviour. Specifically, 87% of the parents indicated that their child had difficulty responding to what other people say or do, while only 17% of the adolescents reported difficulties with their ability to socially respond to others; 70% of the parents (vs. 26% of adolescents) indicated that their child did not consistently point to express interest; 65% of parents (vs. 22% of adolescents) indicated that their child uses socially inappropriate questions or statements; the presence of stereotyped utterances and delayed echolalia was reported by 78% of parents (vs. 22% of
adolescents); and 77% of parents (vs. 36% of adolescents) reported difficulties with changes in
routine/environment.

Correlations between self-perceptions scores on the SPPA and adolescent-parent
agreement were completed with an adjusted alpha of .05/9 = .005. Most of the correlations were
generally low (Table 2.7). There was a significant association between dyad agreement and
adolescent perceptions of Social Acceptance ($r = -.45, p = .028$) and Athletic Competence ($r = -
.42, p = .04$) on the SPPA. The results of the linear regression analysis support the hypothesis
that adolescents with greater self-awareness of their ASD symptomatology tended to have lower
reports of feeling socially accepted by their peers ($\beta = -.45, p < .05$).

**Objective 3: Attributions and Stigmatization of Most Problematic Behaviour**

With regard to Pervasiveness attributions, there was a significant difference between
groups, $F(2, 67) = 5.63, p = .005, \eta^2 = .14$ (see Table 2.8). Follow-up tests were conducted to
evaluate pairwise differences. Compared to TD adolescents, adolescents with ASD and ADHD
were more likely to view their most problematic behaviour as pervasive ($p = .006, .029
respectively). There were no significant difference between adolescents with ASD and ADHD.

The responses on the Controllability questions revealed no differences among the
proportions of adolescents who felt they had little control over their problematic behaviour: (1)
“If you try really hard, do you think you could control your [behaviour]?”, $\chi^2 (2, N = 71) = 1.05,
p = .59$ (ASD = 50.3%, ADHD = 50.0% and TD = 65.0% each reported they have little to no
control over their behaviour); (2) “Do you find your [behaviour] is there even when you don’t
want it to be?”, $\chi^2 (2, N = 70) = 2.94, p = .23$ (ASD = 14.8%, ADHD = 34.8% and TD = 20.0%
each reported the behaviour is present when they do not want it to be); and (3) “Can you control
your [behaviour]?”, $\chi^2 (2, N = 71) = 1.05, p = .59$ (ASD = 74.1%, ADHD = 66.7% and TD = 60.0% each reported they have little to no control of their behaviour).

The Locus of Causality dimension was composed of a single question examining adolescents’ external and internal attributions for their most problematic behaviour (i.e., “Is it something outside of you or inside of you that makes you [behaviour]?”). There was no differences in the proportion of adolescents with ASD (77.8%), adolescents with ADHD (70.8%), and TD adolescents (66.7%) who attributed their most problematic behaviour to internal causes $\chi^2 (1, N = 69) = .72, p = .70$.

The Total Stigmatization attribution did not reveal any significant differences across groups, $F(2, 62) = 2.05, p = .138, \eta^2 = .06$. However, when adolescent scores on items pertaining to parent, teacher, and peer stigmatization were examined results of the MANOVA showed that there was a significant effect of diagnosis on the stigmatization variables (Wilks’ $\Lambda = .67, F(6, 130) = 4.73, p < .001, \eta^2 = .18$). Table 2.8 contains the means and standard deviations on the dependent variables for the three groups. Univariate analysis of each individual dependent variable showed that the three groups differed in Teacher Stigmatization and Parent Stigmatization. There was a trend for group differences of Peer Stigmatization ($p = .061$).

Pairwise post hoc comparisons showed that the ASD group reported significantly lower ratings of Teacher Stigmatization ($p = .001$) and Parent Stigmatization ($p = .043$) than the ADHD group. There were no differences between the ASD and ADHD group in Peer Stigmatization and the differences between the ASD and TD group did not reach significance levels ($p = .073$).
Discussion

Summary of Main Findings

This study aimed to gather information about how adolescents with ASD perceive themselves, interpret their ASD symptoms and behaviours, and to what degree they believe their behaviours are pervasive, uncontrollable, internally caused, and stigmatizing. The main finding across all three research questions suggested that adolescents with ASD have some awareness of the challenges associated with ASD and hold differing self-perceptions of competence and behavioural attributions when compared to ADHD or TD adolescents. Specifically, adolescents rated lower self-perceptions of competence on peer salient domains, as well as lower ratings of job competence, athletic competence, and global self-worth. Secondly, as expected, adolescents reported fewer ASD symptoms than their parents and greater self-awareness was associated with lower self-perceived social acceptance. Lastly, adolescents with ASD believed that their ASD symptoms manifested across contexts and were stable over time. It is not clear, however, that they understand the degree to which their behaviours are uncontrollable. The majority of adolescents with ASD agreed that their most problematic behaviour was due to something inside them; this view was also true for the ADHD and TD adolescents. The stigma attributions revealed differing results for adult contexts, with trends toward group differences in peer stigmatization. Participants reported less adult stigmatization associated with their most problematic behaviour when compared to adolescents with ADHD. The findings and implications of the study are described in more detail below.

Self-Concept and Perceived Competence

Similar to studies using the SPPC, the SPPA provided evidence of differing self-perceptions of competence across domain areas among adolescents with ASD. Adolescents with
ASD were able to reflect on their competence and reported poorer self-perceived competence relative to controls in self-perceptions of Social Acceptance, Close Friendship, Romantic Appeal, Athletic Competence, Job Competence and Global Self-Worth. Differentiation across these domains indicates that this instrument can be meaningfully employed with this special population. Moreover, high internal consistencies suggest that the measure is psychometrically sound for adolescents with ASD.

The current results support previous findings of poorer self-perceptions of social acceptance and athletic competence in children and adolescents with ASD relative to controls (Capps et al., 1995; Jennes-Coussens et al., 2006; Williamson et al., 2008). Adolescents with ASD in the current sample perceived themselves as less competent in their interpersonal relationships, close friendships, and athletic abilities than did their peers with ADHD or no diagnosis, highlighting their awareness and ability to reflect on the specific social and adaptive difficulties they experience.

It was predicted that adolescents with ASD would display lower self-perceptions of competence on peer-salient domains, such as Social Acceptance, Close Friendships and Romantic Appeal. Only scores on the Social Acceptance and Close Friendship domains were significantly different from both the ADHD and TD groups, which is consistent with the inherent social difficulties and reports of limited friendships, loneliness, and poorer friendship qualities in adolescents with ASD (Bauminger et al., 2003; Chamberlain et al., 2007; Locke et al., 2010; Mazurek & Kanne, 2010; Whitehouse et al., 2009). Adolescents with ASD reported lower perceptions on the Romantic Appeal domain when compared to the ADHD group only. This scale taps into the respondent’s belief that he or she is able to initiate intimate relations and that others are interested in initiating intimate relations with them (Harter, 1990). Anecdotally,
questions on this scale tended to be the most difficult for adolescents with ASD, as they often asked clarification questions or indicated that they were not interested in dating. One participant became very uncomfortable and refused to answer questions from the Romantic Appeal domain. Notably, there was a moderate negative correlation between age and Romantic Appeal in the ASD sample, likely because dating becomes more salient for older individuals with ASD (Neemann, Hubbard & Masten, 1995; Shulman & Sharf, 2000). This interpretation could be investigated in future research comparing younger and older adolescents using cross-sectional or longitudinal designs.

When compared to the TD group, adolescents with ASD perceived themselves as being less competent with respect to obtaining and maintaining a job. Self-perception of job competence has not been measured in previous studies, but quality of life studies in young adults with ASD highlight their struggles with job attainment (Jennes-Coussens et al., 2006). These findings also complement the low employment rates among individuals with ASD (Eaves & Ho, 2008; Howlin, 2004; Taylor & Seltzer, 2011).

There were no group differences for self-perceptions of Scholastic Competence and Behavioral Conduct; and ratings of Physical Appearance also did not differ across groups. These findings are consistent with previous studies of self-perceptions in adolescents with ASD (Capps et al., 1995; Williamson et al., 2008).

Global self-worth was significantly lower in the ASD sample relative the ADHD group, but not relative to the TD group. The lack of differences for global self-worth between the ASD and TD groups is similar to findings reported by Williamson et al. (2008) study, but not by Capps et al. (1995). It is not clear why there are inconsistencies across these studies, although there are differences in age (Capps et al. 9-16 years; Williamson et al. 11-15 years; and the
present study 13-18 years). Different recruitment strategies may also explain discrepant findings (i.e., Capps et al. recruitment not described; Williamson et al. participants in mainstream education with no additional diagnoses; and the present study participants in mixed education settings and with comorbid diagnoses). Another possibility for differences in self-worth across studies may be that individuals protect their self-worth by attaching greater value to their competent areas and devaluing those they believe they are less competent in (Rosenberg, 1979). Williamson et al. highlighted this by suggesting that adolescents with ASD placed more emphasis on competencies in which they attain more success and feel they have a greater degree of control. Thus, it may be that individuals with ASD value more success and competence in other areas (e.g., scholastic competence, behavioural conduct) than social acceptance, which in turn has a more positive effect on their overall self-worth. Williamson et al. also found peer and parent salient competencies, rather than peer or parent approval, to be more predictive of global self-worth among adolescents with ASD, whereas among the TD adolescents, peer and parent salient competencies, as well as peer and parental approval, all predicted global self-worth. The authors concluded that this finding reflects a possible difference in the self-evaluation processes among individuals with ASD, in which the social perceptions of others’ opinions are not seen as relevant. It would also be helpful to look at the levels of importance that individuals place on each domain. Harter (1993) suggested that importance levels are more predictive of self-esteem and can be completed as an adjunct to the SPPA. Therefore, perceived competency in domain areas deemed important could predict differences in global self-worth. It remains to be determined whether the same findings would apply to individuals with ASD.

Findings from this study also revealed that adolescents with stronger verbal intellectual abilities were more likely to rate themselves as having lower athletic ability and job competence.
Consistent with Capps et al. (1995) and Vickerstaff et al. (2007), lower ratings of social competence were also moderately associated with verbal intelligence. It is likely that higher functioning individuals with ASD experience greater societal expectations to establish relationships, complete educational programming, become independent, and obtain a job. Sterling et al. (2008) has suggested that for higher functioning individuals with ASD, the developmental gap between themselves and same-aged peers may become more profound in adolescence and young adulthood because they are more aware that they are developmentally behind their peers and lack the skills and competencies to work towards independent living, intimate relationships, and personal job satisfaction. Although there are a number of interventions that target social skill development in adolescence and early adulthood, these findings highlight the need for more support and intervention to address skills and competencies in other key areas (e.g., athletic abilities, job readiness and career planning, romantic appeal and sexuality).

Self-Awareness of ASD Characteristics and Behaviours

Adolescents with ASD in this study demonstrated some awareness of the difficulties associated with their ASD diagnosis, even though they tended to under-reported relative to their parents. The majority of adolescents recognized some symptoms of ASD, including social communication challenges (e.g., difficulties with eye contact, social smiling, use of facial expressions, reciprocal conversation, and atypical speech or voice quality) and fixated interests and repetitive behaviours (e.g., circumscribed interests, negative responses to sensory stimuli, hand/finger mannerisms, and sensory interests). It remains possible that adolescents’ awareness is accurate, and parents tend to overrate their problems. The latter interpretation is less likely
because best estimate diagnoses completed by the clinician confirmed significant social-communication and behaviour difficulties among the adolescents.

When compared to parent ratings, adolescents had significantly less awareness of the amount of ASD and Social Communication difficulties. Such discrepancies are similar to other studies that have examined self- and parent-perceptions of skills and behaviours among children and adolescents with ASD (Cederlund et al., 2010). Other studies have found differences amongst children or adolescents with ASD and their parents with regards to perceived social skills or social competence levels (Barnhill et al., 2000; Koning & Macgill-Evans, 2001; Knott et al., 2006; Nicpon et al., 2010). All of these studies have addressed how discrepancies between self- and parent-ratings may be related to impaired theory of mind in ASD. Another possibility is that adolescents are integrating information about themselves in a self-protective manner, which has been described in the literature as a positive illusory bias (PIB i.e., disparity between self-report of competence and actual competence; Hoza et al., 2002). Researchers working with children and adolescents with ADHD have reported robust findings of PIB (Evangelista et al., 2008; Hoza et al., 2002; 2004; Owens et al., 2007; Owens & Hoza, 2003) and have indicated that PIB may be adaptive in order to maintain self-esteem, motivation, and task persistence. However, a PIB can also be maladaptive by leading to increased resistance to treatment if individuals are less likely to process negative feedback or recognize the need to improve their behaviour (Owens et al., 2007). Factors affecting treatment resistance are an important area of focus for ASD behavioural and social interventions. As such, it would be important for clinicians to get a better sense of the disparity between adolescents’ perceptions of their behaviours and their actual presentation of symptoms, especially since the differences in perceptions can make treatment planning and goal setting difficult. Many social skills intervention programs employ
parent report measures to evaluate social skills, however, the inclusion of self-report measures may result in a better understanding of the adolescent’s awareness and perception of their behaviours and social skills, including attributions about their behaviour. This could then inform treatment planning and goal setting.

Although there was a high rate of parent-adolescent agreement on the majority of the items on the Alex-ASD, there was less agreement on specific items associated with difficulties in social responsiveness, pointing to express interest, the use of inappropriate questions or comments, the presence of stereotyped utterances and delayed echolalia, and changes in routine. It may be that these items are inherently more difficult for adolescents with ASD to objectively evaluate because of their difficulties with perspective taking and theory of mind. They may not be able to accurately evaluate whether their responses or questions to others may be stereotyped, inappropriate, or limited because they are unable to perceive, remember, or adequately interpret social information effectively. Other studies have also found greater parent-child discrepancies between specific items in social-communication areas (Bishop & Seltzer, 2012; Cederlund et al., 2010; Koning & Magill-Evans, 2001). As first suggested by Lee and Hobson (1998) and Jackson et al. (2011), individuals with ASD have specific rather than more global impairments in self-awareness related to the social and psychological aspects of self-concept. Taken together, these studies show that individuals with ASD display some self-awareness of their behaviours and diagnosis and that their self-understanding is not as impaired as has been previously described. Future studies may benefit from exploring the relationship between self-awareness and theory of mind and perspective taking abilities.

In general, parents were more likely to report the presence of ASD behaviours for their adolescent than did the adolescents themselves, with two exceptions: there were trends (albeit
non-significant) for higher reports of hand/finger and complex body mannerisms by the adolescents. This suggests that some individuals with ASD may have more insight into their motor mannerisms and may be better able to self-regulate and consciously control these behaviours, perhaps only engaging in them out-of-sight from parents. Many individuals commented that they are more likely to engage in these behaviours when stressed or excited. One individual reported that he has an “overactive imagination” that leads to his complex body mannerisms. He also indicated that he only engages in these behaviours during the evening when at home, suggesting that he may be more aware of the social implications of displaying these behaviours in public. Studies have found age-related differences in restricted, repetitive behaviours, such that older individuals with ASD exhibit fewer motor stereotypies than younger children (Esbensen, Seltzer, Lam & Bodfish, 2010; Seltzer et al., 2003; South, Ozonoff & McMahon, 2005), but most of these studies rely on parent report or observations of the behaviours rather than self-report (Leekham, Prior & Uljarevic, 2011). Future studies may wish to include self-reports of motor mannerisms and other repetitive and restricted behaviours to better understand and explore the developmental and possible adaptive changes in these behaviours across time.

Although adolescents were, for the most part, less likely to endorse ASD symptoms than their parents, more than half endorsed special isolated skills often associated with ASD (e.g., strengths in reading, memory, computation, visuospatial, and musical abilities). These numbers are far higher than what is typically reported by third-party raters in the literature (Bolte & Poustka, 2004; Howlin et al., 2009). Many of the adolescents also endorsed positive qualities about themselves (e.g., kind and generous person, good at drama, good fashion sense), indicating that they were able to identify individual strengths. They were least likely to endorse strengths in
their leadership and athletic abilities, which was generally consistent with their competency ratings on the SPPA. These results suggest that it was important to include potential strength-based items because most of the ASD behaviours on the Alex-ASD focus on social or communication deficits and odd or atypical behaviours. When responding about the presence of circumscribed interests, many adolescents proudly commented on their extensive knowledge about a particular topic or area of interest (e.g., video games, maps, movies, transportation, music, Japanese animation). Further examination of adolescents’ perceptions of their strengths and weaknesses were explored in Study 2, but the findings from this study highlight the importance of focusing on some of the positive qualities of ASD and utilization of individual strengths when working with individuals with ASD.

One of the aims of this study was to determine if there was a relationship between an adolescent’s understanding or awareness of their ASD symptoms and psychosocial functioning. For this study, self-awareness was operationalized as the total number of ASD behaviours which the adolescent and parent agreed upon. Awareness was not correlated with age but there was a moderate negative association between self-awareness of ASD symptoms and the age an adolescent learned about their diagnosis. As would be expected, adolescents who knew about their diagnosis for a longer period of time had more awareness into the presence or absence of their ASD symptoms. This may also be a function of parent-child dialogue around ASD behaviours. Verbal cognitive ability was also found to impact the degree to which an adolescent is aware of the symptoms associated with their diagnosis. Specifically, adolescents with higher intellectual abilities appear to see themselves more accurately. These results are consistent with other studies that have examined social competence and intellectual functioning (Capps et al.,
1995; Sterling et al., 2008; Vickerstaff et al., 2007) and suggest that higher cognitive ability may be a vulnerability factor for the emotional well-being of some individuals with ASD.

Adolescents who demonstrated more awareness of their difficulties reported lower feelings of social acceptance than adolescents with less awareness of their ASD symptoms. However, the low value for $R^2$ (.20) suggests that these results, though significant, leave much of the variance in the adolescents’ perceptions of social acceptance unexplained. Other studies have demonstrated a negative relationship between social self-awareness and depressive symptomatology (Butzer & Konstantareas, 2003; Capps et al., 1995; Hedley & Young, 2006; Vickerstaff et al, 2007; Wing, 1981). Further long-term research will be important to investigate differences in outcome for adolescents with different levels of awareness of their difficulties. Targeting their awareness and understanding of the social and communicative difficulties with focused interventions may help ameliorate psychosocial difficulties and improve feelings of self-worth among adolescents with ASD. Kanner (1973) suggested that an awareness of differences resulted in best outcomes among individuals with ASD because they had a “conscious effort” to improve their difficulties. This is not surprising given that better insight and an increased awareness into psychiatric and behavioural symptoms are often associated with good clinical outcomes in other clinical populations (Eisen, Phillips, Coles & Rasmussen, 2004; Schwartz et al., 1997; Storch et al., 2008). Self-understanding and awareness have also proven to be important in the psychosocial adaptation among clinical and mental health populations (Davidson, 2003; Davidson & Strauss, 1992) and a successful attribute for individuals with learning disabilities (Goldberg et al., 2003; Raskind et al., 1999).

Previous research has suggested that individuals with ASD display an increased desire for social relations (McGovern & Sigman, 2005) and heightened awareness of social isolation and
incompetence (Ghaziuddin, Alessi & Greden, 1995; Capps et al., 1995) by adolescence and early adulthood. Adults with ASD have also reported making deliberate efforts to improve their social understanding and self-awareness to compensate for the effects of their ASD (Muller et al., 2008). Future research may benefit from comparing children and adolescents to determine if there is a developmental trend in their increased awareness and self-perceptions. Moreover, if significant differences were found, it would be important to discern at what age this typically occurs so that intervention could be directed to develop more effective coping skills; indeed a longitudinal design may yield the best information.

Although there are several third-party diagnostic scales developed for children and adolescents with ASD, there are only two validated, self-administered scales used to measure ASD symptoms in adults (Autism Spectrum Quotient, Baron-Cohen et al., 2001; Ritvo Autism and Asperger Diagnostic Scale, RAADS, Ritvo et al., 2008). Some studies have used modified versions of parent questionnaires (Cederlund et al, 2011) or validated self-administered scales (Bishop & Seltzer, 2012; Johnson et al., 2009) to assess knowledge of ASD symptoms. Gotham (2010) developed a 34-item inventory for her dissertation asking adults with ASD to rate to what degree each ASD symptom described their own behaviour. Like other scales used in previous studies, the Alex-ASD was developed to assess adolescents’ self-identification of their own ASD characteristics and the symptom that they perceived to be their most problematic behaviour. However, unlike the previous instruments described above, this interview utilized a structured-visual method with a projective component to facilitate engagement and to assist with processing and understanding of the ASD symptoms.

Scores on the Alex-ASD were independent of participant characteristics, indicating that there was no relation between age, age of diagnosis, age of diagnosis disclosure, or cognitive
functioning and participant ratings on the Alex-ASD. This experimental tool also showed evidence of good internal consistency for Total ASD behaviours and items on the Fixated Interests and Repetitive Behaviours scale, while the internal consistency was below satisfactory levels for items in the Social Communication domain. Notably, unsatisfactory internal consistency ratings (\( \alpha = .60 \) and \( \alpha = .53 \)) have been reported for other self-report measures of communication in ASD, such as the Language and Communication scale of the Ritvo Autism and Asperger’s Diagnostic Scale (RAADS; Ritvo et al., 2008) and a revised Swedish version of the RAADS, called the RAADS-Revised (RAADS-R; Anderson et al., 2011). These self-rating scales have been devised to assess functioning in the domains of social interaction, language/communication, and sensory motor/stereotypies. In comparison, internal consistencies on the remaining two scales of the RAADS and RAADS-R, Social Relatedness and Sensorimotor and Stereotypies, are adequate (\( \alpha = .86/.87 \) and \( \alpha = .70/.73 \), respectively). Bishop and Seltzer (2012) also reported lower internal consistency ratings on the subscales of the modified version of the Autism-Spectrum Quotient (AQ; Baron-Cohen et al., 2001) that was administered to an intellectually heterogeneous group of adults with ASD. The overall AQ was acceptable (\( \alpha = .74 \)) but the coefficients for some of the subscales of the AQ tended to be lower and more comparable to the present findings (Social Skill, \( \alpha = .76 \); Attention Switching, \( \alpha = .57 \); Attention to Detail, \( \alpha = .59 \); Communication, \( \alpha = .61 \), and Imagination, \( \alpha = .42 \)).

Anecdotally, most of the adolescents responded quite well to completing this type of self-report interview format. For the most part, they were observed to be interested in the picture-based interview. There was no negative reaction to the age or look of the ‘Alex’ character and no participant seemed to be challenged by the task of comparing themselves to Alex. A few participants even asked questions about Alex or commented on Alex’s behaviours. Several
adolescents spontaneously reported they were “a lot like Alex” and one participant asked if Alex had autism. In addition, some of the adolescents used the pictures to launch into a discussion about their own experiences with specific ASD symptoms. Most of the adolescents made spontaneous comments as they responded to each of Alex’s behaviours.

Overall, the Alex-ASD proved to be a useful experimental tool for self-identification of the ASD symptoms experienced by adolescents with ASD. Participants in this study appeared to respond well to this type of self-report interview format and often made spontaneous comments about their own experiences as they responded to the character’s behaviours. A picture-based interview method may be useful to clinicians working with adolescents with ASD in order to help understand an adolescent’s understanding and awareness of their difficulties. By pictorially describing and normalizing the ASD behaviours in a fictional character of the same age, adolescents may have been more willing to acknowledge their difficulties. It would be worthwhile to explore the extent to which the picture-based interview method actually improved comprehension and engagement in the task (i.e., versus a written questionnaire, for example). Future studies are needed to empirically validate the sensitivity and specificity of picture-based interviews over self-report written questionnaires. In addition to ASD symptoms, the utility of using picture-based interviews (e.g., Dominic-R; Valla et al. 1997; or Adolescent Dominic; Smolla, Valla, Bergeron, Berthiaume & St-Georges, 2004) to assess symptoms of mental health problems could be examined for use with the ASD population especially given the high rate of comorbid psychiatric disorders in ASD (Leyfer et al., 2006; Mattila et al., 2010; Simonoff et al., 2008).
Attributions and Stigmatization of Behaviours Associated with ASD

A handful of studies have examined the relationship between social attributions and self-concept in individuals with ASD (Barnhill, 2001; Barnhill & Smith-Myles, 2001; Flood, Hare & Wallis, 2011; Hedley & Young, 2006; Meyer et al. 2006). The current study is the first to examine the attributions that adolescents with ASD make about their own behaviours. According to attribution theory, individuals who view their most problematic behaviour as not within their control, stable in time, and occurring across different situations are more likely to feel that change is hopeless (Weiner, 1985).

The AAPBQ, based on Weiner’s (1985) attribution theory, was the experimental tool adapted from other studies (Varma, 2007; Kaider et al., 2003; Wiener et al., 2012) and used to measure the attributions that adolescents make about their problem behaviours. Compared to previous studies that have examined social attributional style among children with ASD, this questionnaire has the advantage of asking the participants to report their attributions for the ASD behaviour they are most concerned about. It is, however, important to note that different identified behaviours may have influenced the responses in different ways.

The most frequently reported problematic ASD symptoms were lack of friendships, circumscribed interests, or difficulties with changes in routine or their environment. In the present study, adolescents with ASD were more likely to view their most problematic behaviour as pervasive when compared to typically developing peers. However, pervasiveness attributions between adolescents with ASD and ADHD were not different, indicating that both groups believe that the behaviours and characteristics associated with their diagnosis are pervasive across contexts and stable over time. Flood et al. (2011) also found that adolescents with ASD are more prone to global attributions than typically developing peers. According to attribution
theory, adolescents who see their problematic behaviour as more pervasive and unchanging are more likely to have lower self-concepts and lower expectations about their future. In addition, there may be little motivation to change this behaviour or engage in more adaptive and/or socially appropriate responses.

Contrary to our hypothesis, adolescents with ASD did not rate their most problematic behaviours as more *uncontrollable or internally caused* than the comparison groups. The majority of adolescents with ASD made internal attributions, like adolescents with ADHD and TD controls, and showed some awareness that the behaviours associated with their diagnosis are biologically based. Previous researchers have reported that children with ADHD have more global, stable, and uncontrollable attributions when compared to children without ADHD for their self-identified most problematic behaviours (Kaider et al., 2003; Wiener et al., 2012). By adolescence, however, Varma (2007) found that individuals with ADHD reported being better able to control their behaviours and view their behaviours as occurring in specific, rather than global situations, which is similar to the TD group of peers. Adolescents with ADHD were, however, more concerned with the stigmatizing aspects of their behaviour when compared to TD peers (Varma, 2007). Further research examining the behavioural attributions between children and adolescents with ASD may yield support for a similar developmental shift.

With regard to *perceived stigma*, adolescents with ASD in the current study reported that they believed their parents and teachers were less bothered by their ASD behaviour than was reported by adolescents with ADHD. Note, however, that the identified ADHD behaviours were perhaps more disruptive in home and school settings. It may be possible that, in comparison to the ADHD sample, adolescents with ASD receive more support and understanding from adults in their environment. This finding is consistent with reports from the Williamson et al. study, which
suggested that parents of children with ASD are more accommodating of their child’s difficulties than parents of typically developing peers. Results from the present study also suggest that adolescents with ASD perceive greater adult support and understanding than adolescents with ADHD. Current evidence in the ADHD literature suggests that ADHD as a disorder and the specific characteristics associated with the diagnosis are often stigmatized by adults (Martin, Pescosolido, Olafsdottir & McLeod, 2007; Bell, Long, Garuan & Bossing, 2011). As such, adolescents with ASD and comorbid attention difficulties may be at risk for greater stigmatization.

The group difference in perceived peer stigmatization approached significance, with adolescents with ASD reporting that their friends or classmates were more bothered by their problematic behaviour than TD peers. This is consistent with their self-perceptions on the social competency/likeability scale. This trend suggests that some adolescents with ASD may be at risk for believing that their problematic behaviours will continue to be bothersome to their peers in the future. Notably, there were no differences between adolescents with ASD and ADHD. It has been suggested that individuals with a disability might internalize people’s stigmatizing opinions of them (Martz, 2004). Stigma is often mentioned as a risk factor for poor psychological health (Westbrook, Bauman & Shinnar, 1992). Recent literature has also discussed the increased reports of bullying and peer victimization among children and adolescents with ASD (Cappadocia et al., 2012; Humphrey & Symes, 2010; Shtayermman, 2007, 2009). Although bullying issues were not directly measured in this study, some of the adolescents spontaneously reported negative peer victimization and bullying experiences, particularly in their middle school years. Their responses on the SPPA and the attribution questionnaire suggest that many of the adolescents in this study were aware of their difficulties with peer likeability, and some reported peer stigmatization.
Similarly, peers may have insufficient information about their classmates with ASD and could benefit from programs that foster better peer support and interactions.

Other studies highlight the need to find ways to sensitively raise awareness and understanding of ASD among peer groups, such as the Circle of Friends program (Gus, 2000; Fredrickson, Warren & Turner, 2005; Whitaker, Barratt, Joy, Potter & Thomas, 1998). Yet, as this study as shown, in addition to interventions targeting peer awareness and attitudes, it is also important to provide concurrent programs to develop social cognition and problem solving skills, as well as to better understand and address possible stigmatization and pervasiveness attributions, for adolescents with ASD. To date, there is one manualized program that uses attributional training among individuals with ASD to help them achieve more positive and hopeful attribution patterns (e.g., ECLISPE Model; Moyer, 2009). This particular program proposes that attribution training should be an important part of social cognition programs because individuals must be able to attribute or assess their circumstances accurately in order to self-regulate or modulate their behaviours. Although the program uses the principles of attribution theory, empirical evaluation of this program has not been sufficiently examined. More research into the impact of attributions on psychosocial adjustment and possible intervention programs is important.

**Strengths, Limitations and Future Directions**

The current study has several strengths and makes some original contributions to understanding of the self-perceptions, self-awareness and behavioural attributions of adolescents with ASD. First, the ASD sample was recruited from multiple sources (e.g., hospital developmental clinics and research units, online, community programs), which resulted in a heterogeneous, although high-functioning sample. While the study did not intentionally seek a
representative sample, participants also exhibited some of the demographic characteristics (e.g., sex distribution, comorbid disorders) that have been described in the literature. For example, the male-to-female ratio of 8:1 in this study resembles those of other studies with samples of adolescents with High Functioning Autism and Asperger Syndrome (Scott, Baron-Cohen, Bolton & Brayne, 2002; Whiteley, Todd, Carr & Shattock, 2010; Williams, Sidebotham & Emond, 2008). In addition, 83% of the adolescents had at least one comorbid disorder, which is consistent with other studies examining comorbid psychiatric disorders in children and adolescents with high functioning ASD (Leyfer et al., 2006; Mattila et al., 2010; Simonoff et al., 2008). Another strength is in the careful diagnostic process used in screening the sample, including additional testing to confirm diagnosis, and the use of clinical best estimates diagnosis rather than relying solely on parent or previous clinician reports. Finally, care was taken to develop a trusting professional relationship with each of the adolescents in order to enhance the likelihood that they would be comfortable talking about their diagnosis, their individual strengths and weaknesses, and any associated social-emotional challenges.

There were several limitations of the current study. Although the sample size is well within the typical range for autism research, it is small and there may have been limited power to detect some effects. The data on the ADHD and TD groups were collected for a different study. Although an effort was made to select participants who matched the ASD participants in terms of gender, age, and IQ, the age and IQ matching was not perfect. There was some diversity in the sample with respect to ethnic background, socioeconomic status, school board and type of school program, and location of residence (e.g., downtown Toronto, suburbs, and other parts of the province). The sample, however, was largely Caucasian and the majority of the mothers had some college/university and/or graduate education. While the male-to-female ratio in this study
was generally consistent with ratios reported in the literature, the ratio did not allow for an examination of gender differences across the measures. Previous studies have suggested that adolescent girls with ASD have higher internalizing symptoms than boys with ASD (Barnhill & Smith-Myles, 2001; Soloman, Miller, Taylor, Hinshaw & Carter, 2012).

The Alex-ASD and the AAPBQ were novel experimental tools used to assess adolescents’ self-identification of their own ASD characteristics and attributions associated with ASD symptoms. These tools have not been previously validated. As discussed above, the internal consistency for overall ratings on both tools was acceptable, but was more variable in certain domains. It is also important to note that the responses to the AAPBQ were in relation to an ASD behaviour that the adolescent identified as most concerning for them. It is possible that the different behaviours inserted into the questions might have affected the results. There was variation within the ASD group with respect to the type of problematic ASD behaviour that was identified (i.e., social communication or fixated interests and repetitive behaviour) as well as between the ASD and control groups (i.e., ASD behaviours or ADHD-related behaviours).

Longitudinal studies investigating adolescents’ self-report of ASD symptoms and psychosocial functioning over time might provide a better understanding of how individuals’ self-perceptions may change and develop during this difficult developmental transition period. Further, by following a sample of adolescents longitudinally, it would be easier to examine age and cohort effects and identify the factors that promote or exacerbate psychosocial functioning during this critical period of development.

**Conclusion and Clinical Implications**

Adolescents with ASD are aware of and able to share their perceptions of strengths and weaknesses, their perceptions of the behaviours that are problematic for them, and their beliefs
about these behaviours. By gathering this information directly from adolescents themselves, important insights about their perceptions and needs were revealed that could not have been acquired through third-party sources. Consequently, clinicians working with adolescents with ASD should routinely assess psychosocial functioning using multi-informant ratings that include self-report. Multiple informant reports can also be used to facilitate discussions between informants (e.g., adolescents and their caregivers) to increase understanding of the ASD diagnosis and psychosocial functioning, and to support the family as a complex unit. This may be particularly important for adolescents with a new diagnosis.

Findings from this study may also be informative in the development of programs and refinement of strategies for engaging adolescents in intervention designed to enhance their understanding of their diagnosis, and to provide them with more effective coping tools to help them transition through adolescence and young adulthood. Specifically, the current results suggest that adolescents’ perceptions of their self-worth and competence are important target areas for intervention. In addition to social interventions that target social cognition and friendship skills, clinicians should be supporting youth with ASD to address their perceptions and feelings of self-worth about job competence and vocational training, sexual development and romantic appeal, as well as athletic competence. In addition to psychosocial functioning, assessing an individual’s awareness and understanding of their diagnosis can be an important adjunct to beginning treatment with an adolescent with ASD. As this study has shown, adolescents with ASD are capable of recognizing some of the difficulties associated with their diagnosis. The study also supports the clinical impression that earlier diagnosis and disclosure are associated with better self-awareness about ASD symptoms. Clinicians can work collaboratively with youth to help them understand how they experience their world and what
types of interventions might be most beneficial for them. As reported by Muller, Schuler and Yates (2008), some adolescents and young adults with ASD described ongoing efforts to compensate for the effects of their ASDs by developing greater social or self-awareness through reading books and articles about ASD, joining autism support groups, and participating in social skills group. Given this interest, caregivers and clinicians can serve as an additional resource to help connect individuals with ASD with appropriate resources in their community and on the Internet.

The current study also highlighted the importance of acknowledging attributional style to provide a deeper understanding of an individual’s motivation, affect, performance, and expectations about future outcomes. Clinicians can use the Alex-ASD or similar measures to help adolescents identify problem behaviours and to determine attributional patterns. For example, clinicians may find it helpful to address perceived stigma, as well as continue to encourage their clients to see ways in which their behaviours are specific to certain situations, rather than being pervasive. Adolescents with ASD in this study felt more supported by their parents and teachers than did a clinical comparison group, but felt less supported by their peers. School-based interventions to help peers learn to be more sensitive to the feelings of adolescents with ASD may be helpful.
### Table 2.1

**Gender, Age and Verbal Intelligence for ASD and Non-ASD Groups**

<table>
<thead>
<tr>
<th></th>
<th>Diagnostic Group</th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>ASD</td>
<td>ADHD</td>
<td>TD</td>
<td>F(2,69)</td>
<td>p</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>24</td>
<td>21</td>
<td>18</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>3</td>
<td>3</td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>14.96 (1.31)</td>
<td>15.11 (1.44)</td>
<td>15.25 (1.32)</td>
<td>.267</td>
<td>.77</td>
</tr>
<tr>
<td>Range</td>
<td>13.00-18.08</td>
<td>13.19-17.93</td>
<td>13.12-18.57</td>
<td></td>
<td></td>
</tr>
<tr>
<td>IQᵃ</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>100.48 (14.27)</td>
<td>100.25 (6.85)</td>
<td>107.38 (10.55)</td>
<td>2.93</td>
<td>.06</td>
</tr>
<tr>
<td>Range</td>
<td>75-137</td>
<td>86-115</td>
<td>89-132</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Note.** ASD = Autism Spectrum Disorder. ADHD = Attention Deficit Hyperactivity Disorder. TD = Typically Developing.

ᵃIQ scores for the ASD group were derived from the Full Scale IQ scores of the WASI (N = 18), WISC-IV (N = 3) and SB-5 (N = 6). IQ scores for the ADHD and TD groups were derived from an abbreviated measure of the intelligence of the WASI (Vocabulary and Matrix Reasoning subtests).
### Table 2.2

**Self-Perceptions of Competence (SPPA) of Adolescents with ASD, ADHD and TD**

<table>
<thead>
<tr>
<th>SPPA scales</th>
<th>Diagnostic Group - M (SD)</th>
<th>F(2,68)</th>
<th>p</th>
<th>$\eta^2$</th>
<th>Post hoc differences</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>ASD ($N = 26$)</td>
<td>ADHD ($N = 24$)</td>
<td>TD ($N = 21$)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Scholastic Competence</td>
<td>2.91 (0.78)</td>
<td>2.55 (0.70)</td>
<td>2.99 (0.55)</td>
<td>2.67</td>
<td>.077</td>
</tr>
<tr>
<td>Behavioral Conduct</td>
<td>2.85 (0.72)</td>
<td>2.96 (0.44)</td>
<td>3.05 (0.59)</td>
<td>0.63</td>
<td>.538</td>
</tr>
<tr>
<td>Social Acceptance</td>
<td>2.58 (0.64)</td>
<td>3.28 (0.64)</td>
<td>3.28 (0.52)</td>
<td>10.97</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Close Friendship</td>
<td>2.72 (0.74)</td>
<td>3.31 (0.66)</td>
<td>3.42 (0.72)</td>
<td>6.83</td>
<td>.002</td>
</tr>
<tr>
<td>Romantic Appeal</td>
<td>2.40 (0.67)</td>
<td>2.89 (0.65)</td>
<td>2.65 (0.51)</td>
<td>3.81</td>
<td>.027</td>
</tr>
<tr>
<td>Physical Appearance</td>
<td>2.99 (0.59)</td>
<td>3.09 (0.65)</td>
<td>2.97 (0.59)</td>
<td>0.27</td>
<td>.762</td>
</tr>
<tr>
<td>Athletic Competence</td>
<td>2.21 (1.01)</td>
<td>3.02 (0.62)</td>
<td>3.10 (0.71)</td>
<td>9.12</td>
<td>.001</td>
</tr>
<tr>
<td>Job Competence</td>
<td>2.34 (0.61)</td>
<td>2.78 (0.65)</td>
<td>2.95 (0.54)</td>
<td>5.39</td>
<td>.007</td>
</tr>
<tr>
<td>Global Self-Worth</td>
<td>2.95 (0.73)</td>
<td>3.38 (0.40)</td>
<td>3.30 (0.42)</td>
<td>4.27</td>
<td>.018</td>
</tr>
</tbody>
</table>

*Note. ASD = Autism Spectrum Disorder. ADHD = Attention Deficit Hyperactivity Disorder. TD = Typically Developing.*

*p < .05, **p < .01, ***p < .001, difference between adolescent with ASD sample and ADHD or control comparison group.

*aOne participant refused to complete questions for Romantic Appeal and as such was removed from the MANOVA.*
Table 2.3
Frequency of ASD Symptoms Endorsed by Adolescents with ASD

<table>
<thead>
<tr>
<th>Behaviours in each Domain</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Social Communication (15 items)</strong></td>
<td></td>
</tr>
<tr>
<td>Eye contact</td>
<td>70.4% (19)</td>
</tr>
<tr>
<td>Social smiling</td>
<td>55.6% (15)</td>
</tr>
<tr>
<td>Range of facial expressions</td>
<td>55.6% (15)</td>
</tr>
<tr>
<td>Reciprocal conversation</td>
<td>55.6% (15)</td>
</tr>
<tr>
<td>Friendships</td>
<td>44.4% (12)</td>
</tr>
<tr>
<td>Inappropriate use of facial expressions</td>
<td>37.0% (10)</td>
</tr>
<tr>
<td>Offering comfort</td>
<td>33.3% (9)</td>
</tr>
<tr>
<td>Shared enjoyment</td>
<td>33.3% (9)</td>
</tr>
<tr>
<td>Sharing</td>
<td>29.6% (8)</td>
</tr>
<tr>
<td>Conventional or instrumental gestures</td>
<td>25.9% (7)</td>
</tr>
<tr>
<td>Showing and directing attention</td>
<td>22.2% (6)</td>
</tr>
<tr>
<td>Pointing to express interest</td>
<td>22.2% (6)</td>
</tr>
<tr>
<td>Nodding and head shaking</td>
<td>22.2% (6)</td>
</tr>
<tr>
<td>Inappropriate questions or statements</td>
<td>22.2% (6)</td>
</tr>
<tr>
<td>Inappropriate social responses</td>
<td>14.8% (4)</td>
</tr>
<tr>
<td><strong>Fixated Interests/Repetitive Behaviours (12 items)</strong></td>
<td></td>
</tr>
<tr>
<td>Circumscribed interests</td>
<td>92.6% (25)</td>
</tr>
<tr>
<td>Abnormal or negative response to sensory stimuli</td>
<td>63.0% (17)</td>
</tr>
<tr>
<td>Hand or finger mannerisms</td>
<td>55.6% (15)</td>
</tr>
<tr>
<td>Unusual sensory interests</td>
<td>51.9% (14)</td>
</tr>
<tr>
<td>Complex body mannerisms or stereotyped body movements</td>
<td>37.0% (10)</td>
</tr>
<tr>
<td>Changes in routine or environment</td>
<td>37.0% (10)</td>
</tr>
<tr>
<td>Stereotyped utterances and delayed echolalia</td>
<td>33.3% (9)</td>
</tr>
<tr>
<td>Repetitive use of objects or interests in parts of objects</td>
<td>33.3% (9)</td>
</tr>
<tr>
<td>Unusual preoccupations</td>
<td>22.2% (6)</td>
</tr>
<tr>
<td>Compulsions or rituals</td>
<td>22.2% (6)</td>
</tr>
<tr>
<td>Verbal rituals</td>
<td>18.5% (5)</td>
</tr>
<tr>
<td>Neologisms or idiosyncratic language</td>
<td>18.5% (5)</td>
</tr>
<tr>
<td><strong>Other ASD Characteristics</strong></td>
<td></td>
</tr>
<tr>
<td>Voice quality (intonation, volume, rhythm, rate of speech)</td>
<td>66.7% (18)</td>
</tr>
<tr>
<td><strong>Special isolated skills associated with ASD (6 items)</strong></td>
<td></td>
</tr>
<tr>
<td>Reading ability</td>
<td>85.2% (23)</td>
</tr>
<tr>
<td>Memory ability</td>
<td>70.4% (19)</td>
</tr>
<tr>
<td>Computation ability</td>
<td>70.4% (19)</td>
</tr>
<tr>
<td>Visuospatial ability</td>
<td>59.3% (16)</td>
</tr>
<tr>
<td>Musical ability</td>
<td>59.3% (16)</td>
</tr>
<tr>
<td>Drawing skill</td>
<td>48.1% (13)</td>
</tr>
<tr>
<td><strong>Positive behaviours (5 items)</strong></td>
<td></td>
</tr>
<tr>
<td>Kind and generous person</td>
<td>85.2% (23)</td>
</tr>
<tr>
<td>Good at drama</td>
<td>70.4% (19)</td>
</tr>
<tr>
<td>Good fashion sense</td>
<td>48.1% (13)</td>
</tr>
<tr>
<td>Good leader</td>
<td>40.7% (11)</td>
</tr>
<tr>
<td>Good at sports</td>
<td>40.7% (11)</td>
</tr>
</tbody>
</table>

*Note.* Values enclosed in parentheses represent number of participants.
Table 2.4

*Frequency of Most Problematic Behaviour Endorsed by Adolescents with ASD*

<table>
<thead>
<tr>
<th>Behaviour</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Friendships (S/C)</td>
<td>22.2% (6)</td>
</tr>
<tr>
<td>Circumscribed interests (FI/RB)</td>
<td>18.5% (5)</td>
</tr>
<tr>
<td>Changes in routine or environment (FI/RB)</td>
<td>11.1% (3)</td>
</tr>
<tr>
<td>Voice Quality (Other)</td>
<td>7.4% (2)</td>
</tr>
<tr>
<td>Complex body mannerisms or stereotyped body movements (FI/RB)</td>
<td>7.4% (2)</td>
</tr>
<tr>
<td>Stereotyped utterances and delayed echolalia (FI/RB)</td>
<td>7.4% (2)</td>
</tr>
<tr>
<td>Eye contact (S/C)</td>
<td>3.7% (1)</td>
</tr>
<tr>
<td>Showing and directing Attention (S/C)</td>
<td>3.7% (1)</td>
</tr>
<tr>
<td>Pointing to express interests (S/C)</td>
<td>3.7% (1)</td>
</tr>
<tr>
<td>Reciprocal conversation (S/C)</td>
<td>3.7% (1)</td>
</tr>
<tr>
<td>Compulsions or rituals (FI/RB)</td>
<td>3.7% (1)</td>
</tr>
<tr>
<td>Hand or finger mannerisms (FI/RB)</td>
<td>3.7% (1)</td>
</tr>
<tr>
<td>Repetitive use of objects or interests in parts of objects (FI/RB)</td>
<td>3.7% (1)</td>
</tr>
</tbody>
</table>

*Note.* Values enclosed in parentheses represent number of participants.

*Abbreviations:* S/C = Social Communication domain, FI/RB = Fixated Interests and Repetitive Behaviours domain.
Table 2.5

<table>
<thead>
<tr>
<th>Number of ASD Behaviours Endorsed by Adolescents with ASD and their Parents</th>
<th>Adolescents (Alex-ASD)</th>
<th>Parents (ADI-R)</th>
<th>t-value</th>
<th>p</th>
<th>d</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total ASD (28 items)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>10.78 (4.42)</td>
<td>15.78 (4.44)</td>
<td>4.58</td>
<td>&lt;.001</td>
<td>0.57</td>
</tr>
<tr>
<td>Median</td>
<td>10</td>
<td>17</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Range</td>
<td>3-20</td>
<td>6-21</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social Communication (15 items)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>5.44 (2.41)</td>
<td>9.48 (3.86)</td>
<td>5.04</td>
<td>&lt;.001</td>
<td>1.25</td>
</tr>
<tr>
<td>Median</td>
<td>6</td>
<td>11</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Range</td>
<td>0-11</td>
<td>2-14</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fixated Interests/ Repetitive Behaviours (12 items)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>5.22 (2.31)</td>
<td>6.30 (1.80)</td>
<td>2.07</td>
<td>.051</td>
<td>0.54</td>
</tr>
<tr>
<td>Median</td>
<td>4</td>
<td>7</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Range</td>
<td>1-11</td>
<td>2-9</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

N = 23. Higher scores, more ASD traits.
### Table 2.6

**Proportion of Adolescents and Parents Endorsing the Presence of ASD Behaviours**

<table>
<thead>
<tr>
<th>ASD Behaviours</th>
<th>Presence of Behaviour</th>
<th>% of parents (n)</th>
<th>% of adols (n)</th>
<th>$\chi^2$</th>
<th>Effect Index</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Social Communication</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eye contact</td>
<td></td>
<td>78% (18)</td>
<td>70% (16)</td>
<td>0.66</td>
<td>.08</td>
</tr>
<tr>
<td>Social smiling</td>
<td></td>
<td>78% (18)</td>
<td>60% (14)</td>
<td>1.60</td>
<td>.18</td>
</tr>
<tr>
<td>Range of facial expressions</td>
<td></td>
<td>60% (14)</td>
<td>56% (13)</td>
<td>0.14</td>
<td>.04</td>
</tr>
<tr>
<td>Friendships</td>
<td></td>
<td>78% (18)</td>
<td>48% (11)</td>
<td>4.45</td>
<td>.30</td>
</tr>
<tr>
<td>Showing and directing attention</td>
<td></td>
<td>52% (12)</td>
<td>26% (6)</td>
<td>3.00</td>
<td>.26</td>
</tr>
<tr>
<td>Sharing</td>
<td></td>
<td>56% (13)</td>
<td>30% (7)</td>
<td>3.60</td>
<td>.26</td>
</tr>
<tr>
<td>Shared Enjoyment</td>
<td></td>
<td>30% (7)</td>
<td>39% (9)</td>
<td>0.40</td>
<td>.09</td>
</tr>
<tr>
<td>Offering comfort</td>
<td></td>
<td>56% (13)</td>
<td>35% (8)</td>
<td>3.57</td>
<td>.21</td>
</tr>
<tr>
<td>Inappropriate use of facial expressions</td>
<td></td>
<td>61% (14)</td>
<td>35% (8)</td>
<td>3.60</td>
<td>.26</td>
</tr>
<tr>
<td>Inappropriate social responses</td>
<td></td>
<td>87% (20)</td>
<td>17% (4)</td>
<td>16.00*</td>
<td>.70</td>
</tr>
<tr>
<td>Pointing to express interest</td>
<td></td>
<td>70% (16)</td>
<td>26% (6)</td>
<td>7.14*</td>
<td>.44</td>
</tr>
<tr>
<td>Nodding and head shaking</td>
<td></td>
<td>48% (11)</td>
<td>22% (5)</td>
<td>3.60</td>
<td>.26</td>
</tr>
<tr>
<td>Conventional and instrumental gestures</td>
<td></td>
<td>43% (10)</td>
<td>36% (7)</td>
<td>0.69</td>
<td>.13</td>
</tr>
<tr>
<td>Reciprocal conversation</td>
<td></td>
<td>83% (19)</td>
<td>57% (13)</td>
<td>3.00</td>
<td>.26</td>
</tr>
<tr>
<td>Inappropriate questions or statements</td>
<td></td>
<td>65% (15)</td>
<td>22% (5)</td>
<td>6.25*</td>
<td>.43</td>
</tr>
<tr>
<td><strong>Fixated Interests/Repetitive Behaviours</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stereotyped utterances and delayed echolalia</td>
<td></td>
<td>78% (18)</td>
<td>35% (8)</td>
<td>8.33*</td>
<td>.43</td>
</tr>
<tr>
<td>Neologisms and idiosyncratic language</td>
<td></td>
<td>35% (8)</td>
<td>17% (4)</td>
<td>2.00</td>
<td>.18</td>
</tr>
<tr>
<td>Hand or finger mannerisms</td>
<td></td>
<td>49% (11)</td>
<td>57% (13)</td>
<td>0.40</td>
<td>-.08</td>
</tr>
<tr>
<td>Complex body mannerisms or stereotyped body movements</td>
<td></td>
<td>22% (5)</td>
<td>39% (9)</td>
<td>2.67</td>
<td>-.17</td>
</tr>
<tr>
<td>Repetitive use of objects or interests in parts of objects</td>
<td></td>
<td>39% (9)</td>
<td>35% (8)</td>
<td>0.14</td>
<td>.04</td>
</tr>
<tr>
<td>Verbal rituals</td>
<td></td>
<td>35% (8)</td>
<td>17% (4)</td>
<td>2.00</td>
<td>.18</td>
</tr>
<tr>
<td>Compulsions or rituals</td>
<td></td>
<td>39% (9)</td>
<td>26% (6)</td>
<td>0.82</td>
<td>.13</td>
</tr>
<tr>
<td>Changes in routine or environment</td>
<td></td>
<td>77% (17)</td>
<td>36% (8)</td>
<td>7.36*</td>
<td>.41</td>
</tr>
<tr>
<td>Unusual preoccupations</td>
<td></td>
<td>26% (6)</td>
<td>22% (5)</td>
<td>0.20</td>
<td>.04</td>
</tr>
<tr>
<td>Circumscribed interests</td>
<td></td>
<td>100% (23)</td>
<td>96% (22)</td>
<td>.00</td>
<td>.00</td>
</tr>
<tr>
<td>Unusual sensory interests</td>
<td></td>
<td>57% (13)</td>
<td>57% (13)</td>
<td>.00</td>
<td>.00</td>
</tr>
<tr>
<td>Abnormal or negative response to sensory stimuli</td>
<td></td>
<td>82% (18)</td>
<td>73% (16)</td>
<td>0.67</td>
<td>.09</td>
</tr>
<tr>
<td><strong>Other ASD Characteristics</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Voice quality</td>
<td></td>
<td>95% (21)</td>
<td>68% (15)</td>
<td>6.00</td>
<td>.31</td>
</tr>
</tbody>
</table>

*Note. McNemar’s Test, *$p < .025$ (family-wise error correction). Effect index is the difference in the proportion of parents who reported the presence of a behaviour versus the proportion of adolescents who fall into the same category.*
Table 2.7

**Correlation Matrix of Adolescent-Parent Agreement and Perceptions of Self-Competence**

<table>
<thead>
<tr>
<th>Measures</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Agreement</td>
<td>-</td>
<td>.07</td>
<td>.16</td>
<td>-.45*</td>
<td>.01</td>
<td>-.18</td>
<td>.10</td>
<td>-.42*</td>
<td>-.01</td>
<td>.04</td>
</tr>
<tr>
<td>2. Scholastic Competence</td>
<td>-</td>
<td>.57**</td>
<td>.14</td>
<td>.25</td>
<td>-.06</td>
<td>.39*</td>
<td>.04</td>
<td>.28</td>
<td>.56**</td>
<td></td>
</tr>
<tr>
<td>3. Behavioral Conduct</td>
<td>-</td>
<td>.05</td>
<td>.16</td>
<td>.00</td>
<td>.40*</td>
<td>.16</td>
<td>.03</td>
<td>.58**</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Social Acceptance</td>
<td>-</td>
<td>.44*</td>
<td>.46*</td>
<td>.17</td>
<td>.66**</td>
<td>.19</td>
<td>.43*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Close Friendship</td>
<td>-</td>
<td>.22</td>
<td>.19</td>
<td>.34</td>
<td>.32</td>
<td>.46*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Romantic Appeal</td>
<td>-</td>
<td>.21</td>
<td>.46*</td>
<td>.20</td>
<td>.31</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Physical Appearance</td>
<td>-</td>
<td>.22</td>
<td>.26</td>
<td>.46*</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Athletic Competence</td>
<td>-</td>
<td>.18</td>
<td>.36</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Job Competence</td>
<td>-</td>
<td>.30</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. Global Self-Worth</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Note. *p < .05, **p < .01*
Table 2.8

<table>
<thead>
<tr>
<th>Attributions</th>
<th>Diagnostic Group - M (SD)</th>
<th>F(2,61)</th>
<th>p</th>
<th>η²</th>
<th>Post hoc differences</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>ASD (N = 24)</td>
<td>ADHD (N = 21)</td>
<td>TD (N = 19)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total Stigmatization</td>
<td>17.25 (4.05)</td>
<td>19.81 (4.55)</td>
<td>18.11 (3.28)</td>
<td>2.32</td>
<td>.107</td>
</tr>
<tr>
<td>Parent Stigmatization</td>
<td>3.92 (1.14)</td>
<td>5.38 (1.43)</td>
<td>4.79 (1.62)</td>
<td>6.33</td>
<td>.003</td>
</tr>
<tr>
<td>Teacher Stigmatization</td>
<td>3.54 (1.29)</td>
<td>5.05 (2.04)</td>
<td>4.16 (1.29)</td>
<td>5.66</td>
<td>.006</td>
</tr>
<tr>
<td>Peer Stigmatization</td>
<td>5.79 (2.13)</td>
<td>4.86 (1.15)</td>
<td>4.68 (1.00)</td>
<td>3.24</td>
<td>.046</td>
</tr>
<tr>
<td>Pervasiveness</td>
<td>7.50 (1.61)</td>
<td>7.10 (1.87)</td>
<td>5.84 (1.43)</td>
<td>5.62</td>
<td>.006</td>
</tr>
</tbody>
</table>

Note. ASD = Autism Spectrum Disorder. ADHD = Attention Deficit Hyperactivity Disorder. TD = Typically Developing.
*p < .05, **p < .01, ***p < .001, difference between adolescent with ASD sample and ADHD or TD group.
CHAPTER 3

STUDY 2

Study 1 revealed that adolescents with ASD are aware of and able to share their perceptions of their competencies, their perceptions of the behaviours that are problematic for them, and their beliefs about these behaviours. The main finding from Study 1 suggested that adolescents with ASD have some awareness of the challenges associated with their diagnosis and hold differing self-perceptions of competence and behavioural attributions when compared to typically developing adolescents and adolescents with ADHD. The second study of this dissertation extends these findings to gain further insight into the perspectives, beliefs and experiences adolescents with ASD have about their diagnosis. Such findings have important clinical and educational implications for interventions and programs aimed at addressing self-concept and adjustment, treatment compliance, transition services and long-term outcomes.

Introduction

The impact of receiving and learning about a diagnosis in childhood and adolescence has been well researched for physical disorders and medical diseases (e.g., HIV, diabetes, cancer) and has emphasized the benefits of open illness-related communication between patients, parents, and professionals (Wiener et al., 2007; Young et al., 2003). In many cases, open communication has been found to improve children’s psychological adjustment (Katz & Jay, 1984). However, very little has been written about disclosure of an ASD diagnosis to children and adolescents. Clinically, there are some resources and workbooks that provide parents and professionals with information and tools to talk about ASD with them (Attwood, 2004; Faherty, 2000; Gray, 1993; Vermeulen, 2001). Additional autobiographical accounts by individuals with ASD provide insight into individuals awareness of ASD, the benefits of diagnosis disclosure, and
open communication in families (Grandin, 2012; Jackson, 2002). However, no empirical studies to date have examined the process of informing individuals with ASD about their diagnoses.

The literature discusses two types of models used to explain ASD. Biomedical models view ASD as a neurodevelopmental disorder with neurological and genetic aetiologies. This type of explanation is the most common and is used in the current medical classification systems of ASD (e.g., DSM-IV, ICD-10). The alternative conceptualization of ASD is aligned with the social model of disability (Oliver, 1990). Social theorists of ASD argue that ASD is socially constructed because society views ASD behaviours as abnormal (Molloy & Vasil, 2002, 2004). Molloy and Vasil (2002) critique biomedical models of ASD because a child’s behaviour is viewed as symptoms of ASD, rather than expressions of a unique personality. Within this model, ASD is viewed as a differing cognitive style, rather than a disorder. Some researchers have discussed the stigmatizing potential of the ASD label and propose that ‘disorders’ be replaced with ‘conditions’ (i.e., Autism Spectrum Conditions or ASC; Baron-Cohen et al., 2009) or ASD should be viewed as a ‘normal personality variant’ (Frith, 1991).

Although clinical accounts and qualitative studies have begun to generate a better understanding of how individuals with ASD perceive and understand their diagnosis, more studies are needed to document their process of self-understanding and psychological acceptance. Most of the literature and research about ASD is from the professional or parent perspective. To date, there have been a handful of qualitative studies reporting on the perceptions and experiences of adolescents and young adults with ASD (Carrington & Graham, 2001; Howard et al, 2006; Huws & Jones, 2008; Molloy & Vasil, 2004). Several studies have also described the perceptions of adults with AS who have reflected back on their life experiences.
with their diagnosis (Griffith et al., 2011; Hurlbutt & Chalmers, 2002, 2004; Muller et al., 2003, 2008; Punshon et al., 2009).

Many of these studies document individuals’ experiences with feeling different. Some qualitative studies and clinical literature suggest that individuals with ASD develop inappropriate compensatory reactions (e.g., reactive depression, self-blame, denial, arrogance, imitation, masquerading) as a response to their realization that they are different (Attwood, 2006; Carrington & Graham, 2001). Humphrey and Lewis (2008) discovered that adolescents with ASD either reported negative (e.g., ‘being different’ or ‘not normal’) or positive (e.g., acceptance of diagnosis and celebration of differences) narratives in the descriptions of themselves. Huws and Jones (2008) also found that disclosure of a diagnosis of ASD was viewed as either beneficial (e.g., able to accommodate to their diagnosis and seek new information) or detrimental (e.g., disliked having ASD and avoided seeking information about ASD).

Molloy and Vasil (2004) examined the direct impact of a diagnosis of AS by conducting in-depth biographical interviews to create life stories. The authors described six key themes that emerged from their description of life stories of six adolescents with AS (12-18 years) and their families. These themes included diagnosis as a sense-making narrative, labeling and identification, socializing and establishing friendships, difficulties associated with schooling, relationships with family, and dealing with feelings of anger and sadness. With regard to diagnostic issues, participants in this study indicated that a formal diagnosis of AS provided an explanation for their unusual behaviours. Initial reactions to the diagnosis included feelings of shock and disbelief, but ultimately, each of the participants indicated that the diagnosis brought a sense of relief and reduced feelings of confusion and failure. Most of the adolescents in this sample believed that the diagnostic criteria accurately described their characteristics. The authors
concluded that AS became a fundamental part of their self-identity; however, there were differences in the degree to which each of the adolescents identified with the diagnosis and defined themselves as a person with AS. All of the participants were able to incorporate their feelings of difference into their identities and self-perceptions. Some were able to feel positive about their diagnosis and recognize the benefits of increased access to supports and interventions, particularly in the school context.

Overall, the research on how individuals with ASD come to understand and accept their diagnosis is limited. The process of diagnosis acceptance has not been formally evaluated with this population; however, qualitative studies have begun to document differing feelings and reactions to the ASD diagnosis, including themes of alienation, feelings of difference, isolation, bullying, rejection, and pride (Griffith et al., 2011; Hebron & Humphrey, 2012; Hurlbutt & Chalmers, 2002; Muller, Sculer & Yates 2008; Portway & Johnson, 2005; Punshon et al., 2009; Rosqvist, 2012). More research is needed to better understand these experiences in adolescence in order to help guide developmentally appropriate interventions and supports to decrease the significant potential for long-term psychological consequences.

**Current Study**

The aim of this study is to gain a first-hand understanding of individuals’ understanding and awareness of their strengths and weaknesses, what they attribute their difficulties to, and how that information impacts outcomes and adjustment. This type of research has significant clinical benefits that can inform programming and help to educate families and professionals about working with individuals with ASD.

A qualitative design, involving thematic analysis, was used to extend the current understanding of the meaning and experience of living with ASD from adolescents’ perspectives.
Qualitative designs provide a means to obtain a deeper understanding of experiences, beliefs, feelings, and thought processes than what could be determined from conventional research designs (Strauss & Corbin, 1998).

The general research question that guided this study was “How do adolescents with ASD understand and experience their diagnosis?” By using first-hand accounts the study aimed to capture the participants’ language, experiences and understanding about their diagnosis as a means to better understand the concept of “acceptance” of their diagnosis. Data about their perceptions and experiences provided information about how they interact with peers, parents, and teachers to guide clinical and educational practice. Specific questions were designed to explore issues about individuals’ understanding of ASD and general feelings about what it is like to be an adolescent with ASD and what types of supports might help them.

**Method**

**Participants**

Thirteen of the 27 participants from Study 1 participated in the second study (see Table 2.1 for the demographic information of each participant). Inclusion criteria included: (1) chronological age between 13 years, 0 months and 18 years, 11 months; (2) verbal IQ of 80 or greater; (3) a clinical diagnosis of an ASD, including Autistic Disorder (i.e., autism), Asperger syndrome, or Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS); (4) the individual’s awareness of their ASD diagnosis (i.e., adolescent discussed their diagnosis with a parent and/or professional); (5) ability to fluently speak, understand, and read in English, as the interview and assessment tasks were validated and completed in English; and (6) agreement that at least one parent/caregiver would complete an interview and some questionnaires related to the adolescent’s past and current functioning. Exclusion criteria included significant neurological,
psychiatric, sensory, or motor impairment (e.g., traumatic brain injury, blindness) that would preclude the completion of the standard assessment battery.

Ten males and three females comprised the sample, with a mean chronological age of 14.83 years ($SD = 1.38$; range 13.0 to 17.47). Mean verbal IQ was 102.62 ($SD = 14.87$; range 82 to 132) and mean nonverbal IQ was 100.77 ($SD = 16.32$; range 69 to 129). Twelve of the participants were European-Canadian and one was Asian Canadian. All of the participants were living at home with one or both biological parents or legal guardian (one was living with his grandmother). Eight of the participants’ parents were married and the remaining five were from divorced or separated families. Two of the male participants were fraternal twins both with a diagnosis of ASD.

Six participants were in middle school (2 in grade 7 and 4 in grade 8) and 7 participants were in high school (4 in grade 10, 2 in grade 11, and 1 in grade 12). The type of school program varied across the sample: 3 participants were in a special education program for adolescents with special needs, 5 were integrated into a regular program with some specialized support (2 of these participants attended an ASD class for part of the day), 1 participant attended a regular high school program with no specialized support, 2 were homeschooled, and 2 participants attended an alternative school program for complex behaviour and learning needs.

The average age of diagnosis was 5.92 ($SD = 4.70$). Initial diagnoses included Autism or Autistic Disorder ($n = 4$), Asperger’s Disorder ($n = 4$), or a more general ASD (e.g., ASD, PDD, or PDD-NOS; $n = 5$). All adolescents had been aware of their diagnosis for at least one year at the time of the study, and had discussed their diagnosis with a parent and/or professional. The average age that participants had learned about their ASD diagnosis was 10.17 ($SD = 2.30$). All participants received a best estimate clinical diagnosis of an ASD and continued to have
significant social-emotional challenges and restricted and repetitive interests that met clinical criteria for an ASD diagnosis at the time of the current study.

With regard to comorbid diagnoses, all but two of the participants had at least one comorbid diagnosis (8 had Learning Disabilities, 6 had Attention Deficit Hyperactivity Disorder, 6 had an Anxiety Disorder or significant anxiety symptoms, 1 had a Mood Disorder). Four participants were receiving additional support from a mental health professional (e.g., psychiatrist, psychologist, social worker). As participants were not required to provide formal clinical documentation of any comorbid diagnoses, this information was based on parent and/or adolescent report.

**Measures**

The WASI, ADOS, and ADI-R were employed in both studies to collect descriptive information about the sample. These measures are described in Study 1.

**Semi-structured interview.** The primary source of data collection for this study was a semi-structured (open-ended) interview that was designed to gather information about adolescents’ lived experiences and their perceptions of their diagnosis that could not be predetermined by quantitative or categorical data. These types of open-ended questions allowed the participants to respond freely. In addition to audio recordings, the researcher took detailed notes to record the participants’ responses to and observations of the interview questions.

Guided by clinical observations and the current literature on ASD, the interview questions were developed by the researcher with input from the thesis committee and experts from an ASD research clinic with which the primary researcher was affiliated (W. Roberts, J. Brian, personal communication). In addition, several other qualitative studies examining self-awareness, identity formation and the lived experiences among children and adolescents with
developmental or neurobiological disabilities were also reviewed to determine the structure and format of successful qualitative interviews (Cunningham & Glen, 2004; Damon & Hart, 1988; Daniels, 2006; Muskat, 2008). The questions were designed to focus on participants’ awareness of their diagnosis with specific questions related to their descriptions, experiences and beliefs about ASD. The interview questions were developed so as not to force a preconceived framework but rather to help elicit participants’ descriptions and reflections of their own experiences (Charmaz, 2006).

Interview questions were initially piloted on the first cohort of participants from Study 1 \((n = 14)\). Based on this initial piloting of the interview format, some of the questions were removed and others were added or modified to allow for participants to talk more freely and openly about their descriptions and experiences of living with ASD. Additional interview questions were also developed to address themes that emerged from the pilot interviews (i.e., adolescent perceptions of ASD in the media, advice they would give to others). The revised interview allowed for greater flexibility in follow-up questions and prompts in order to elicit information from the participants.

The interview began with open-ended questions that were designed to encourage participants to describe themselves and to determine if there was anything about themselves that they would want to change if they could. Participants were then encouraged to reflect on their individual strengths and weaknesses. Worksheets from *I Am Special* (My Talents and My Not So Strong Points; Vermeulen, 2001), a workbook designed to introduce children and young people to ASD were used to prompt this discussion. In his manual, Vermeulen utilizes worksheets that focus on talents and strengths as a platform to help individuals with ASD think about their areas of difficulty. This type of worksheet format was used to ease participants into a discussion of
their interests, characteristics, talents and challenges. Participants were given the option of completing the worksheets on their own or with the examiner depending on their comfort level.

These opening questions and activities were followed by a more structured group of questions that focused on participants’ experiences and descriptions about ASD and whether they thought they had ASD. The questions probed for adolescents’ understanding of the concept of ASD, their experiences as an adolescent living with ASD, and the meaning they gave to their experiences. An example of the types of questions that were devised according to the major research questions are presented below. Summarizing and reflecting techniques were used to encourage further participant elaboration.

<table>
<thead>
<tr>
<th>Research Questions</th>
<th>Example questions posed during the interview</th>
</tr>
</thead>
<tbody>
<tr>
<td>How is ASD understood by adolescents with ASD?</td>
<td>Have you heard of ASD? Have you heard anything on the TV, in the movies, or on the internet about ASD?</td>
</tr>
<tr>
<td></td>
<td>Have you seen anyone on TV or in the movies with ASD? Do you know of anybody famous with ASD? What do you think of that?</td>
</tr>
<tr>
<td>How is ASD experienced by adolescents with the diagnosis?</td>
<td>Do you think you have ASD? Are there good things (strengths) or hard things (weaknesses) that have resulted from your ASD behaviours?</td>
</tr>
<tr>
<td></td>
<td>How do you feel about having ASD? How, if at all, has having ASD changed your life?</td>
</tr>
<tr>
<td></td>
<td>Is there someone in your life that you feel comfortable talking to about ASD? If so, who is that person?</td>
</tr>
<tr>
<td></td>
<td>What advice would you give to another kid that found out they had ASD? What would you tell them?</td>
</tr>
<tr>
<td></td>
<td>What advice would you give to the parents of a teen with ASD?</td>
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</table>
The interview ended by asking participants for any advice they would give to newly diagnosed adolescents with ASD and parents of adolescents with ASD. See Appendix E for a complete list of the interview questions used in this study.

**Procedures**

The study was approved by the SickKids Research Ethics Board and the University of Toronto Offices of Research Ethics. All participants and their caregivers gave informed consent. The interviews were completed by the author at the Autism Research Unit at SickKids with the exception of one interview that was completed at the participant’s home. This interview was included in the larger study protocol described in Study 1. The study protocol was administered in the following order: picture-based interview about ASD characteristics (Alex-ASD), behavioural attributions questionnaire (AAPBQ), semi-structured interview, WASI, ADOS, and paper-and-pencil questionnaires to assess psychosocial outcomes.

The interviews were digitally audiotaped, totalling over 416 minutes of voice tape, ranging in length from 9 to 59 minutes with an average interview length of 32 minutes. Each recording was transcribed. In addition to interview data, the researcher maintained reflective and descriptive notes about each interview.

Participant responses varied across interviews. Some participants, particularly older adolescents, were more talkative and descriptive in their responses. Many of the younger participants required additional prompting, which included repeating or rewording questions, as well as comprehension checks. Some participants responded with concrete, one-word answers. When they were asked to elaborate on their responses, they indicated that they did not have much more to say. One participant responded with “I don’t know” to most of the questions. Although this participant recognized that he had a diagnosis, he did not respond to or elaborate
on the questions. At the end of the interview, he indicated that it was difficult for him to answer the questions. He was included in this study because his responses highlight the range of expressiveness, insight, and individual ability/willingness to reflect on feelings and experiences associated with the diagnosis of ASD in this sample.

Time was taken at the beginning of each interview to learn more about individual interests and strengths in order to develop rapport. Snacks and refreshments were also offered throughout each session. Participants were asked at the end of the interview how they felt the interview went. More than half of the participants were pleased to be finished the interview and did not have many additional comments to add. One participant reported that the interview was “long” and another stated that she found the interview “kind of difficult as I’m always trying to think of good answers”. Additional participant responses are presented below and highlight the participants’ perceptions of the benefits of participating in the interview. Some of the comments underscore the importance of providing opportunities for individuals with ASD to express and process their feelings and experiences.

Um, it kind of felt good to get [these feelings] off my back but in a way I was a little bit nervous when I came in here.

I believe it’s helped me (How has it helped you?) Helped to discuss it. (Do you discuss these thoughts with anyone?) Not always. Sometimes I talk to Mom.

I know that it’s important to help other kids. I’m taking one for the team.

The interview…well, at first I thought it was just going to be a bunch of questions. It was fun and easy and I felt quite relaxed. And the snack made me feel quite comfortable. And, the juice.
Data Analysis

All interviews were transcribed verbatim and then re-read against the original tapes for accuracy by the primary researcher. Transcripts and observational notes were reviewed and analyzed by this author using the method of open coding, which is the process of “breaking down, examining, comparing, conceptualizing, and categorizing data” (Strauss & Corbin, 1990, p. 61) and then grouping concepts into more abstract categories.

The interview data were analyzed in four stages. The first stage involved an independent analysis noting for emerging themes by all participants. Adolescent responses to questions about their understanding of the concept of ASD (e.g., What is ASD? How do you know if someone has ASD? Have any of your friends got ASD? Media perceptions of ASD, strengths and weaknesses of ASD) were coded separately from their responses to questions that elicited more open-ended information about their experiences as an adolescent living with ASD and the meaning they gave to their experiences. Most individual responses were coded under single themes; however, there were instances, particularly among lengthier responses, when multiple themes were coded within the same response. Words or phrases that identified the main idea of each of the participant responses were then generated. The second stage involved a review of the themes with the dissertation supervisor. In the third stage, the researcher conducted debriefing with colleagues who were familiar with the research topic but who were not involved in the development of the study. Emergent themes and data conceptualization were reviewed to reach consensus and agreement on the final set of categories, themes, and subthemes that emerged from the data. In addition, after open coding the data for themes and categories, a random sample of three transcripts were cross-coded by an independent rater to establish inter-rater agreement and to increase the dependability of the identified themes. Coding categories and discrepancies
were discussed and adjusted accordingly. As a result of debriefing with the dissertation supervisor and colleagues, as well as second rater coding, there was some revising and re-categorization of the data to ensure valid representation. The primary researcher identified seventy-five phrases in the first stage of analyses. The patterns and themes were generated from the data by identifying recurring topics or comments and counting the number of times they occurred. After numerous modifications (as discussed above), the final coding system consisted of 19 themes (organized within 4 categories; see Appendix F for a breakdown of the themes and categories). The final category, Advice to Others, was not analysed using qualitative thematic analysis.

In the last stage, the researcher finalized the themes, reread all the interview data and used the amended themes and categories to color-code the phrases and comments that typified the revisions. These phrases were entered into a database and a frequency count was generated for each theme.

**Reliability and Trustworthiness of Data**

In qualitative research, the commonly applied criteria used to establish reliability and trustworthiness of results include credibility (i.e., prolonged engagement, persistent observation, peer debriefing, triangulation, negative case analysis, member checks) and transferability (i.e., thick descriptive data), as well as dependability and confirmability (i.e., external audit; Lincoln & Guba, 1985, 2007). To enhance the credibility of this study, the primary researcher engaged in peer debriefing with researchers external to the study to discuss research data and interpretations. This approach was completed by sharing ongoing thoughts and analyses with individuals working with the primary researcher at an ASD research centre, colleagues in clinical psychology, as well as members of the thesis committee. Triangulation, or cross-checking of the
data by use of different sources or time points, was not a specific focus of this study; however, self-perceptions and awareness data were collected in Study 1 using other types of interview formats and rating scales (e.g., SPPA, Alex-ASD, AAPBQ). Findings from these sources were consistent with some of the qualitative themes that resulted from the semi-structured interviews in Study 2 (e.g., low self-perceived social competence, romantic appeal, close friendships, athletic competence, job competence; some awareness of ASD symptoms and characteristics; reports of peer stigmatization). Triangulation also occurred by reviewing and comparing interview material with previously published studies and dissertations that evaluated the perceptions and lived experiences of adolescents and adults with ASD.

In reporting the findings, every attempt has been made to respect the anonymity of the participants, with only general details, and no identifiable data presented. For quotes that may have contained identifying information, the participants and their parents were contacted and shown the quote that would be presented in the study, and consent was obtained to share specific information.

Results

The themes were divided into five major categories. The first category was Self-Awareness and Understanding of ASD and encompassed themes of meaning and identity of ASD, causes of ASD, recognizing ASD in others and in the media, and perceived strengths and weaknesses. The second category, Psychosocial Stress, included themes of feelings of despair, not fitting in or isolation, stigma, disclosure and hiding behaviours, and not feeling heard or being misunderstood. The third category, Social-Ecological Factors, included themes within the family environment (parents and siblings), social context (peer interactions and relationships), and school environment. Sources of Support, the fourth category, encompassed self-education,
social support, and mental health support. The final category was *Advice to Others* and included participant recommendations for newly diagnosed peers with ASD and their parents. Each of the themes will be described below with specific participant examples. As much as possible, the findings are described using the original wording. Frequencies of themes are provided in Appendix F.

**Self-Awareness and Understanding of ASD**

*Meaning and Identity of ASD*

When participants were asked about what they learned about ASD, it was clear that the diagnosis was most often described to them by their parents or guardians, and in some cases physicians and teachers. One participant noted how he became increasingly aware of his difficulties with age.

> I remember the first time I was aware of it I was like in grade 1 or something. I remember my mom telling me stuff about that. I didn’t notice that I was like that back then but like the older I got, the more I noticed that I’m different.

For some participants, the label itself was not that significant to them (e.g., “no matter what the label is I’m still the same person”, “Sometimes I think it’s a bunch of quirks that happen to come in a label and I need to just keep on being”).

Some of the participants diagnosed after age 10 described extensive testing experiences (e.g., “I’ve been tested a lot”) and that they had been given many different diagnoses (e.g., “It went from something, something, something, to ADD to Autism to Asperger’s”). Another participant described some confusion over the labels of Autism and Asperger’s syndrome (e.g., “I used to have Autism…but not anymore, so now I’m more like Asperger’s. And like there’s a psychiatrist who thinks I have Asperger’s. So I’m not really sure. I probably have Asperger’s,”).
but I don’t know”). Despite this confusion, many of the participants recognized that there were differences in the expression of ASD across individuals in terms of clinical features and severity of symptoms. Several participants made reference to lower and higher functioning individuals with ASD and described themselves as being higher functioning because of their intelligence or language abilities.

Although all of the participants believed they had ASD, not everyone could define ASD. The literature discusses two types of explanations for ASD: biomedical models of ASD (i.e., neurodevelopmental disorder with neurological and genetic aetiologies) or an alternative conceptualization that views ASD as being a differing cognitive style, rather than a disorder (i.e., Autism Spectrum Conditions, normal personality variant, symptoms are expressions of a unique personality). The participants used both types of explanations. Five participants who defined ASD using a biomedical model defined ASD as a “disease”, but prefaced that it was not “fatal” or “not going to kill you”. Four of the participants gave neurological explanations of ASD (e.g., “condition of the brain” or that ASD “affects the brain”). One participant stated that he was “biologically different” and indicated that ASD was described to him as a “social learning disability”.

In addition to the above biomedical perspectives, the majority of the adolescents (n = 9) described ASD as a difference in their thinking or behaviour. They indicated that ASD “affects the way you speak and the things you do”. Most of the participants also included specific characteristics of ASD in their definition. This included circumscribed interests, social interaction difficulties (e.g., “social difficulties”, “poor social skills”, “target of bullying”), physical or motor difficulties (e.g., “difficulty with sports”, “physical difficulties”, “walking and sitting [in an] unusual [way]”), language (e.g., “talking is weird”), motor mannerisms or
movements, and sound sensitivities. Another participant stated “obviously, socially I am at a huge disadvantage. If anybody talks to me for any amount of time they will know that I’m different and I just can’t read anything”.

Both positive and negative appraisals were used in the participants’ constructions of ASD. A few participants described their differences positively (e.g., “it’s good that you’re so different”) and reframed their behaviours or characteristics as “special”, “unique”, “impressive” or “awesome”. The majority, however (n = 10), used descriptions with negative connotations. Some of the descriptive terms used to describe individuals’ ASD behaviours and characteristics included “weird”, “lazy”, “wimp”, “bad”, “less good”, “crumby”, “really limited”, “quirky”, “impaired” and “awkward”. There were also other participants who struggled with both the positive and negative connotations of their diagnosis. For example, one participant stated “sometimes I think it’s kind of cool that I’m biologically different. And sometimes I feel kind of…disgusting, like a specimen”.

In addition to describing ASD as part of one’s identity, 2 participants described ASD as being a separate part of them that either moderates or changes their behaviour. For these participants, ASD was constructed as external to the self. For example, ASD was described to negatively impact behaviour (e.g., “Sometimes I wish it would go away because it doesn’t usually make me behave”, or that ASD “making me feel bad or crumby because I can’t do things right”). One participant also described ASD as sometimes “feel[ing] like there is two heads on myself”, which included an “autism head” and his own head. He indicated that the “autism head” “sometimes pushes me away from others” or that it “pushes me towards regret”.

Among the 13 participants, only one could not describe ASD and reported “I don’t feel any different” when asked how he feels about having ASD. This was the same individual who
spoke very little during the interview and often responded with “I don’t know”. Most of the participants accepted their diagnosis \( n = 12 \) and some provided a rationale for doing so.

There was no defining moment. I just realized that denying it would be impractical. It just wouldn’t be logical because then I wouldn’t be able to do anything.

When one of your parents says ‘You have Asperger’s’ you don’t know what to think. You think, ‘What do I do, what do I do?’. You can try to reject it or you can just go with the flow…if not, it just haunts you.

I’m actually fine because I know I can handle it.

Only one participant expressed confusion about his diagnosis and the presence of symptoms. He suggested that “it’s a general consensus that some of the symptoms would easily apply to anyone who’s engaged in cyber-bullying and lack of social empathy and everything” and later added, “I am pretty sure I have empathy and I can recognize non-verbal cues. I think the only thing I have that’s close to lack of social empathy is not understanding certain things that some peers do”. He later added that he was only “50 percent sure” that he had ASD. Notably, relative to the other participants, this individual was the most recently diagnosed (within the 18 months prior to his participation in the study) and had only recently started to learn more about ASD and access to services. As will be described later in this section, there were also considerable trust issues that have contributed to his confusion and acceptance of the diagnosis.

Although many participants recognized that they had been diagnosed with ASD and appeared to have accepted the diagnosis, there were some participants who reported “hating” their diagnosis. Their stated hatred, however, was often followed by a coping statement (e.g., “I
hate but I have it…I have accepted it now”). This same participant speculated what her life would be like if she did not have a diagnosis.

Kids would’ve probably been a little more accepting throughout my life. I wouldn’t have had to put up with as much. Wouldn’t be anxious all the time. Wouldn’t be afraid of stupid things. My parents wouldn’t have to be doing a million times more for me because I could just do it for myself…everything’s harder for me.

Some of the participants described positive outcomes from their diagnosis ($n = 4$). For example, one participant indicated that her diagnosis provided her with an explanation and answered questions about some of the challenges and supports she had been given when she was younger.

I just learned why I have to use all these different schedules when I was like five with all these different pictures and why I had those schedules. It just started to clear things up a little bit on why I needed to do those things and why my brother didn’t. That was kind of nice in a way, but in a way it was kind of like ‘oh no, now I have a disability’.

Other participants emphasized the different types of positive experiences or outcomes they have experienced as a result of their diagnosis of ASD.

People have gotten a better understanding of what I’m like and what it’s like to have learning disabilities, social disabilities, and mental disabilities and it mean that like I’ve gotten some opportunities to meet some people and take part in studies like this.

When you go to Wonderland and you say you have Asperger’s you don’t have to go in the lines.
Causes of ASD

Participants were asked about what they think caused them to have ASD. Some adolescents reported that heredity and family genes contributed to the presentation of ASD. A small subset further described ASD symptoms in their father \((n = 2)\) or an ASD diagnosis in other extended family members \((e.g.,\, siblings, cousins;\, n = 4)\). Five participants provided explanations that suggested ASD is a developmental disorder by reporting that they were “born with it” or that there was some neurodevelopmental delay \((e.g.,\, “something didn’t develop properly”, \text{“my brain didn’t develop properly at birth”}, \text{or ASD is \text{“something that functions the brain unlikely [sic] from others” or \text{“makes one part of the brain less good [sic] than the others”}}\). Another participant described ASD as a “neurogenetic thing” and suggested possible overlaps with other neurobiological disorders \((e.g.,\, \text{“it comes with other disorders, like schizophrenia I think, and one of the psychological ones is OCD and ADHD”})\).

External or environmental factors were only described by two participants; one who was generally unsure, but speculated that vaccinations cause ASD, and another who described her frustrations with reference to environmental causes and the emotional impact that those types of explanations have on her self-concept.

I don’t believe in that theory that vaccines or pollution or whatever could cause ASD. That just seems well, so demeaning to me. I don’t want to be a vaccine-caused accident thing or the result of some chemicals from outside getting inside me. I want what I am to be like something in my genes and something that has gone on from evolution like positive selection and can be passed down to like my descendants if I ever have any…I don’t know but it just seems more maybe honourable for it to be a gene thing or more replicable or more for me to be proud…it means well that ASD comes from good things and it is a good thing.
Recognizing ASD in Others

Participants were asked how they would know if someone has ASD. All but two were able to describe recognizable ASD characteristics or behaviours. The first characteristic reported by most participants was speech or voice quality. Participants described speech and language characteristics in various ways including differences in voice quality (e.g., “not being able to speak properly”, “weird tone of voice”, “loud”, “yelling”, “speaks sort of funny”, “sounds so slow”) and repetitive or idiosyncratic language (e.g., quoting movies). They also reported difficulties with social interaction (e.g., social difficulties, few friendships) and social communication (e.g., limited eye contact and range of facial expressions). Other observable characteristics included special interests, mannerisms and repetitive behaviour, poor coordination or gross motor skills, sensory sensitivities, and emotional control or dys-regulation.

Nine participants reported that they had friends with ASD mostly through school; although only two of these participants described regular contact with their friend. Three felt they identified better with other individuals on the autism spectrum. As a result, they appeared to find more comfort in connecting with other individuals with ASD. Their responses highlight the psychological benefit of feeling a sense of belonging and identity in their ability to share their experiences and seek support.

I can relate to them more than neurotypical people and like I probably have like some common interests with them and I feel like I could fit in for once, like I could have a world of my own to fit in with rather than just having to be like a misfit in mainstream society.

Another participant described how she has become good friends with two other individuals with ASD. She described several situations in which they have been able to help each other out with difficult social situations or sensory aversive events. When asked further about
the support she has provided she reported: “I get how it feels…I just get him so I can just help him out with stuff like that”.

In addition to recognizing other individuals with ASD, participants were also asked about their experiences with ASD in the media, including television, movies, or the internet. Some of their responses to this question highlighted their awareness of how individuals with ASD are portrayed in the media. For some, there seemed to be a sense of commonality when talking about both real and/or fictional characters on television and in the movies. For example, one participant stated “it’s really funny because he is just so awkward and I’m like ‘I feel your pain man’”.

The majority of participants (n = 9) were able to identify famous individuals or characters in the movies or on television shows that either had a diagnosis of ASD or presented with features of ASD. Three identified Temple Grandin, one reported on a family they had read about on the internet but could not elaborate further, and another participant emphasized the likelihood that some great inventors, scientists, artists, and musicians have been suspected of having an Asperger’s diagnosis. A few participants reported that they had read books by individuals with ASD but did not specify the authors’ names. All but four participants indicated that they had seen several television shows (e.g., Criminal Minds, Big Bang Theory, House, Bones, Family Guy, America’s Next Top Model) and movies (e.g., Adam, Rainman) with characters that were diagnosed with ASD or that presented with features associated with ASD. One adolescent commented on the frequency of such depictions and suggested that ASD is the “new Hollywood disability”. When asked about their thoughts on media portrayals, most of the participants did not express any feelings or opinions associated with the media representations. There were, however, a few who described feelings of disappointment in how ASD is sometimes presented in the media. For example, one participant stated:
I don’t really like reading about it because some of it’s completely wrong. Some of the things I’ve read and it’s just terrifying to me that that’s all people will read about and they will just assume that everybody who has Asperger’s is like that…and well sometimes it’s completely wrong. Not all people with Asperger’s are angry and OCD.

Although frustrated with misinterpretations or stereotypes, she was satisfied “as long as they do it right”. Another participant commented on one actor’s portrayal of an individual with ASD stating “I didn’t think it was really accurate. He doesn’t even have it but he was just mocking someone”.

**Perceived Strengths and Weaknesses**

Part of learning about one’s diagnosis is recognizing the pattern of strengths and weaknesses that are associated with it. All of the participants were able to identify some strengths and nearly all could identify weaknesses. Many of the participants connected their own experiences to their theoretical constructs and definitions of ASD.

**Strengths.** Six participants listed their special interests as a personal strength. Their circumscribed interests included video games, maps, building things, drama, or writing or reading about folklore. For a small number of participants, a sense of individuality and pride emerged in their discussion about their special interests. Some participants described positive consequences from their special interests, such that they are able to help people with their special interests or they have received special attention because of their talent.

I’m glad that I’m good at like maps and stuff like that so I can give people directions. People will always ask me and like quiz me on capitals of different countries because they know that I know that kind of thing. And like they’re always amazed that I know all these different countries.
Participants also described cognitive strengths, including their intelligence and memory abilities. Two participants also reported that ASD has given them a more “practical outlook on things” or a more “balanced view of thinking”, and one believed that he was more likely to display logical thinking because of his ASD. Many of the participants also described specific talents or strengths (e.g., arts, music, drama, martial arts, building things or completing puzzles).

**Weaknesses.** With regard to individual weaknesses associated with ASD, most of the participants described difficulties with social interaction and making friends. Some participants were specific about their challenges (e.g., “keeping in conversations”, “talking to others”, “trying to get into a sport or game with friends”, “hard to share ideas”, “meeting a girl for the first time”) and others described their socialization weaknesses in more general terms. In addition to social weaknesses, some participants described that they lacked behavioural control (e.g., “controlling” their special interests, “stimming”, “having to do things in a certain order”, “easily distracted by sparkly or shiny things”) or emotional expression/regulation (e.g., “can’t feel things”, “hard to control my temper and emotions”, “controlling my emotions”). A few participants described specific difficulties with changes or transitions (e.g., “losing video games”, “having to leave a place I like”, “when people can’t accommodate my needs, it’s hard for me to cope”). Six participants described cognitive weaknesses related to their thinking and perception (e.g., “memory”, “getting lost in details”, “always have to be thinking”) and executive functioning (e.g., “organizing myself”, “attention”, “staying focused”, “losing track of things”, “getting my homework done”, “keeping my room clean”). Additional weaknesses related to physical or motor skills (e.g., “not good at sports”, “physical stuff”) and sensory sensitivities (e.g., “food issues”, food textures) were also reported.
With regard to identifying what they would like to change about themselves, a few participants described social challenges (e.g., social interactions and conversations, ability to make friends, develop relationships with the opposite sex). The behavioural aspects of change, such as better emotional regulation or behavioural control (e.g., obsessions, difficulty with mistakes) were described by a few participants. One participant wished to study harder in school and another wanted to improve her organizational skills. Two participants described wanting to change some aspect of their disability (e.g., “Sometimes I wish I could just live regular [sic] sometimes, just not do weird stuff”, “Sometimes I wish it would go away because it doesn’t usually make me behave”). Despite the number of personal and ASD-related weaknesses reported throughout this study, six of the adolescents reported that there was nothing they wanted to change about themselves.

**Psychosocial Stress**

Strong themes of psychosocial stress related to living with ASD emerged from the interviews, including feelings of despair, experiences of feeling different and unable to fit in, concern about disclosure and stigma, hiding or limiting the expression of ASD behaviours, and frustrations with not feeling heard or being misunderstood as an individual with ASD. Although participants’ descriptions of psychosocial distress were not the same, their experiences appeared to arise from a complex interplay of feelings about themselves and perceptions of others. These types of feelings and experiences are described further below.

**Feelings of Despair**

Feelings of shame and embarrassment were common among some of the participants ($n = 6$). For example, one participant stated “sometimes I am frustrated and embarrassed when I catch
myself doing something that is a trait of Asperger’s. Like, I hate that”. Additional experiences of embarrassment and shame are described below.

I hate it but I have it. It makes everything harder…it’s just so unfair that everything’s ten times harder for me. In that I am so awkward and I can’t touch certain things and I can’t keep up with people. And I’m just, you know, such a sore thumb in so many situations. It’s absolutely so frustrating. Just the everyday things…When I feel material and I’ll flap my hands or something. I get so mad at myself. I get so embarrassed at myself. I think “As if you just did that!” and I’m like “Oh great, that’s what they just showed on Autism 101…awesome”…it’s still frustrating and embarrassing sometimes.

Another participant described feeling “upset about the syndrome” due to recent difficulties communicating with opposite sex peers.

Participants also expressed failure in their abilities to complete daily tasks (n = 7). They often recognized that they were less able than others and often ruminated about their perceived inability. For example, one participant stated “I’m not sure whether I’m just lazy or whether I’m delayed, like mentally delayed. I feel like everyone’s serving me and I feel like I should be doing my part”. He also described hopelessness in his ability to complete tasks.

I feel like I don’t have a lot of hope. I just feel…I dunno…I feel like I’m sort of lazy. It may be partly because I’m lazy and partly just because I have autism and like things are harder for me. I just feel like anything is going to be too difficult for me.

Several participants believed that their ASD made things more difficult for them.

It makes everything harder. I can’t just be normal and get things like other people. Look, alright, I used to hate it. I’ve accepted it now but just in the last 6 months have I accepted it. I used to like freak out if anybody brought it up and get like really, really, really mad when anybody brought it up…it would make me feel terrible because of I’m so incapable of feeling anything.
There are so many things I can’t do. I can’t do sports and stuff. I can’t have, you know, just the normal interactions with people. And I always have to be thinking. I always have to be on my toes. I can’t just be relaxing with somebody as I have to be interpreting…it just makes everyday stuff harder.

One participant also expressed concern about post-secondary education. He indicated that he didn’t want to think about college or university. He reported that thinking about college or university was “too scary” because “I feel like I can’t do anything…I feel like a total wimp”. He also expressed some frustration in his ability to meet job expectations.

I feel like I should just like go out and get a job already like my mom wants me to get a part-time job this summer and I just don’t know if I’ll be able to….I don’t know at the moment, that just seems like just too complicated for me.

**Not Fitting In/Alienation**

Several participants made comments to suggest perceived difficulties with fitting in ($n = 6$). They often used descriptive terms to describe their perceptions of social isolation and separation from society (e.g., “misfit in mainstream society”, “specimen”). Notably, many used vivid expressions to describe their feelings of alienation from humanity (e.g., “not human”, “different from the rest of humanity”, “special magical species”, “fairy”). Others described belonging to a different subculture or community of individuals with ASD (e.g., Aspies community).

I’d like to meet some more people who are more like me because I feel like I’m the only one. I feel like I’m different than everyone else. I feel like there’s no one else that’s like me. Like I just feel I can’t really fit in anywhere.
I feel like I wasn’t made for this universe’s sort of society. I should belong to a whole other culture…or belong to like a whole country or planet or like an area full of people with autism. Like I fit in better with Aspies than like with neurotypical people.

Although most of their comments about not fitting in were negative, one participant described having ASD as “magical” and “fairy-like”. She also referenced the Changeling myth in Western European folklore to possibly conceptualize ASD behaviours and differences. According to this myth, it was believed that mythological creatures snuck into the bedrooms of sleeping infants and replaced them with a new child or changeling that presented with symptoms of ASD (Leask, Leask & Silove, 2005). Her description was as follows:

It’s like being different from normal society and how having and like stronger abilities than real society and well just in a way it’s like being some special magical species or something. Except for the old magic…and I think our genomes are pretty much the homosapiens type. So now we don’t qualify as a separate species…When I was younger I used to believe I was half-fairy, but unfortunately I’m not…I think the half-fairy thing might have to with like how I am an Aspie and I am always different and that I think about things is different and like I’m super sensitive and like in some ways my abilities are stronger than other kids and in some ways they are absolutely weaker. And also I have heard something about changelings may be based on people having Asperger kids.

Of note, this same participant believed that her parents and society needed to “accommodate” to her rather than feeling like she was expected to fit in or adapt her behaviour. Her beliefs conflict with many typical therapeutic interventions in ASD in which the goal is to change undesirable behaviour and replace with more acceptable behaviour.
Stigma, Disclosure, and Hiding Behaviours

Some of the participants described worries or concerns with stigma and sharing information about their diagnosis ($n = 6$). One participant reported that ASD is “not something you should be open about” because “there is a stigma and some people are just shallow because they see someone flapping their hands and they think they are not someone you could talk to”. Another participant indicated that she keeps her diagnosis “a secret” at school. She stated that “no one at school really knows and I want to keep it that way because it just makes me feel normal and everything”. When asked about whether she feels comfortable talking to anyone about ASD, she stated “I like to keep some of my personal autistic stuff to myself usually because it just makes me feel a little bit better”. Similarly, another participant recognized the benefits of keeping his thoughts or ideas about “immature subjects” to himself due to embarrassment and possible victimization. For example, he stated that it is “hard to share” these ideas because of “humiliation”; however, he did note feeling more comfortable sharing his ideas with his mother who accepts and supports him.

One participant also described feeling safe in his home environment when compared to other settings. For example, he indicated that he did not have to worry about how others will perceive him at home.

I always feel awkward at school both like socially and academically and I always just feel like I want to get home at the end of the day. When I’m at home that’s when I’m safe there…I don’t have to act or have people think of me as unusual just like I don’t have much to worry about when I’m at home so I just like to be in the safety of my own house rather than at school.
Another participant indicated that he has tried to limit his engagement in repetitive behaviour to his home environment because he is not subjected to peer victimization (e.g., “I stim but I try my best not to play with my pencil and eraser at all unless I’m at home or in my room”). This particular participant described a period of significant peer victimization in his elementary school because of some of his behaviours. He was particularly focused on his “stimming behaviour” (i.e., repetitive movements with his pencil) as that was a source of peer victimization for him when younger.

**Not Feeling Heard and Being Misunderstood**

Several of the participants expressed their desire to be better understood by parents, teachers, or professionals (n = 5). This theme arose through their descriptions of scenarios in which individuals did not feel like they were being heard or understood by others close to them. It became clear that these feelings impacted how they feel about themselves and their perceptions of their diagnosis.

Among these included one participant who felt like her parents were unable to hear what she was saying about her feelings and experiences because of their insistence on reinterpreting her thoughts and actions in terms of her ASD diagnosis.

You know I still get frustrated when, particularly my mom, says “Well, that’s an Asperger thing”. No, it’s not. It’s how I’m feeling…I still get defensive about that because it feels like she’s saying -- it’s not actually valid it’s just a symptom or something.

Another individual described frustrations with communication and disclosure about the diagnostic process. His teachers first identified concerns in high school and he received his diagnosis shortly thereafter. The participant described frustration with teachers and his parents because of lack of communication with him around their concerns. This appears to have resulted
in a significant amount of distrust with the adults in his life, and confusion about his diagnosis. Given his age, the issue of diagnosis and disclosure was sensitive and he appeared to struggle with his right for privacy and restructuring his experiences within the context of ASD.

I did hear that this one teacher who I suspected had armchair diagnosed me…a teacher whose name no one is telling me, noticed something. More than one teacher actually, which kind of kills my self-esteem a little…Some teachers are friends with each other and so just spread it around while they were eating.

He also indicated he was “tested against my will”. When asked what he meant by this statement, he suggested that his parents were not open about why he was going to see a clinician. The effects of this diagnostic process were salient for this individual and as a result he has continued to struggle with diagnosis acceptance and disclosure.

My parents booked an appointment for a paediatrician and they said it was just for a check-up. And I just had a gut feeling…plus I would ask what for and they wouldn’t answer me and then I’d get kind of angry because I would ask and they’d say ‘oh, it’s just a check-up’…and when I realized, it was really insulting.

One participant provided advice for professionals working with ASD, likely based on her extensive assessment experience prior to her ASD diagnosis. Her recommendations highlight the importance of taking the time to recognize and understand the individual with ASD.

Don’t talk to them any differently than you would talk to anybody because we are smart and know when you’re talking down to us. Like we can tell when you’re acting differently around us and that really hurts because it makes us feel like some sort of zoo specimen…it makes us feel really awkward and uncomfortable and it makes us feel like we’ve got a third eye or something. Like, we’re just people who happen to think a little differently sometimes.
One participant also spoke about his frustrations with the concept of “curing” ASD and the importance of listening to the needs and perceptions of individuals with ASD.

I think there should be a more balanced view in the media because most of the people who get attention are non-profits and most of them make it out to be [an] epidemic that needs to be cured. And if someone needs to be cured then that’s the affected and that’s really the affected person’s choice.

Social-Ecological Factors

Family Environment: Parents and Siblings

Although there were no specific questions that addressed how ASD affected family members, some participants spoke openly about their parents, and more specifically, their mothers, within the context of the interviews. When asked about whom they feel most comfortable talking to, the majority of respondents indicated that they feel most comfortable talking to their mother (n = 9). One participant also suggested that the interviewer ask his mother for an answer to several of the questions. Another participant requested to have his mother present and often checked in with her and attempted to elicit information from her during the interview. These examples highlight ongoing reliance on parents in the age group studied here.

One female participant described worries about her mother’s health and her perceptions of parental stress because they “always need to be thinking and worrying about me”. She expressed a lot of frustration with herself for being so dependent on them and indicated that she felt like a burden to her parents because of the amount of care she believed she required.

They have enough crap to deal with and I just times everything by ten. They are busy people and they’ve got a lot they need to be doing and my mom needs to be taking care of herself and I’m probably the reason she doesn’t sleep half the time because I know that she worries about me so much and she just is always making calls and doing stuff to
make sure that I have stuff but she doesn’t think about herself…She doesn’t even realize, like having me, has probably aged both of them like a million years. ‘Cause they have all this extra stress because they care too much. So they’re always thinking and worrying about me…they’ve got enough problems of their own to deal with. They shouldn’t have to put up with mine.

Although sibling issues have been identified in the literature, only one participant described differential treatment at home between her and her younger brother (e.g., “My brother gets more flexibility than I do”). When asked about potential reasons for the differential treatment, she reported “usually I just think it’s ‘cause I have a disability”.

Another participant reflected on how his diagnosis has benefited his mother in that it has given her an opportunity to connect and meet with new people.

I think it’s actually helped my mom a lot because she’s been able to learn about autism, since I was diagnosed she has been able to learn about autism and like join the autism society. She’s working for like good causes and she has like tons and tons of friends that she knows from the autism society so it’s like I helped her social life.

**Social Context: Peer Interactions and Relationships**

Experiences and struggles with peers came up as a recurring theme among the participants, although there was not a specific question directed at peer relationships. Most of the participants reported difficulty meeting new peers and maintaining friendships ($n = 8$). A few participants described themselves as having no real friends. Feelings of awkwardness and difficulty interacting with peers permeated the descriptions of their peer interactions.

I find it hard really to make friends and like I really don’t have a social life. And I can’t relate to a lot of things people talk about because they talk about their friends and things I can’t relate to.
I feel like if I’m out of sight, then I’m also out of mind. Like no one would think about me or talk about me except when I’m around. I feel like even the people who are good friends to me don’t mind me when I’m around but as soon as I’m gone they just forget about me….I feel like a lot of the time even when I’m with my friends I don’t know what to talk about or what to say. I feel awkward.

Some of the participants described specific peer scenarios they had encountered. For example, a female participant described her difficulties with female peer groups and her inability to “pick up on social cues”.

Like not being able to tell what somebody is feeling, especially with teenage girls, you know because girls they don’t tell you and then throw Asperger’s in there and crap, it’s like not only are they not telling you but you’re going in there blindfolded.

She also reported that her negative experiences with female peers has resulted in her being unable to go back to her school or go into town because she is “totally traumatized by what happened”. Several other participants also reported additional peer victimization and bullying experiences.

In addition to difficulties with peer groups, a male participant described his recent struggles with communicating appropriately with peers of the opposite sex. He also described how these negative experiences have made him “upset about the syndrome”.

I’m saying things wrong to people and I just can’t control myself…I don’t know why I did this but I was having problems with socializing but I kept saying things that come [sic] out of my mouth…they started screaming and ran away…guess they weren’t interested in me.
Another participant described his desire to participate in athletic programs or clubs as a means to develop new friendships, despite his athletic weaknesses. For example, “I’m not athletic at all and I’m not really into sports but I think I’d enjoy it because I’d get to meet new people and get to make new friends and occasionally I’d get to go somewhere”.

**School Environment**

Experience with struggles at school came up spontaneously among several of the adolescents. Their comments about school varied; some participants reported that they liked the extra help at school and others reported that school was more difficult. There was one participant who described hating school because he feels awkward “socially and academically”. One participant described her frustration with a teacher not understanding her. She expressed a strong desire to be treated fairly with other students and indicated that teachers “just think I want a special preference”.

It’s like sometimes it feels with certain aspects that we are running a race but I have to run it up hill and I think what some teachers don’t understand is that I don’t want to be running downhill, I just want to be on an even playing field. I don’t want more. I don’t think I’m better or worth more or smarter or more talented than any other kid, I just want to be able to keep up.

Other participants described discomfort at school, which was mostly related to negative peer experiences and awkward social interactions and perceptions that things are more difficult for them. A few participants also alluded to difficulties at school because of their organization and difficulty completing their homework.
Sources of Support

Sources of support were grouped into three major categories: (1) self-education, (2) social support, and (3) mental health support.

Self-Education

Several participants indicated that they had actively sought ASD information online through ASD-specific websites or YouTube videos \((n = 4)\).

There’s actually a website and it’s like a blog for people with Asperger’s and you – and I go on it sometimes and you get to like post your opinions about like different topics and like your interests and like what life’s like having autism. They have like real life stories that are written by people with autism and things like that.

Online access was more common among the older participants and those who seemed to report more psychosocial stresses. Two participants expressed some concern about the credibility of internet sources, especially if the information was not written or posted by other individuals with ASD. In addition to online resources, participants also accessed books or movies about ASD. Maternal influence was often reflected in some of the participants’ choices of information sources. Although many parents provided their adolescents with reading material or encouraged them to watch movies about ASD some participants indicated that they independently accessed their parents’ parenting books or books about ASD without telling their parents \((n = 3)\). In these cases, there seemed to be inadequate communication about ASD within the families, which may have led participants to acquire information about ASD on their own.

Social Support

As indicated above, many participants reported that they felt most comfortable talking to their mothers about issues or concerns associated with their diagnosis \((n = 9)\). One participant
also indicated that rather than speaking with her mother, she chose to speak with her younger sister who also had an ASD diagnosis.

One participant stressed the benefits of participating in activity-based groups for individuals with ASD or accessing resources from local autism organizations. Some participants suggested that individuals with ASD can become an effective source of support to meet new people, develop friendships, and share experiences. Meeting other individuals with ASD appeared to provide them with a sense of belonging and to help them negotiate their perceived feelings of isolation and alienation from mainstream society.

I wish I could meet more people with Asperger’s or high functioning autism and then I could have more friends with Asperger’s and stuff.

I’d like to meet some more people who are more like me because I feel like I’m the only one. I feel like I’m different than everyone else. I feel like there’s no one else that’s like me. Like I just feel I can’t really fit in anywhere.

Another participant reflected on the importance of shared experiences and how they are able to help each other in difficult situations. For example, she described one specific scenario in which she was able to relieve her friend’s worry and anxiety about a sensory aversive situation.

He’ll be freaking out saying ‘No, no. I don’t want to get my makeup done’. And I’ll be like ‘You’re getting your makeup done. Come with me and I’ll do it’. Because I like know how to do stage make up and I know how to do it so that it doesn’t feel gross. Because I get how it feels (You understand him?) Yes, so I just get him. So I can just help him out with stuff like that.
Mental Health Support

A small subset (n = 3) of participants actively sought some professional support from either a psychiatrist and/or psychologist for mental health issues. Professionals were reportedly managing a number of concerns (e.g., “things about my daily life and routines”, “trouble sleeping and prescribing medication”, “gives me advice”, “social skills things”). Two of the three participants indicated that they found this source of support helpful. The other participant had seen a number of different professionals over the past few years and was in the process of finding a new therapist.

Advice to Others

The final few questions of the interview asked participants what they would tell others (e.g., a newly diagnosed student with ASD, parents of a teen with ASD) about ASD and/or their experience of it. Their advice is presented below. No additional interpretations have been provided so the information can be presented in the individuals’ own words. Participant responses were amalgamated into a single message written from the first person perspective. Minor transition words or phrases were added when necessary to assist with the flow and organization.

To newly diagnosed youth with ASD…

Even though it feels like it, it’s not the end of the world...It doesn’t mean that you have to be the stereotype...You’re the same as you were before you found out, it’s just that some things are harder for you and you will be able to get help for it now...You’re just different in some ways even though some people might have a hard time accepting that but when you accept it, it makes everything easier...You gotta like yourself the way you are because the way you are is awesome...Autism doesn’t make you like advantaged or disadvantaged - you’re just like a
normal person... If someone really likes you then they’re not going to judge you by your label....It really shouldn’t be something that you are ashamed of because everyone’s different and you just happen to be different on, you know, a physical level...It has advantages and disadvantages...Learn to live with it and move along....It’s not all that bad...You can cope with it...It’s awesome and special...Autism may actually make you greater at something...It may actually make you have much greater talents...You have special abilities...You are really super awesome because you can think really intensely about things....It’s a good thing you have a syndrome just like me...I’d tell them about ASD - like what it’s like and what it does...I’d probably like tell them how my life is and like how I’ve had trouble and I’d try to give them social advice and I’d probably ask them like what their interests were and like tell them what my interests were...I might suggest a Teen Adventure Club that I’ve been in...I might suggest clubs or local organizations...There is actually a really cool website called ‘wrongplanet.net’ and it’s a blog for people with Asperger’s...Actually that’s a hard question and it all depends on the kid and on what they were struggling in. Say, for instance, they want to learn how to stop the stimming thing, I’d give them like maybe baby steps. First, like wait until you’re finished your work or completed something and then you can stim. Or maybe well if it’s a communication problem, I can say just start with something easy, like “Hi” or “How are you?”...Try not to say personal things...Keep calm and just try do a little bit better in school and in talking to people and keeping things more appropriate...Don’t be afraid to get help whenever and wherever you need it.

To parents of adolescents with ASD...

Don’t blame or write off anything they do...don’t put everything on Asperger’s because it’s still your kid...Just because you now know that there could be a contributing factor nothing will
make your kid stop talking to you faster than feeling like they’re not anything or that what they do is not valid...If you just think that they’re a statistic or stereotype or they’re just doing this because all kids with Asperger’s do this, they won’t feel special and unique and they’ll feel like it doesn’t matter what they do because they have Asperger’s and that really hurts...They need to feel like they’re an individual person, and that just because they might do certain things that some people have said are things that people with Asperger’s do doesn’t mean that’s why...Know that they seriously try - sometimes I try and do the least amount of things I don’t want to do as possible...It’s probably best not to disturb them because if you push them away the more they are going to do it...Don’t make them act like normal children by force by keeping them from doing the things an autistic child would do on their own...Do research to learn more about autism...Try and find out more information about ASD and see what it’s all about...Learn more about why their kids have these interests and social and learning disabilities...Try and see the Temple Grandin movie so you know how to make the person with autism reduce the numbers in their brain...Research it...Help cure it...There are resources available for treating weaknesses or inappropriate behaviour...Try and find a good attribute that the child likes...To try and help them get into some organizations, like some social clubs that might be able to help them find friends...Look for groups of people that share common interests with them... If they don’t like to talk to people, just their parents, then encourage them to talk to more people...Always ask them before borrowing something of theirs...Always tell them before anything happens...You should accommodate them in any way that you can - your kid will really like you if you do...Know the foods they like and the things they like to do...Let them pursue their special interests...Let them eat the food they like and try not to make them try new foods all the time... Don’t force them to do a lot of physical things...Appreciate them for their
strengths…Don’t yell at them and maybe talk to them a bit…Know that I am awesome…Talk to your child.

Discussion

Summary of Main Themes

The aim of this study was to enhance our understanding of how adolescents with ASD experience their diagnosis and the types of supports that might be most helpful to them. The question that initially guided this study was: how is ASD understood and experienced by adolescents with ASD? Although the responses of adolescents varied substantially across the interviews, the key themes offered insight into some of the issues these adolescents subjectively experience. The adolescents’ perspectives also offered valuable information about how parents and professionals can help support them during a key developmental phase in their lives.

Interviews with the adolescents revealed that the majority of them had some understanding of the concept of ASD. Most could describe strengths and weaknesses associated with their diagnosis. There did not appear to be one moment that defined how individuals came to understand their diagnosis, rather it appears to have been a process of development and change that continued to evolve over time; as pointed out by several participants, they became increasingly aware of their differences and diagnosis with age. However, other participants described specific adolescent events that seemed to trigger predominantly negative reactions associated with their diagnosis (e.g., romantic feelings for others, peer rejection and victimization, vocational or post-secondary aspirations). Social-ecological experiences (e.g., perceived stigma, peer victimization and bullying) and supports (e.g., presence of similar others, supportive relationships with parents and teachers, open communication, role models in the media) also appeared to impact individuals’ reactions to their diagnosis. These findings are
consistent with the learning disabilities literature, which suggests that the developmental process of self-understanding and self-acceptance in adolescence is guided by interactions with family members, school personnel, and peers (Cosden et al., 2002).

Several studies have proposed models of diagnosis acceptance or adjustment among individuals with learning disabilities (Higgins et al., 2002) and ADHD (Young, Bramham, Gray & Rose, 2008). Although this study was not specifically designed to evaluate these processes of diagnosis acceptance, participants’ responses to questions about ASD and their descriptions of their experiences shed light on how they have adjusted to their diagnosis. Their responses revealed an awareness of differences and some understanding of the limiting nature of their diagnosis and the services available to them. It was not, however, clear whether participants were able to “compartmentalize” their ASD diagnosis. According to Higgins et al. this stage involves being able to “minimize weaknesses and maximize strengths”. While the majority of adolescents in this study recognized their diagnosis and could identify some strengths or talents associated with it, their general descriptions and experiences of ASD were often characterized by negative perceptions and appraisals (e.g., “weird”, “lazy”, “bad”, “wimp”, “impaired”, “awkward”, “disgusting”). This contrasts some of the findings from adult studies where the ASD label was reported to be a source of pride that helped foster a positive self-concept (Hurlbutt & Chalmers, 2002; Portway & Johnson, 2005). There may be developmental factors that differentiate diagnosis acceptance between adolescents and adults, suggesting that this process may continue on past adolescence.

The pattern of themes and categories from the interviews suggest that it may be helpful to examine the stressors and the match between the environment and the adolescent when examining factors of adjustment, coping, and interventions. Some of the adolescents in this study
emphasized a need for better communication and understanding. Their advice to parents and professionals exemplified their desire to be heard and supported. One participant specifically described her frustrations with how her parents viewed her behaviour as expression of ASD symptoms rather than expressions of her own personality. This view is consistent with bodies of work that criticize the medical model of developmental disorders because of an assumption that children are labeled or defined by their diagnosis which affects their individuality and limits other people’s expectations of them (Molloy & Vasil, 2002).

Age of disclosure may be another factor impacting how individuals adjust to their diagnosis. Eight of the adolescents in this study were diagnosed with ASD before the age of 6 years, and all but one participant had known about his/her diagnosis for more than 3 years. The one participant who appeared to be struggling the most to accept and acknowledge his diagnosis had only been diagnosed 18 months prior to participating in this study. This individual required more post-diagnostic support to work through what his diagnosis means for him and his family. More longitudinal research is required to understand the impact of early versus late diagnosis and/or disclosure of diagnosis among individuals with ASD. Punshon et al (2009) speculated that people diagnosed with Asperger’s syndrome in adulthood experienced lifelong feelings of difference and not ‘fitting in’ because they did not have the framework of a diagnosis in childhood and adolescence that would explain their symptoms. Although the benefits of early identification and support are well substantiated, it is important to note that several adolescents in this study who were diagnosed in early childhood and told about their diagnosis prior to adolescence also continued to struggle with feelings of difference, inferiority, and psychosocial distress. More research is required to determine if there would be qualitative differences between individuals who learn about ASD in childhood, adolescence or adulthood. It is likely that other
individual (e.g., temperament, problem solving abilities, behavioural attributions, and coping skills) and family (e.g., family environment, family members’ adjustment and perceptions of the diagnosis) factors would interact with how individuals experience, understand, and accept their diagnosis. Future studies may wish to examine how these factors are related and the different types of trajectories children and adolescents may experience once they learn about their diagnosis.

**How does the experience of having an ASD diagnosis impact self-concept and adjustment in adolescence?**

Adolescence is a time of intense social pressure to “fit in” and to be “normal”. Adolescents are often trying to make sense of the self, while at the same time developing peer and social relationships and comparing their abilities and differences with peers. For many adolescents, group or peer acceptance is an important part of their development. Adolescents are faced with several important developmental tasks that include self-reflection and evaluation of their life experiences, identity formation, and increased autonomy and agency. During adolescence, the emergence of abstract thinking, introspection, and self-reflection compel adolescents to have differentiated perceptions of their competence in various domains (Harter, 1990).

Findings from this dissertation underscore the importance of exploring the role of self-perceptions and self-awareness in adolescents with ASD. As was shown in Study 1, adolescents have some awareness of the challenges associated with ASD and hold differing self-perceptions of competence and behavioural attributions when compared to same-age peers. Results from Study 2 enhance these findings by providing more information about adolescents’ understanding of themselves, their experiences of living with ASD, and the potential factors that have
influenced their self-awareness. In exploring these and related issues, it is also important to keep in mind the neurobiology of ASD, which includes significant challenges with social competence, social cognition, social communication, emotion decoding, perspective taking, cognitive flexibility and abstract reasoning, likely complicates the process of adolescent development.

Findings from this study also provide insights into the subjective experience of stress and negative self-perceptions experienced by youth with ASD. Feelings of despair, such as shame and embarrassment, and feelings of not fitting in or being separated from society permeated the narratives of many of these adolescents. Many of their reports were from past experiences, but there were some participants who also expressed concerns regarding their future. Concerns about social acceptance, loneliness, and the inability to develop relationships have also been reported in the literature (Carrington & Graham, 2001; Howard et al., 2006; Jones & Meldal, 2001; Portway & Johnson, 2003). Feelings of alienation and difference from others has been described in several other studies (Humphrey & Lewis, 2008; Molloy & Vasil, 2004; Punshon et al., 2009; Ruiz Calzada et al., 2012) and autobiographical accounts (Grandin, 2012; Jackson, 2002).

Harter’s theory of the self is in part based on Cooley’s (1902) theory of the looking glass self, which emphasizes the importance of others’ appraisal of the self. These evaluations are internalized and incorporated as part of the self. Some of the participants in this study described their negative perceptions of how ASD was viewed in their immediate context (i.e., parents, teachers, or peers) and in the media. Furthermore, many of the general descriptions and experiences of ASD were characterized by negative perceptions and appraisals (e.g., “weird”, “lazy”, “bad”, “wimp”, “impaired”, “awkward”, “disgusting”), which to some degree became a part of the participants’ narrative and descriptions of self.
Identity development is a normative developmental task for adolescents transitioning into adulthood. Early adolescence is the stage at which active identity exploration begins and one of the goals of adolescence and emerging adulthood is to develop a coherent and cohesive personal identity (Cote, 2006; Erikson, 1980). Experiences of stigmatization may result in an internalized stigma and diminished sense of self (Link, Cullen, Struening, Shrout & Dohrenwend, 1989). Some participants described ways in which they have learned to limit or hide their behaviours to avoid peer victimization and stigmatization. Similar reports have been described in the literature (Attwood, 2007; Carrington & Graham, 2001). Some participants also struggled with disclosing their diagnosis to others, likely because they did not have the emotional resources to face the challenges of disclosure. These risks of disclosure have been discussed in previous research studies and clinical resource materials (Molloy & Vasil, 2004; Portway & Johnson, 2005; Whitaker, 2006). It is likely that these attempts to prevent disclosure or distance themselves from ASD may be one way that individuals manage the negative stigma associated with ASD.

As individuals start to understand their diagnosis, they appear to become increasingly aware of their difficulties and how these may separate them from their peers. Learning about one’s disability may cause feelings of flawed identity in adolescents (Chigier, 1992). Studies on chronic illness in adolescents have suggested that adolescents may have difficulty achieving a sense of identity because their illness forces dependence on parents or guardians (Rainey, 1982). Several adolescents in this study expressed a sense of failure in their ability to complete daily tasks. Such perceptions of inability have an impact on their autonomy and sense of agency.

Although this study did not specifically examine the process of identity formation in adolescents with ASD, individuals did express feelings of difference and isolation, which are often key components of identity theories. Many, however, were able to separate some of their
descriptions of self from their ASD. Some of the adolescents appeared to have difficulty integrating and adapting to their identity as an individual with ASD. This was particularly true of one youth who was diagnosed at an older age. His later diagnosis may have made it more difficult for him to incorporate ASD into a more well-developed identity. With additional time to process and consolidate this information, however, he may achieve this adaptation later on in adulthood.

Although most of the participants in the current study were able to describe some positive characteristics associated with their diagnosis, only one individual appeared to experience a sense of acceptance and pride when talking about her diagnosis, by using statements of ownership over her diagnosis and personal identification with ASD. Her process of self-understanding and acceptance paralleled how individuals with learning disabilities in the Higgins et al. (2002) study were able to “transform” or “reframe” the negative attitudes of their disability into an appreciation of the positive influence on their lives and character. She also described her environment as needing to “accommodate” to her. This type of thinking emphasizes the importance of contextual factors and environmental adaptations, as opposed to solely focusing on individual changes, which may further exacerbate feelings of isolation and not fitting in. The impact of feeling accepted and supported may be an important factor in helping individuals with ASD cope with and accept their diagnosis.

Along with feelings of differentness, some of the participants considered themselves a different subculture or community (e.g., “Aspies”) that was different from the mainstream culture. As noted in several studies of adults with Asperger’s syndrome (Punshon, et al., 2009; Rosqvist, 2012) it may be useful to consider the research on the coming-out process among lesbian, gay, bisexual and transgender (LGBT) individuals as a possible template for
understanding this process. Researchers studying sexual minorities have developed several models of identity development (Corrigan & Matthews, 2003; Rosario, Hunter, Maguen, Gwadz & Smith, 2001). Such research may shed light on how minority individuals experience feeling different, understand and accept their differences and integrate their identity into their self-concept.

The family’s perspective of ASD and general communication style may also play a role in how adolescents understand and accept their diagnosis. Many of the participants learned about their diagnosis through their parents and some frequently sought support from parents with day-to-day issues and concerns. This study did not examine parental perspectives but several studies have examined parents’ perceptions and explanations (Ruiz Calzada et al., 2012; Edler, 1994; Gray, 1995; Hines, Balandin, & Togher, 2012; Mercer, Creighton, Holden & Lewis, 2006). Among these studies, parents often attributed their child’s ASD diagnosis to a variety of perinatal and postnatal factors and experienced blame and guilt. More research is needed to examine the effects of these parental perceptions on their children’s adjustment or acceptance. Several adolescents in this study described their frustrations with their degree of dependency, and one participant believed she was a “burden” to her parents. The extent to which adolescents were aware of potential parental sensitivities and perceptions was not examined in this study.

Cosden, Brown, and Elliot (2002) proposed that children with learning disabilities who had parents and teachers that did not fully understand or communicate their diagnosis with them were more likely to develop self-perceptions that either globalized their disability or were inaccurate (e.g., they viewed themselves as slow or stupid). Some research has also found that psychological acceptance may be an important intervention factor for parents of young people with ASD (Blackledge & Hayes, 2006; Weiss, Cappadocia, MacMullin, Viecili & Lunsky,
Future research may consider the influence of parent, teacher and peer feedback on the development of ASD awareness and positive or negative self-perceptions among adolescents with ASD.

**Implications for Clinical and Educational Practice**

The key themes that emerged from the analysis revealed several important clinical and educational implications. Understanding an individual’s conceptualization of ASD is important to help them better understand and come to terms with their diagnosis. Understanding their knowledge about their diagnosis could also provide information about their help-seeking and treatment utilization patterns. Using diagnostic descriptions of ASD often means emphasizing deficits and describing observable behaviour symptoms in terms of behaviours that are lacking or atypical. Such labels and negative terminology may affect the behaviour and self-representations of individuals with ASD (i.e., “looping effects of human kind”, Hacking, 1995). Clinicians working with individuals should be mindful of how individuals with ASD understand and incorporate diagnostic descriptions of ASD into their identity, and may consider exploring individual talents and unique personality styles (Gray, 1996; Vermeulen, 2001) as means of identity development. Jacobsen (2003) suggests examining the ASD symptoms as an “attempt at mastery of something difficult”, which focuses on enhancing growth in the individual rather than focusing on areas in which they are lacking. It will also be important for parents and clinicians to revisit adolescents’ understandings over time, as their perceptions and experiences may alter with changes in context and their relationships at key developmental periods in adolescence and into adulthood (e.g., elementary to middle to high school; puberty).

Many of the adolescents in this sample were open to accessing services and discussed a number of different sources of support. Notably, some of the participants independently sought
information about ASD through the internet or in books and movies. Consistent with research on typically developing adolescents (Gray, Klein, Noyce, Sesslberg & Cantrill, 2005), some of the adolescents in this study perceived the internet as an alternate information source for health-related issues. Limited education and lack of open communication about ASD within some families may have encouraged adolescents to acquire more information on their own. Some adolescents talked about the usefulness of resources that included personal accounts and guidance written by other individuals with ASD (e.g., autobiographies, ASD-related public websites). Some studies have reported on the relevance and benefits of online technology formats to support children and adolescents with special needs (Raskind, Margalit & Higgins, 2006; Seymour & Lupton 2004; Barak & Sadovsky, 2008). Raskind et al. found that their carefully monitored website by adult professionals provided a safe environment where children and adolescents with learning disabilities (LD) could disclose their LD identity and share their experiences of living with a learning disability. To date, a small number of studies have examined the social and adaptive benefits of online communication media among adults with ASD (Jones & Meldal, 2001; MacLeod, 2010; Muller et al, 2008). More research is required to look at the effects of Internet communities as a means to foster resilience and increase positive self-identity among individuals with ASD. Families and clinicians may need to help children and adolescents with ASD find safe and secure internet sites due to vulnerabilities with online victimization, exposure to inappropriate or inaccurate material, and invasion of privacy.

Strategies involving others, including social support, were also beneficial for some individuals in this study. Social support included talking to parents or participating in activity-based groups with other individuals with ASD. These experiences seemed to provide individuals with a sense of belonging (e.g., “Aspie community”) or shared identity with similarly labeled
peers. Such experiences have also been reported in the literature (Jones & Meldal, 2001; Muller et al., 2008; Murray, 2006) and highlight the need for social interaction or support groups for individuals with ASD. These support groups can provide individuals with opportunities to identify, describe, and perhaps challenge their worries, frustrations and feelings of despair. Although not reported by participants in this study, some adolescents from the pilot group of interviews discussed the benefits of attending specialized ASD programs at school because they were with other students with similar interests and challenges. Future studies may wish to explore the benefits of social groups and ASD educational programs on individual self-concept, diagnosis acceptance, and identity formation.

In addition to self-education and social support, mental health or counseling support may be beneficial for some individuals and should be considered at the point of disclosure. More specifically, clinicians may consider the use of cognitive behavioural techniques to address feelings of distress, negative core beliefs and appraisals, and to help individuals develop better coping skills. To date, several studies have demonstrated the effectiveness of using modified cognitive behavioural strategies to address symptoms of anxiety, anger management, and social functioning in individuals with ASD (Gutstein, Burgess & Montfort, 2007; Lang, Regester, Lauderdale, Ashbaugh & Haring, 2010; Reaven & Hepburn, 2003; Sofronoff, Attwood & Hinton, 2005; Sofronoff, Attwood, Hinton & Levin, 2007; Sze & Wood, 2007; Wood et al., 2009). Clinicians can also help individuals and families explore the positive aspects of their diagnosis and/or personal strengths. For example, acceptance-based interventions have been proven to be effective for some chronic health conditions in children and adolescents (Masuda, Cohen, Wicksell, Kemani & Johnson, 2011; Wicksell, Melin, Lekander & Olsson, 2009) and for parents of children with autism (Blackledge & Hayes, 2006).
Finally, this study has highlighted the importance of using a systems perspective to better understand the role of the environment in adapting to the needs of individuals and the fit between an adolescent with ASD and his or her surroundings. Some of the themes from this study aptly fit into a systems-oriented perspective, such as the bioecological model of development (Bronfrenbrenner, 1995; Bronfrenbrenner & Ceci, 1994), to explain the complex interactions and relationships between an individual with ASD and their surroundings during adolescence. This model suggests that life’s course is shaped by the levels of influence imposed through the interplay among individual, family, school, peer, and community factors (Bronfrenbrenner, 1995). Bronfrenbrenner defines “proximal processes” as the reciprocal interactions between the developing individual and their environment. These processes are described as the key factor in development. The nature of the environment and the developmental outcomes, as well as the relevance of the biological and genetic aspects of the person must be considered. As such, this type of model emphasizes the ways in which the unique strengths and challenges of individuals with ASD interact with the environment in bidirectional ways. Similar systems-oriented models have been applied to pediatric illness (Hosek, Harper, Lemos, & Martinez, 2008; Kazak, Segal-Andrews, & Johnson, 1995) and emphasize how adolescents with a diagnosis experience identified stressors related to their diagnosis, family, peers, community resources, and mental health settings, as well as broader societal structures (e.g., media, culture, technology, societal stigma and attitudes, policies and laws). This framework offers a way to organize how adolescents, families, schools, and healthcare or community resource settings interact with issues related to ASD. The model emphasizes that the environment does not only support the adolescent with ASD, but rather the adolescent with ASD is embedded within the environment. It is important that interventions are developed to help adolescents address ASD-specific
concerns such as relationships and social competence (e.g., family, peers, teachers, romantic partners), diagnosis disclosure, school or work-related issues, vocational planning, mental health support, and social stigma.

This study has elucidated some of the psychosocial challenges experienced by adolescents with ASD and may help to increase awareness and guide the development of more effective interventions that address feelings of alienation, difference, loneliness, and relationship challenges that have been reported in the literature and voiced by adolescents themselves in this study. Many of the current interventions for individuals with ASD are designed to focus on skill development within peer contexts; however, this study further highlighted the importance of interventions aimed at improving communication between parents and adolescents to maintain adaptive levels of communication and family cohesion. Given the stress related to raising a child with ASD (Dumas, Wolf, Fisman, & Culligan, 1991; Fong, Wilgosh & Sobsey, 1993; Lounds, Seltzer, Greenberg & Shattuck, 2007; Schieve, Blumberg, Rice, Visser & Boyle, 2007), intervention programs should also consider how to provide support and knowledge about ASD to parents so they can help empower their children to understand, accept and advocate for themselves.

Research has demonstrated that the quality of parent-child relationships has an effect on the child’s competence in school and peer relationships (Howes, Hamilton & Matheson, 1994; Pianta & Harbers, 1996). Several studies are starting to explore the quality of mother-child relationships among adolescents and adults with ASD (Orsmond, Seltzer, Greenberg & Krauss, 2006; Taylor & Seltzer, 2010), but these are often from the perspective of the mother. Future studies may wish to explore the impact of parent-child relationships on adolescents and young adults with ASD. It is also plausible that adolescents with ASD are less capable of identifying
and expressing their feelings and communicating effectively because of social cognition and communication challenges. Difficulties with communication may not necessarily be related to strained parent-child relationships, but rather a result of ASD symptomatology.

In addition to parent-child communication, adolescents with ASD discussed general challenges associated with not feeling heard or with being misunderstood. Educators and clinicians need to be mindful of how they communicate with adolescents. It will be important to involve adolescents in individual education planning and therapeutic goal planning.

**Limitations and Directions for Future Research**

The results of this study are limited to a small sample drawn from adolescents residing in Ontario. Due to the limited time period to collect the research and the specific population recruited, theoretical sampling, which means seeking and collecting pertinent data to elaborate and refine categories in grounded theory research (Charmaz, 2006) was not feasible. Adolescents participated in the study in the order in which they consented. Caution should be taken with respect to the generalizability and application of these results to other adolescents with ASD. Not all of the participants were able to successfully participate in the open-ended structure of the interview (i.e., four of the 13 participants’ interviews lasted less than twenty minutes). Alternative interview or narrative formats (e.g., diaries, artwork) may be necessary for participants who have more difficulty with the open-ended approach. In addition, adolescent experiences on the basis of age, gender, socioeconomic status, schooling backgrounds, comorbid diagnoses, psychosocial functioning and intellectual abilities were documented, but not accounted for. The sample consisted of adolescents between 13 and 17 years of age, spanning a large developmental period, including early, middle and late adolescence. Although the themes were generally reported across all age groups, the qualitative and developmental experiences in
middle and high school may be quite different. This sample was also limited with regard to
ethnic diversity, as participants were predominantly European-Canadian. It is not known to what
degree the findings from this study would generalize to children or adults with ASD with other
cultural backgrounds and differing levels of functioning. While some of the themes and
experiences of adolescents in this study appear consistent with previous studies on ASD, the
extent to which they can be generalized to the ASD adolescent population remains unclear.

This study focused primarily on the adolescents’ perspectives. Parent interviews
exploring similar themes might have provided more information about family factors and
parents’ perceptions and reactions to ASD and how they make decisions about when and how to
disclose the diagnosis to their child. It may also be interesting to comparatively study the themes
and experiences among other groups of adolescents with non-visible disabilities, such as
Attention Deficit Hyperactivity Disorder or learning disabilities. The extent to which the themes
and experiences expressed by adolescents in this study are specific to ASD or relevant to other
adolescents with varying diagnoses is not known. Other comorbid diagnoses, such as learning
disabilities, ADHD or mental health difficulties, may have also contributed to individual
experiences.

Another limitation of this study was the cross-sectional design. The study only captured
retrospective and current descriptions of the adolescents’ experiences in one interview session.
Interviewing the adolescents at one time point did not permit further examination of the themes
across different developmental time points, nor did it allow for an examination of adolescents’
adjustment to their diagnosis over time. Another possible limitation may be the reliance on recall
to explore adolescent perceptions. Participants had been aware of their diagnosis for at least one
year so that they could reflect back on their experiences. However, the distance in time between
diagnosis disclosure and participation could be a limitation depending on the reliability of the participants’ self-report. Adolescents were also more likely to describe more recent or salient issues that they had experienced. Furthermore, this study did not specifically focus on how adolescents were told about their diagnosis. It would be interesting to collect more information about how their disclosure processes unfolded over time. These questions would involve multiple perspectives, including parents, adolescents, and professionals that may have been involved in the disclosure process. Such information could shed light on appropriate timing and determinants of disclosure, which are questions parents and clinicians often ask.

A limitation with respect to methodology also lies in the reliability and trustworthiness of the data. The purpose of qualitative research is to understand the participants’ perceptions, interpretations, and experiences, and it was felt that thematic analysis would be most suitable for analyzing interview data. Although attempts were made to ensure credibility of the data through peer debriefing and triangulation of the data (e.g., reviewing and comparing material from previous studies and cross-checking the qualitative themes from Study 2 with the self-report data in Study 1), additional criteria could have been applied. For example, member checking (Lincoln & Guba, 1985) is one approach in which interview data are played back to the participants to ensure accurate descriptions of their interviews. This was not done for the current study, in part due to the desire to reduce the demands on participants. It is also unclear whether similar issues would have emerged had the interview not been focused around the ASD diagnosis. That is, would adolescents make reference to their experiences in the same way had ASD not been specifically mentioned in the interview?

Finally, it is important to consider how a researcher’s discipline orientation can have an impact on the ways in which qualitative research is framed and analyzed (Thorne, Joachim,
Paterson, & Canam, 2008). The investigator was a child clinical psychology graduate student with training in developmental psychology and developmental psychopathology. Given this perspective, ASD was initially defined from the perspective of a biomedical model of disability. However, through review of the literature on ASD and the experiences described by the youth in this study, the principles of the social model of disability were highlighted. According to this model, the challenges experienced by individuals with ASD are not due to individual impairment, rather they result from the socially constructed views of ASD behaviours as being abnormal. Although models from these two perspectives are often seen in opposition to each other in the literature, there has been a shift towards combining perspectives, resulting in a more comprehensive approach that recognizes the unique strengths, perceptions and skills in individuals with ASD, and moves beyond viewing ASD as a collection of impairments or deficits. Informed by the experience of working clinically with individuals with ASD, together with additional insights gained from conducting this study, this researcher espouses an integrated approach, which recognizes the strengths and unique characteristics of the individual, but with an awareness of the deficits and challenges that can cause distress.

**Conclusion**

In summary, this study has shown that some adolescents with ASD are able to self-reflect and provide insight into their life experiences. These findings are within a Canadian context and add to the other studies that have been conducted within European and American contexts. The psychosocial impact on individuals with ASD is significant and demonstrates that an awareness about ASD presents challenges during the adolescent period even after their diagnosis has been disclosed to them. Adolescents with ASD appear to be vulnerable to developing negative
perceptions and experiencing psychosocial distress as they become increasingly aware of their differences and the challenges associated with their diagnosis.

This study highlights the importance of working with children and adolescents with ASD using a bioecological context to help them accept and value their differences and to enable them to feel competent, recognize their strengths, and to foster opportunities to address their psychosocial challenges and feelings of indifference and despair. The final words, left by one adolescent participant, highlight the importance of acceptance and support for individuals with ASD:

*You’re just different in some ways even though some people might have a hard time accepting that but when you accept it, it makes everything easier... You’re the same as you were before you found out, it’s just that some things are harder for you and you will be able to get help for it now.*
### Table 3.1

**Participant Demographics**

<table>
<thead>
<tr>
<th>Participant</th>
<th>Gender</th>
<th>Age/Grade</th>
<th>Diagnosis</th>
<th>Age of ASD Diagnosis</th>
<th>Age of ASD Disclosure</th>
<th>Comorbid Diagnosis</th>
<th>Intellectual Ability</th>
<th>Verbal/Nonverbal&lt;sup&gt;a&lt;/sup&gt;</th>
<th>Descriptive Range</th>
<th>Length of Interview (min:s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>M</td>
<td>15/10</td>
<td>AS</td>
<td>10</td>
<td>10</td>
<td>LD</td>
<td>Very Superior/Superior</td>
<td>Average/Average</td>
<td>21:54</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>F</td>
<td>16/11</td>
<td>ASD</td>
<td>13</td>
<td>13</td>
<td>LD, Anx</td>
<td>Average/Average</td>
<td>Average/High Average</td>
<td>59:11</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>M</td>
<td>13/8</td>
<td>ASD</td>
<td>1</td>
<td>9</td>
<td>LD, Anx</td>
<td>Average/High Average</td>
<td>Average/High Average</td>
<td>12:38</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>M</td>
<td>14/8</td>
<td>Autism</td>
<td>4</td>
<td>10</td>
<td>LD, ADHD</td>
<td>Average/High Average</td>
<td>Average/Average</td>
<td>18:06</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>M</td>
<td>16/11</td>
<td>PDD</td>
<td>3</td>
<td>8</td>
<td>LD, Dep, ADHD</td>
<td>High Average/Average</td>
<td>Average/Average</td>
<td>56:10</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>M</td>
<td>14/8</td>
<td>AS</td>
<td>7</td>
<td>11</td>
<td>LD, ADHD</td>
<td>Average/Average</td>
<td>Average/Average</td>
<td>28:54</td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>M</td>
<td>13/7</td>
<td>Autism</td>
<td>3</td>
<td>8</td>
<td>Anx</td>
<td>Average/Average</td>
<td>Average/High Average</td>
<td>18:32</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>M</td>
<td>13/8</td>
<td>PDD</td>
<td>2</td>
<td>10</td>
<td>Anx</td>
<td>Average/Extremely Low</td>
<td>Average/High Average</td>
<td>26:17</td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>M</td>
<td>13/8</td>
<td>PDD-NOS</td>
<td>3</td>
<td>NA</td>
<td>None</td>
<td>High Average/Average</td>
<td>Average/High Average</td>
<td>50:51</td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>F</td>
<td>15/10</td>
<td>PDD-NOS</td>
<td>3</td>
<td>NA</td>
<td>None</td>
<td>High Average/Average</td>
<td>Average/High Average</td>
<td>35:51</td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>M</td>
<td>17/12</td>
<td>AS</td>
<td>16</td>
<td>16</td>
<td>LD, Anx</td>
<td>Average/Average</td>
<td>Average/High Average</td>
<td>9:14</td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>M</td>
<td>16/10</td>
<td>Autism</td>
<td>9</td>
<td>10</td>
<td>LD, ADHD</td>
<td>Low Average/Low Average</td>
<td>Average/High Average</td>
<td>23:20</td>
<td></td>
</tr>
<tr>
<td>13</td>
<td>F</td>
<td>14/10</td>
<td>ASD</td>
<td>3</td>
<td>10</td>
<td>None</td>
<td>Low Average/Low Average</td>
<td>Average/High Average</td>
<td>23:20</td>
<td></td>
</tr>
</tbody>
</table>


<sup>a</sup>IQ scores were derived from the Verbal and Nonverbal IQ scores on the WASI (N = 6), WISC-IV (N = 2) or SB-5 (N = 5). The descriptive ranges correspond to commonly used standard score ranges: Very Superior (130 and above), Superior (120-129), High Average (110-119), Average (90-109), Low Average (80-89), Borderline (70-79), Extremely Low (69 and below).
CHAPTER 4
GENERAL CONCLUSION AND IMPLICATIONS

The primary objective of this dissertation was to make a unique contribution to existing knowledge about the self-perceptions and lived experiences of adolescents with ASD. This exploratory mixed-methods project aimed to fill a void in the ASD adolescent literature by working directly with adolescents to explore their own perspectives and perceptions of their individual strengths and weaknesses, what they attribute their difficulties to, and how they understand and interpret their ASD diagnosis. This final chapter will provide a synthesis of the major findings by integrating the results from the quantitative and qualitative studies. General implications for interventions within family, school, therapeutic, and broader societal contexts will also be considered.

Overview of the Major Findings

Studies 1 and 2 were carried out with a mixed-methods design aimed at investigating adolescents’ life experiences with ASD. Quantitative measures were used to examine self-concept and self-perceived competence, self-awareness of ASD characteristics and behaviours, and the types of behavioural attributions adolescents ascribe to their ASD symptoms. Concurrently, qualitative data were collected to better capture how ASD is perceived and experienced by adolescents with ASD. Together, these results provided insights about how adolescents perceive themselves and their ASD diagnosis and some of the individual, family, and school factors that may be related to their self-perceptions and self-awareness.

Results from the quantitative investigations enhance the current understanding of the developmental strengths, needs and challenges experienced by adolescents with ASD. The main finding from Study 1 suggests that adolescents with ASD have some awareness of the challenges
associated with their ASD and, as a group, hold different self-perceptions of competence and behavioural attributions than adolescents without ASD. Consistent with Harter’s (1999) perspective of self-concept, competence scores varied across different domains. As a group, these adolescents recognized the social and adaptive difficulties they face when compared to same-age peers. Lower self-perceptions of competence on peer-salient domains, such as social acceptance, close friendships, and romantic appeal, are important areas that may be targeted for intervention when working with this age group. In addition to social supports, programs and services may be needed to address challenges in other areas of adolescent development, such as athletic ability, job readiness skills, and issues related to romantic relationships and sexuality.

The absence of significant differences between ASD and non-ASD adolescents in other domains, such as physical appearance, scholastic competence, and behavioural conduct, suggest that in some areas adolescents with ASD have self-perceptions that do not differ from typically developing peers, demonstrating that their awareness of their differences is domain-specific, rather than global.

Study 1 also examined the attributions that adolescents with ASD make about their own behaviours. Key findings revealed that adolescents with ASD, like their ADHD counterparts, are more likely to see their problematic behaviour as pervasive and unchanging, when compared to adolescents with no diagnosis. According to attribution theory (Weiner, 1985), these types of global attributions negatively impact individuals’ self-concept and lower their expectations about the future. Adolescents with ASD reported less parent and teacher stigmatization than individuals with ADHD, suggesting that they may experience more adult support and understanding. Consistent with their perceptions of poor social competence, adolescents with
ASD reported trends towards greater peer stigmatization than same-aged typically developing peers.

Qualitative analyses, in Study 2, provided a means to further explore adolescent perceptions and experiences of their diagnosis. Results revealed subjective experiences of stress and negative self-perceptions. Although the participants were able to recognize some of the strengths associated with their diagnosis, many of the participants were knowledgeable about the social struggles and the neurobehavioural differences between them and their typically developing peers. They experienced feelings of shame and embarrassment, as well as perceptions of being misunderstood and of being different from their peers. Similar to the quantitative findings from Study 1, the adolescents’ perceptions of stigmatization and not fitting in, as well as their experiences of repeated social failure and peer victimization appeared to negatively impact their self-concept and self-image. It is likely that the role of media, as well as the lack of knowledge and stereotypes about individuals with ASD, play a role in how these perceptions are internalized. Some participants expressed the importance of a “more balanced view in the media” by listening to the needs and perceptions of individuals with ASD, and emphasized the importance of participating in groups and activities with other individuals with ASD to increase their sense of belonging and shared identity. The qualitative data also provided insights into the types of social and emotional supports this group felt they needed to better understand and cope with their diagnosis. Only one participant appreciated the positive impact of her diagnosis and appeared to have embraced ASD in ways that had been reported in studies of adults with ASD and other disability acceptance literature. For the remainder of the adolescents in this study, their reactions to and experiences with their diagnosis were far more complex as they appeared to struggle with both the positive and negative aspects of their ASD. This suggests that the positive
interpretations previously reported in adulthood may evolve slowly, throughout adolescence and into adulthood.

Consistent with findings from Study 1, which suggested that adolescents with ASD experienced less stigmatization from parents, some of the adolescents described more comfort and safety at home when compared to school environments. School experiences illuminated their difficulties with ‘fitting in’ and feeling misunderstood, which for some participants resulted in attempts to limit or hide their ASD behaviours. Fears of facing disclosure were present for some participants, and it is evident that some individuals may require support around diagnosis disclosure.

This dissertation makes a major contribution to the literature by highlighting the need to consider the complex interplay of individual and social-ecological factors in determining how adolescents with ASD perceive themselves and experience their own adolescence. Qualitative and quantitative methods converge to underscore the importance of considering the interactions between adolescents and their families, peers, school, community and greater society, as well as the fit between adolescents and these environments, when undertaking individual assessment of needs and treatment planning. As discussed in Study 2, a systems-oriented bioecological model offers a way to organize how adolescents, families, schools, and other environmental settings interact with issues of ASD.

Findings from this dissertation also reveal that certain risk factors, such as verbal cognitive ability and age of diagnosis disclosure, may impact the process of awareness and acceptance. Increased awareness can have both positive and negative effects on psychosocial adaptation. Although greater awareness and knowledge about one’s diagnosis may lead to better clinical outcomes and treatment compliance, this research program has shown that for some
adolescents with ASD, increased awareness is related to lower feelings of social acceptance and increased psychosocial distress. Given the developmental stages of adolescence and emerging adulthood, during which acceptance and belonging are important, individuals’ awareness of negative perceptions and social rejection can have a profound impact. The findings from this dissertation suggest that more research is needed to investigate how knowledge and awareness of a diagnosis over time impacts self-perceptions and psychological adaptation, which have important implications for self-concept, identity development, and autonomy during the adolescent period.

These results have implications for ASD interventions and services to assist with the transition into young adulthood. Interestingly, some recommendations were directly made by the participants themselves in response to the ‘advice to others’ questions. This suggests that individuals with ASD should be directly included in research and community efforts to develop appropriate supports and programs. The recommendations that follow are aimed at ways adolescents with ASD and their families can be supported in family, school, and community settings. The findings also have direct implications for clinicians and educators working with adolescents with ASD and may further assist with the research and development of best practice models with respect to this population.

**Implications for Adolescents with ASD and their Families**

Results from this research program demonstrated that adolescents with ASD experience myriad stressors in many areas of their lives, including perceptions of low self-worth and competence, feelings of alienation and difference, loneliness, peer rejection and victimization, and social stigma. As such, it is important that interventions are developed to teach and/or enhance skills across various content domains. Interventions are needed to help adolescents
address concerns with peer relationships and social competence, as well as with family, school and work-related issues. Transition programs need to foster the development of skills and competencies to prepare adolescents for independent living, integrated employment, and intimate relationships. Adolescents in this study also described difficulties with athletic competence, and as indicated by Jennes-Coussens et al. (2006), they will benefit from assessment of and intervention to support their physical functioning.

Adolescents also need to be assisted to understand their diagnosis and associated challenges and to recognize and celebrate their strengths. Programs aimed at increasing self-awareness and self-advocacy skills are important so that individuals can become aware of the types of accommodations and supports available to them. Several participants in this study were empowered to challenge the negative stereotypes and participated in groups or online discussions. Caregivers and clinicians may help adolescents connect with appropriate community and online ASD advocacy organizations. Adolescents and their families may also need support and guidance with diagnosis disclosure. It is, however, important to recognize that adolescents with ASD, like those described in this study, need time and appropriate support to understand what ASD is and what it means for them before making decisions about disclosing to other individuals (Pukki, 2006).

In addition to individual interventions, supports should be offered to families of adolescents with ASD. Parents need support and knowledge about ASD to help their children understand their strengths and challenges and to empower them to develop self-advocacy skills.

**Implications for Clinicians**

Assessing an individual’s awareness and understanding of their diagnosis, as well as attributional patterns, can be an important adjunct to treatment with adolescents with ASD to
better understand their motivation, affect, performance and expectations about future outcomes. Cognitive behavioural techniques may be helpful to address feelings of distress, negative core beliefs and attributions, and to assist in the development of better coping skills.

Clinicians should also be particularly sensitive to issues around identity development and stigma among adolescents with ASD. The concept of shame has been referenced in relation to disability (Scheff, 1997). Clinicians working with adolescents with ASD may want to recognize that some youth may be experiencing shame or embarrassment associated with their diagnosis and specific ASD behaviours, and this may be contributing to a reluctance to disclose their diagnosis to others.

Findings from this dissertation also highlight the importance of focusing on the positive qualities of ASD and on the use of individual strengths in treatment planning. It is also important that clinicians revisit their clients’ understandings and perceptions of ASD over time due to the complex interplay of individual and social-ecological factors throughout development.

**Implications for Educators**

With the increasing prevalence of ASD, school personnel are educating more students with ASD. Adolescents in this study emphasized specific areas of need at school (e.g., feeling misunderstood, experiences with social isolation, peer victimization, desire to fit in, difficulty with schoolwork). Similar findings were reported by Scuitto et al (2012) who examined the firsthand accounts of school-related challenges by individuals with Asperger’s syndrome. Adults with AS and parents described teacher qualities (e.g., acceptance of differences, empathy, flexibility) and instructional practices (e.g., flexibility with assignments, allocating time for breaks, providing visual prompts and choices, focusing on child’s strengths and building on their interests) that had a positive impact on school experiences. Teachers and school personnel are
encouraged to understand the importance of recognizing the individuality of each student with ASD. Focusing on individual competencies, interests, and adaptive potential, rather than their deficits and challenges, will assist with facilitating learning, promoting social development, and alleviating some of the psychosocial distress. As this dissertation has shown, adolescents with ASD want to feel heard and understood. Educators need to involve adolescents in educational goal-setting, transition planning, and self-evaluation, which will help support the development of academic commitment, achievement, and confidence, and will also foster self-advocacy skills.

**Implications for Practice and Policy**

Many of the adolescents in this study were aware of the negative attitudes and stigma associated with a diagnosis of ASD. A more positive image of individuals with ASD, including successful individuals and role models with ASD, needs to be brought to the public forefront. Over the past few decades, autism awareness has increased considerably, resulting in a greater appreciation of the needs associated with this disorder. Increased research funding and services for individuals with ASD have also emerged, although the focus has been largely on the early years, with a heavy emphasis on early intervention. Only in the last few years has there been a slight shift, with increased advocacy and research attention starting to turn to the adolescent and adult years. By continuing to increase public awareness about the unique needs and strengths of adolescents with ASD, including listening to their voices, it is hoped that research, educational, treatment and policy efforts will collaborate to promote more positive outcomes for these individuals.
References


Daniels, L.A. (2006). “If school was only four months long, I would have a very good average” *Understanding the school experiences of adolescents with attention-deficit/hyperactivity disorder*. (Unpublished Doctoral Dissertation). University of Toronto.


Pediatric Psychology, 36, 398-408.


## Appendix A

### List of ASD Behaviours included in the Alex-ASD (adapted from the ADI-R Algorithm)

#### A: Qualitative impairment in social interaction

<table>
<thead>
<tr>
<th>DSM-IV-TR: Impaired Social Development</th>
<th>ADI-R Symptoms → Alex-ASD Pictures</th>
</tr>
</thead>
</table>
| A1. Marked impairment in the use of multiple non-verbal behaviours such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction | **Direct Gaze**  
**Social Smiling**  
**Range of Facial Expressions Used to Communicate** |
| A2. Failure to develop peer relationships appropriate to developmental level | (Imaginative Play with Peers)  
(Interest in Other Children)  
(Response to Approaches of Other Children)  
**Friendships** |
| A3. Markedly impaired experience of pleasure in other people’s happiness | **Showing and Directing Attention**  
**Offering to Share**  
**Seeking to Share Enjoyment with Others** |
| A4. Lack of social or emotional reciprocity. | (Use of Other’s Body to Communicate)  
Offering Comfort  
(Quality of Social Overtures)  
**Inappropriate Facial Expressions**  
**Appropriateness of Social Responses** |

TOTAL = 10 pictures  
Note: Behaviours in brackets were not chosen because of their developmental inappropriateness for adolescence or the behaviour could not be effectively illustrated.

#### B: Qualitative impairment in communication

<table>
<thead>
<tr>
<th>DSM-IV-TR: Impaired Communication</th>
<th>ADI-R Symptoms → Alex-ASD Pictures</th>
</tr>
</thead>
</table>
| B1. A delay in, or total lack of the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime) | **Pointing to Express Interest**  
**Nodding/Head Shaking**  
**Use of Conventional or Instrumental Gestures** |
| B2. Marked impairment in the ability to initiate or sustain a conversation with others despite adequate speech. | **Reciprocal Conversation** |
| B3. Stereotyped and repetitive use of language or idiosyncratic language. | **Stereotyped Utterances and Delayed Echolalia**  
**Inappropriate Questions or Statements**  
**Neologisms/Idiosyncratic Language** (Pronominal Reversal) |
| B4. Lack of varied spontaneous make-believe play or social imitative play appropriate to the developmental level. | (Spontaneous Imitation of Actions)  
(Imaginative Play)  
(Imitative Social Play) |

TOTAL = 7 pictures
Note: Behaviours in brackets were not chosen because of their developmental inappropriateness for adolescence or the behaviour could not be effectively illustrated.

**C: Restricted, repetitive, and stereotyped patterns of behavior interest**

<table>
<thead>
<tr>
<th>DSM-IV-TR: Repetitive Stereotypic Behavior</th>
<th>ADI-R Symptoms → Alex-ASD Pictures</th>
</tr>
</thead>
<tbody>
<tr>
<td>C1. Encompassing preoccupation with one or more stereotyped and restricted patterns of interest abnormal either in intensity or focus.</td>
<td>Unusual Preoccupations Circumscribed Interests</td>
</tr>
<tr>
<td>C2. An apparently compulsive adherence to specific nonfunctional routines or rituals.</td>
<td>Verbal Rituals Compulsions/Rituals</td>
</tr>
<tr>
<td>C3. Stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting or complex whole body movements)</td>
<td>Hand or Finger Mannerisms Other Complex Mannerisms or Stereotyped Body Movements</td>
</tr>
<tr>
<td>C4. Persistent preoccupation with parts of objects.</td>
<td>Repetitive Use of Objects or Interest in Parts of Objects Unusual sensory interests</td>
</tr>
<tr>
<td></td>
<td>TOTAL = 8 pictures</td>
</tr>
</tbody>
</table>

**Other ASD Characteristics:** 9 pictures

- Intonation/Volume/Rhythm/Rate
- Abnormal, Idiosyncratic, Negative Response to Specific Sensory Stimuli
- Difficulties with Changes in Routines or Environment

Special Isolated Skills (one picture for each skill below):

- Visuospatial Ability
- Memory Ability
- Musical Ability
- Drawing Skill
- Reading Ability
- Computational Ability

**Positive General Attributes or Skills:** 5 pictures

- Kind and generous person
- Good at drama
- Good fashion sense
- Good leader
- Good at sports
Appendix B

Sample Picture Items from the Alex-ASD (Male and Female versions)

1. Eye Contact

2. Friendships
Appendix B.1: Eye Contact Picture Item for Male and Female Participants

Do you have trouble looking at people in the face when doing things when them or talking to them? Do you not make eye contact when talking, like Alex?

Do you have trouble looking at people in the face when doing things when them or talking to them? Do you not make eye contact when talking, like Alex?
Appendix B.2: Friendships Picture Item For Male and Female Participants

Do you find it hard to make and keep friends, like Alex?

Do you find it hard to make and keep friends, like Alex?
Appendix C

Adolescent Attribution for Problem Behaviour Questionnaire, modified for ASD behaviours

Sample behaviours:

1. Special Hobbies or Interests

2. Making and Keeping Friends
SPECIAL HOBBIES OR INTERESTS

Stigmatization:

Parents

1. A) Do your parents get bothered by your special hobbies or interests?
   - never
   - a little
   - a lot

B) Do you think that you sometimes cause your parents to be embarrassed by your special hobbies or interests?
   - never
   - a little
   - a lot

C) Do you think your parents treat you differently from your brothers or sisters because of your special hobbies or interests?
   - never
   - a little
   - a lot

D) Do you think your parents sometimes get disappointed by your special hobbies or interests?
   - never
   - a little
   - a lot

E) Give an example of how your parents treat you differently, get disappointed, and get embarrassed by your special hobbies or interests.

________________________________________________________________
Teachers

2. A) Do your teachers get bothered by your special hobbies or interests?
   □ never
   □ a little
   □ a lot

B) Do you think that teachers sometimes don’t like you because of your special hobbies or interests?
   □ never
   □ a little
   □ a lot

C) Do you think teachers treat you differently from other students because of your special hobbies or interests?
   □ never
   □ a little
   □ a lot

D) Give an example of how teachers treat you differently.

____________________________________________________________________________________
____________________________________________________________________________________
____________________________________________________________________________________
Peers

3.  A) Do your friends or classmates get bothered by your **special hobbies or interests**?
    - □ never
    - □ a little
    - □ a lot

B) Do you think that you sometimes cause your friends to be embarrassed by your **special hobbies or interests**?
    - □ never
    - □ a little
    - □ a lot

C) Do you think that some classmates don’t like you because of your **special hobbies or interests**?
    - □ never
    - □ a little
    - □ a lot

D) Do you think some classmates treat you differently from your other peers and classmates because of your **special hobbies or interests**?
    - □ never
    - □ a little
    - □ a lot

E) Give an example of how some of your classmates treat you differently and get embarrassed by your **special hobbies or interests**.

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
4. A) Do you get in trouble because of your special hobbies or interests?
   □ I never get in trouble
   □ I get in a little trouble
   □ I get in a lot of trouble
   B) Give an example of how you get in trouble.

5. A) Are you sometimes embarrassed by your special hobbies or interests?
   □ never
   □ a little
   □ a lot
   B) Give an example of how you feel embarrassed.

   _______________________________________________________________
   _______________________________________________________________
   _______________________________________________________________

Controllability:
6. If you try really hard, do you think you could control your special hobbies or interests?
   □ not at all
   □ a little
   □ a lot

7. On a scale of 1 to 5, with 1 being easy and 5 being very hard, how easy or hard is it for you to control your special hobbies or interests?

   1  2  3  4  5

8. A) What helps you control your special hobbies or interests?
B) Which of the following helps you control your **special hobbies or interests**?

- □ Being in a quiet non-distracting environment
- □ Having other people remind me of my special hobbies or interests
- □ Trying really hard
- □ The pills I take

9. Do you find that your **special hobbies or interests** are there even when you don’t want them to be?

- □ never
- □ a little
- □ a lot

10. Can you control your **special hobbies or interests**?

- □ a lot
- □ a little
- □ never

*Locus of Causality:*

11. A) Why do you think you have **special hobbies or interests**?

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

B) Is it,

- □ Something around you (like people) that makes you have **special hobbies or interests**?

  OR

- □ Something inside of you that makes you have **special hobbies or interests**?
**Stability:**

12. Have you always been interested in your **special hobbies or interests**:

   □ only a short time
   □ a few years
   □ as long as you can remember

13. Do you have **special hobbies or interests**:

   □ almost never
   □ only some of the time
   □ all the time

14. A) Do you think that your **special hobbies or interests** are going to:

   □ disappear soon
   □ last only a few years
   □ last forever (even when you are an adult)

   B) If you think that your **special hobbies or interest** are going to last, do you think it is going to:

   □ get better with time
   □ stay the same with time
   □ get worse with time

15. Do you think you can change your **special hobbies or interests**?

   □ a lot
   □ a little
   □ not at all
16. You said that you are like Alex because you have **special hobbies or interests**. When do you find that you have this difficulty?

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________
MAKING AND KEEPING FRIENDS

Stigmatization:

Parents

1. A) Do your parents get bothered by your difficulty making and keeping friends?
   □ never
   □ a little
   □ a lot

   B) Do you think that you sometimes cause your parents to be embarrassed by your difficulty making and keeping friends?
   □ never
   □ a little
   □ a lot

   C) Do you think your parents treat you differently from your brothers or sisters because of your difficulty making and keeping friends?
   □ never
   □ a little
   □ a lot

   D) Do you think your parents sometimes get disappointed by your difficulty making and keeping friends?
   □ never
   □ a little
   □ a lot

   E) Give an example of how your parents treat you differently, get disappointed, and get embarrassed by your difficulty making and keeping friends.

   ____________________________________________
Teachers

2.  A) Do your teachers get bothered by your **difficulty making and keeping friends**?

   □ never
   □ a little
   □ a lot

B) Do you think that teachers sometimes don’t like you because of your **difficulty making and keeping friends**?

   □ never
   □ a little
   □ a lot

C) Do you think teachers treat you differently from other students because of your **difficulty making and keeping friends**?

   □ never
   □ a little
   □ a lot

D) Give an example of how teachers treat you differently.

__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________

Peers

3.  A) Do your friends or classmates get bothered by your **difficulty making and keeping friends**?

   □ never
   □ a little
   □ a lot
B) Do you think that you sometimes cause your friends to be embarrassed by your difficulty making and keeping friends?

- never
- a little
- a lot

C) Do you think that some classmates don’t like you because of your difficulty making and keeping friends?

- never
- a little
- a lot

D) Do you think some classmates treat you differently from your other peers and classmates because of your difficulty making and keeping friends?

- never
- a little
- a lot

E) Give an example of how some of your classmates treat you differently and get embarrassed by your difficulty making and keeping friends.

__________________________________________________________________________
__________________________________________________________________________

4. A) Do you get in trouble because of your difficulty making and keeping friends?

- I never get in trouble
- I get in a little trouble
- I get in a lot of trouble

B) Give an example of how you get in trouble.

__________________________________________________________________________
5. A) Are you sometimes embarrassed by your difficulty making and keeping friends?
   □ never
   □ a little
   □ a lot

   B) Give an example of how you feel embarrassed.
   ___________________________________________________________
   ___________________________________________________________
   ___________________________________________________________

   Controllability:
   6. If you try really hard, do you think you could have more friends?
      □ not at all
      □ a little
      □ a lot

   7. On a scale of 1 to 5, with 1 being easy and 5 being very hard, how easy or hard is it for you to make and keep friends?
      ___________________________________________________________
      ___________________________________________________________
      ___________________________________________________________
          1  2  3  4  5

   8. A) What helps you control your ability to make and keep friendships?
      ___________________________________________________________
      ___________________________________________________________
      ___________________________________________________________
B) Which of the following helps you control your ability to make and keep friends?

- [ ] Being in a quiet non-distracting environment
- [ ] Having other people remind me to make friends
- [ ] Trying really hard
- [ ] The pills I take

9. Do you find that your ability to make and keep friendships is poor even when you don’t want them to be?

- [ ] never
- [ ] a little
- [ ] a lot

10. Can you control your difficulty making and keeping friends?

- [ ] a lot
- [ ] a little
- [ ] never

Locus of Causality:

11. A) Why do you think you have difficulty making and keeping friends?

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________
B) Is it,

☐ Something around you (like people) that makes you have difficulty making and keeping friends?

OR

☐ Something inside of you that makes you have difficulty making and keeping friends?

**Stability:**

12. Have you always had difficulty making and keeping friends:

☐ only a short time

☐ a few years

☐ as long as you can remember

13. Do you have difficulty making and keeping friends:

☐ almost never

☐ only some of the time

☐ all the time

14. A) Do you think that your difficulty making and keeping friends is going to:

☐ disappear soon

☐ last only a few years

☐ last forever (even when you are an adult)

B) If you think that your difficulty making and keeping friends is going to last, do you think it is going to:

☐ get better with time

☐ stay the same with time

☐ get worse with time
15. Do you think you can change your **difficulty making and keeping friends**?

☐ a lot  
☐ a little  
☐ not at all

_Globality:_

16. You said that you are like Alex because you have **difficulty making and keeping friends**. When do you find that you have this difficulty?

________________________________________________________________________  
________________________________________________________________________  
________________________________________________________________________
Appendix D

*Correlation Matrix of Adolescent and Parent Total and Domain Scores of ASD Behaviours*

<table>
<thead>
<tr>
<th>Measures</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Adolescent Total ASD</td>
<td>-</td>
<td>.86**</td>
<td>.89**</td>
<td>.30</td>
<td>.28</td>
<td>.16</td>
</tr>
<tr>
<td>2. Adolescent Total Soc-Com</td>
<td>-</td>
<td>-</td>
<td>.52**</td>
<td>.35</td>
<td>.41*</td>
<td>-.03</td>
</tr>
<tr>
<td>3. Adolescent Total FI/RB</td>
<td>-</td>
<td>.21</td>
<td>-</td>
<td>.12</td>
<td>.27</td>
<td></td>
</tr>
<tr>
<td>4. Parent Total ASD</td>
<td>-</td>
<td></td>
<td>-</td>
<td>.92**</td>
<td>.51**</td>
<td></td>
</tr>
<tr>
<td>5. Parent Total Soc-Com</td>
<td></td>
<td>-</td>
<td></td>
<td>.12</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Parent Total FI/RB</td>
<td></td>
<td></td>
<td>-</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Note.* Soc-Com = Social Communication domain, FI/RB = Fixated Interests and Repetitive Behaviours domain.

*p < .05, **p < .01
Appendix E

Semi-Structured Interview

Awareness and Acceptance Interview: ADOLESCENT

Date: _____________________  ID: ______________________________

Gender: ___________________  CA: ____________________________

DIAGNOSTIC INFORMATION (Collected by parent report)

<table>
<thead>
<tr>
<th>Diagnosis</th>
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</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Date/Age of Diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Diagnosed by:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

INTERVIEW QUESTIONS

I am interested in learning more about how teens your age think about themselves, who they are, and how they describe themselves, or how they think others think about them.

General Questions

1. Tell me about yourself? What kind of person are you?

2. What would you tell somebody about yourself (e.g., the name of somebody they knew)?

3. What sort of things would you say (Prompt: (e.g., Well, for example, what’s your name, are you male or female, anything else? Probes: appearance, sports ability, school work, friendships, abilities, hobbies, your family)

4. Is there something you would like to keep the same or something you would like to change about yourself? If you could change something about yourself what would it be (e.g., if you had a magic wand)?

Strengths & Weaknesses Activity

Now that you have told me some things about yourself, I want to talk about your talents, which includes things you do well.

☐ Complete My Talents and My Talents According to Other People

Now I want to talk about your not-so-strong points, which are things that you might not be good at or things you have trouble with.

☐ Complete My Not-So-Strong Points and My Not-So-Strong Points According to Other People
Now that you have told me about yourself, like things you are good at and things you have trouble with I want to ask you some more questions. Many people have difficulties, which may make them feel different from other kids or teens. One special difference that some people have is autism/ASD/Asperger’s Syndrome.

Have you heard of ASD? ____________________________________________________________

5. What is it?

6. How do you know if someone has ASD?

7. Have any of your friends got ASD?

8. Have you ever heard anything on the TV, in the movies, or on the internet about ASD? Have you seen anyone on TV or in the movies with ASD? Do you know of anybody famous with ASD? What do you think of that?

9. Do you think you have ASD? (If no, why do you think you are participating in this study?)

10. Who told you about ASD?

   Do you remember being tested? How were you told about your ASD?

Like Alex, you said that you

________________________________________________________________________________

________________________________________________________________________________

________________________________________________________________________________

   (include items endorsed on Adapted Alex).

11. What do you think caused you to be this way?

I have known many kids and teens with autism/ASD/Asperger’s Syndrome. I have often found that teens like you, with ASD, are the real experts who can let others know, like parents, teachers, and doctors, about what it has been like for you. I want to ask you more questions to learn more about what it is like for you to have ASD, how it affects you and how it makes you feel.

12. How do you feel about having ASD?

13. Are there other good things (strengths) or not-so-good or hard things (weaknesses) that have resulted from your ASD behaviours?
   (a) Strengths:

   (b) Weaknesses:
14. How, if at all, has having ASD changed your life?

15. Is there someone in your life that you feel comfortable talking to about ASD? Who?

16. Does your family talk to you about ASD?

17. What advice would you give to another kid that found out they had ASD? What would you tell them?

18. What advice would you give to the parents of a teen with ASD?

_Before we end, is there anything you would like add? Can you think of anything else you would like to tell me before we end?_

_What has it been like for you to do this interview?_

_I would like to thank you for taking part in this interview and for helping with this research study. You have made an important contribution, not only to the research but also in helping other kids with ASD._
Appendix F

Frequencies of Themes and Subthemes

Themes and Subthemes for Self-Awareness and Understanding of ASD

<table>
<thead>
<tr>
<th>Theme</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Definitions of ASD</td>
<td></td>
</tr>
<tr>
<td>Medical model (disease, condition, disability)</td>
<td>5</td>
</tr>
<tr>
<td>Difference</td>
<td>9</td>
</tr>
<tr>
<td>Specific ASD characteristics</td>
<td>12</td>
</tr>
<tr>
<td>Positive Appraisals of ASD</td>
<td>9</td>
</tr>
<tr>
<td>Negative Appraisals of ASD</td>
<td>10</td>
</tr>
<tr>
<td>Separate from Identity</td>
<td>2</td>
</tr>
<tr>
<td>Positive Outcomes of Diagnosis</td>
<td>4</td>
</tr>
<tr>
<td>Causes of ASD</td>
<td></td>
</tr>
<tr>
<td>Neurobiological/genetic</td>
<td>5</td>
</tr>
<tr>
<td>Neurodevelopmental</td>
<td>5</td>
</tr>
<tr>
<td>External/Environmental</td>
<td>2</td>
</tr>
<tr>
<td>Recognizing ASD in Others</td>
<td></td>
</tr>
<tr>
<td>Knows someone with ASD</td>
<td>9</td>
</tr>
<tr>
<td>Individuals or characters in the media</td>
<td>9</td>
</tr>
</tbody>
</table>

Themes and Subthemes for Psychosocial Distress

<table>
<thead>
<tr>
<th>Theme</th>
<th>Frequency Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feelings of Despair</td>
<td></td>
</tr>
<tr>
<td>Shame/Embarrassment</td>
<td>6</td>
</tr>
<tr>
<td>Failure</td>
<td>7</td>
</tr>
<tr>
<td>Not Fitting In/ Alienation</td>
<td>6</td>
</tr>
<tr>
<td>Stigma</td>
<td>4</td>
</tr>
<tr>
<td>Disclosure</td>
<td>3</td>
</tr>
<tr>
<td>Hiding Behaviours</td>
<td>2</td>
</tr>
<tr>
<td>Not feeling heard or being misunderstood</td>
<td>5</td>
</tr>
</tbody>
</table>
### Themes and Subthemes for Social-Ecological Factors

<table>
<thead>
<tr>
<th>Theme</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Family Environment</strong></td>
<td></td>
</tr>
<tr>
<td>Parent in supportive role</td>
<td>9</td>
</tr>
<tr>
<td>Worries about parent</td>
<td>1</td>
</tr>
<tr>
<td>Differential treatment</td>
<td>1</td>
</tr>
<tr>
<td>Diagnosis helpful for parent</td>
<td>1</td>
</tr>
<tr>
<td>Lack of parent understanding</td>
<td>2</td>
</tr>
<tr>
<td><strong>Social Context</strong></td>
<td></td>
</tr>
<tr>
<td>Peer difficulties</td>
<td>8</td>
</tr>
<tr>
<td><strong>School Environment</strong></td>
<td></td>
</tr>
<tr>
<td>Extra help</td>
<td>1</td>
</tr>
<tr>
<td>Not safe at school</td>
<td>2</td>
</tr>
<tr>
<td>Peer victimization and bullying</td>
<td>7</td>
</tr>
<tr>
<td>Lack of teacher understanding</td>
<td>2</td>
</tr>
<tr>
<td>Academic difficulties</td>
<td>2</td>
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</tbody>
</table>

### Themes and Subthemes for Sources of Support

<table>
<thead>
<tr>
<th>Theme</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Self-Education</strong></td>
<td></td>
</tr>
<tr>
<td>Online</td>
<td>4</td>
</tr>
<tr>
<td>Books</td>
<td>6</td>
</tr>
<tr>
<td>Videos</td>
<td>4</td>
</tr>
<tr>
<td><strong>Social Support</strong></td>
<td></td>
</tr>
<tr>
<td>Parent support</td>
<td>9</td>
</tr>
<tr>
<td>Social or activity-based groups</td>
<td>1</td>
</tr>
<tr>
<td>Friends with ASD</td>
<td>3</td>
</tr>
<tr>
<td>Family members with ASD</td>
<td>4</td>
</tr>
<tr>
<td><strong>Mental Health Support</strong></td>
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</tr>
</tbody>
</table>
Appendix G

Research Consent Forms$^3$

1. Adolescent Research Consent Form

2. Parent Research Consent Form

$^3$ The title of the Research Project changed once the data had been collected.
Research Consent Form: Adolescent

**Title of Research Project:**
An Evaluation of Self-Awareness and Behavioural Attributions in Adolescents with Autism Spectrum Disorder: Implications for Psychosocial Functioning

**Investigator(s):**
**Primary Investigator:**
Jessica A. Brian, Ph.D., C. Psych.
Department of Paediatrics
The Hospital for Sick Children
(416) 813-8748

**Co-Investigator:**
Kelley D. Drummond, M.A.
Doctoral Candidate and Research Coordinator
Ontario Institute for Studies in Education/University of Toronto (OISE/UT)
Autism Research Unit, Hospital for Sick Children
(416) 813-8748

**Purpose of the Research:**
You have been asked to participate in this study because you have been given a diagnosis of Autism Spectrum Disorder (ASD; also known as Autism, Asperger’s syndrome, Pervasive Developmental Disorder) at some point in your life. In this study, we will gather information to learn more about the beliefs young people with autism spectrum disorders (ASD) have about the behaviours that commonly occur with ASD. We will compare how teenagers with ASD understand their strengths and weaknesses of their diagnosis and to what extent they agree or disagree with their parents’ ratings of their behaviours. By gaining a better understanding of how young people with ASD view their behaviours and their disorder we hope to help parents, teachers, and professionals provide better services and develop more effective interventions for teenagers with ASD and their families.

**Description of the Research:**
If you take part in this study today, it will take approximately 3 to 4 hours. During this time, the examiner will get you to answer questions, look at pictures and put puzzles together that will tell us more about your thinking and reasoning skills. The examiner will also ask you to look at some pictures with a teenager in them behaving in different ways and ask you to tell me which of the pictures are like you. The examiner will also ask you to answer some questions about yourself, such as what you think about your behaviours, and about Autism Spectrum Disorder.
The examiner will read the questions to you. Sometimes the examiner will write your answers down for you and sometimes you will have to check off or circle an item on a form. Your answers to these questions will help me understand how you think about your behaviours and about Autism Spectrum Disorder. The examiner will ask you to fill out some rating scales for me that tell me more about how you view your behaviours. You will also talk about what interests you and how you like to spend your time. Some of these sessions will be video or audiotaped.

When we are about half way through these activities we will take a break. We can also take other short breaks if you need them.

**Potential Harms:**
We know of no harm that taking part in this study could cause you.

**Potential Discomforts or Inconvenience:**
The only thing that might happen is that you may feel uncomfortable talking about yourself and how you feel about some things. If you feel that you don’t want to answer some of the questions, you can tell me and we will talk about it. You may also tell me that you want to stop, skip the question or that you need a break and want to continue some other time.

Kelley Drummond and her supervisor, Dr. Jessica Brian, will be available by phone or email if you have any questions or concerns after you leave. We also have a list of resources for teenagers and their parents available, if you would like one.

**Potential Benefits:**

**To individual subjects:**
You will not benefit directly from participating in this study. Some people like to participate in this type of research because their answers to the study questions will help them learn more about what their strengths are and what areas they need to work on. Knowing information about your strengths and weaknesses is important because it can help you and your parents understand how to help you better. You can choose if you want to receive a brief Research Report that will tell you about your thinking and reasoning skills, social skills, and behaviours.

**To society:**
A good thing about this study is that it will help us learn more about teenagers with ASD. We want to listen to what you say and think and then use that information to help other teens with ASD. Information from this study will give us important information to parents, teachers, and clinicians working with young people with ASD.

**Confidentiality:**
Do you know what confidentiality is? It means that everything you tell me today will stay between you, myself, and Dr. Brian, my supervisor.

We will respect your privacy. The questionnaire will not have your name on them. A number code will be used in place of your name. Because we are working with many teenagers on this
project, people hearing our presentations or reading what we write will not know which teenage
teenagers has said what. When we write or talk about the results, no information about who you
or your parents are will be given to anyone, unless required by law. For example, the law could make us give information about you:
- If you are being hurt or harmed by anyone
- If you have an illness that could spread to others
- If you or someone else talks about suicide (killing themselves), or
- If the court orders us to give them the study papers.

If these were to happen, as required by law, we would inform you and appropriate mental health,
child protection, or law enforcement officials.

Sick Kids Clinical Research Monitors or the regulator of the study may see your health record to
check on the study. By signing this consent form, you agree to let these people look at your
records. We will put a copy of this research consent form in your patient health record and give
you a copy as well.

The data produced from this study will be stored in a secure, locked location. Only Kelley
Drummond or her supervisor, Dr. Jessica Brian, will have access to the data. Following
completion of the research study the data will be kept as long as required then destroyed as
required by Sick Kids policy. Published study results will not reveal your identity.

The results of the tests we describe in this form will be used only for this study. If another doctor
or caregiver caring for you needs to see these results, you and your parents will have to give us
permission. We will ask you to sign a form saying that you agree that this person can see your
results. We recommend that only a registered psychologist or doctor tell you what the results of
these tests mean.

**Reimbursement:**
Participation in research is completely voluntary. We will pay for your travelling expenses for
being in this study (e.g., parking expenses or the cost of using public transit). If you stop taking
part in the study, we will pay you for your expenses for taking part in the study so far.

We will also provide you with some compensation in recognition of your time and effort.

You can also ask for a research report of your thinking and reasoning skills and social and
emotional functioning if you would like.

**Participation:**
It is your choice to take part in this study. Your mother/father signed a letter saying that she/he
agrees for you to be in the study, but you don’t have to participate if you don’t want to. If you
say you will take part in the study and then change your mind, that is okay. Nobody will be
angry or upset if you do not want to be in the study. You can stop at any time. The care you get
at Sick Kids will not be affected in any way by whether you take part in this study.
New information that we get while we are doing this study may affect your decision to take part in this study. If this happens, we will tell you about this new information. And we will ask you again if you still want to be in the study.

During this study we may create new tests or other things that may be worth some money. Although we may make money from these findings, we cannot give you any of this money now or in the future because you took part in this study.

**Conflict of Interest:**
Kelley Drummond and her supervisor, Dr. Brian, have no conflict of interest to declare.

**Consent:**
By signing this form, I agree that:
1) You have explained this study to me. You have answered all my questions.
2) You have explained the possible harms and benefits (if any) of this study.
3) I know what I could do instead of taking part in this study. I understand that I have the right not to take part in the study and the right to stop at any time. My decision about taking part in the study will not affect my health care at Sick Kids.
4) I am free now, and in the future, to ask questions about the study.
5) I have been told that my medical records will be kept private except as described to me.
6) I understand that no information about who I am will be given to anyone or be published without first asking my permission.
7) I agree, or consent, to take part in this study.

____________________________________  ____________________
Printed Name of Participant & Age  Participant’s signature & date

____________________________________  ____________________
Printed Name of person who explained consent  Signature of Person who explained consent & date
consent & date

____________________________________  ____________________
Printed Witness’ name (if the subject/legal guardian does not read English)  Witness’ signature & date

If you have any questions about this study, please call Kelley Drummond or Dr. Jessica Brian at 416-813-8748.

If you have questions about your rights as a subject in a study or injuries during a study, please call the Research Ethics Manager at 416-813-5718.
Research Consent Form: Parent

Title of Research Project:
An Evaluation of Self-Awareness and Behavioural Attributions in Adolescents with Autism Spectrum Disorder: Implications for Psychosocial Functioning

Investigator(s):
Primary Investigator:
Jessica A. Brian, Ph.D., C. Psych.
Department of Paediatrics
The Hospital for Sick Children
(416) 813-8748

Co-Investigator:
Kelley D. Drummond, M.A.
Doctoral Candidate and Research Coordinator
Ontario Institute for Studies in Education/University of Toronto (OISE/UT)
Autism Research Unit, Hospital for Sick Children
(416) 813-8748

Purpose of the Research:
In this study, we will gather information to learn more about the beliefs young people with autism spectrum disorders (ASD) have about the behaviours that commonly occur with ASD. We will compare how teenagers with ASD understand their strengths and weaknesses of their diagnosis and to what extent they agree or disagree with their parents’ ratings of their behaviours. By gaining a better understanding of how young people with ASD view their behaviours and their disorder we will hope to help parents, teachers, and professionals provide better services and develop more effective interventions for teenagers with ASD and their families.

Description of the Research:
If you agree to let your adolescent take part in this study today, your adolescent will work with the investigator for approximately 3 to 4 hours. The session will be done in a quiet room at the Autism Research Unit. This will include a clinical interview and a standardized observation session (involving the observation of a play and interview sequence, providing information about social situations, verbal and gestural communication and repetitive behaviours), as well as an evaluation of his/her thinking and reasoning skills. The structured interview and observation task will be videotaped so we can look in more detail later on at how the adolescent responded to certain social situations. Your adolescent will also participate in an interview and answer
questions about ASD behaviours that commonly occur with ASD. Each adolescent will also complete questionnaires about their current social and emotional functioning.

As the parent or guardian who knows the participant well, you will be asked to complete additional questionnaires (approximately 20 minutes of your time) and participate in an in-depth clinical interview (90 minutes or more) about your adolescent’s development and current functioning.

**Potential Harms:**
We know of no harm that taking part in this study could cause you or your adolescent.

**Potential Discomforts or Inconvenience:**
The only potential risk to study participation is that your adolescent may feel uncomfortable talking about themselves and how they feel about some things. We will clearly inform your adolescent that he/she may decline to participate and that if he/she does decide to participate he/she may skip questions, request a break, or withdraw from the study at any time without repercussions.

Following the session, if your adolescent found the discomfort to be more than minor, please contact us so that we can discuss how to provide appropriate support for him/her. In addition, should we feel at any time during or after the session with your adolescent that he/she would benefit from a referral to a mental health professional, we would inform you of that recommendation and provide an appropriate community referral. Kelley Drummond and her supervisor, Dr. Jessica Brian, will be available by phone or email if you have any questions or concerns after you leave. We also have a list of resources for teenagers and their parents available, if you would like one.

**Potential Benefits:**
**To individual subjects:**
You and your adolescent will not benefit directly from participating in this study. Some people like to participate in this type of research because their answers to the study questions will help them learn more about what their strengths are and what areas they need to work on. Knowing information about your adolescent’s strengths and weaknesses is important because it can help you understand how to help him/her better. Your adolescent can choose to receive a brief Research Report that will tell him or her about their thinking and reasoning skills, social skills, and social-emotional functioning.

**To society:**
A good thing about his study is that it will help us learn more about teenagers with ASD. We want to listen to what your adolescent says and thinks and then use that information to help other teens with ASD. Findings from this study will give us important information for parents, teachers, and clinicians working with young people with ASD.
**Confidentiality:**
Confidentiality will be respected and no information that discloses the identity of the participant will be released without consent unless required by law. For example, the law could make us give information about you or your adolescent:
- If a child/adolescent has been abused
- If you or your adolescent has an illness that could spread to others
- If you or someone you else talks about suicide (killing themselves), or
- If the court orders us to give them the study papers.

If these were to happen, as required by law, we would inform you and appropriate mental health, child protection, or law enforcement officials.

Sick Kids Clinical Research Monitors or the regulator of the study may see your adolescent’s health record to check on the study. By signing this consent form, you agree to let these people look at your adolescent’s records. We will put a copy of this research consent form in your adolescent’s patient health record and give you a copy as well.

The data produced from this study will be stored in a secure, locked location. Only Kelley Drummond or her supervisor, Dr. Jessica Brian, will have access to the data. Following completion of the research study the data will be kept as long as required then destroyed as required by Sick Kids policy. Published study results will not reveal your or your adolescent’s identity.

The results of the tests we describe in this form will be used only for this study. If another doctor or caregiver caring for you or your adolescent’s needs to see these results, you and your adolescent will have to give us permission. We will ask you to sign a form saying that you agree that this person can see your results. We recommend that only a registered psychologist or doctor tell you what the results of these tests mean.

**Reimbursement:**
Participation in research is completely voluntary. We will pay for your travelling expenses for being in this study (e.g., parking expenses or the cost of using public transit). If you stop taking part in the study, we will pay you for your expenses for taking part in the study so far.

If your adolescent chooses to participate in this study, he or she will receive a $20.00 gift certificate, and if your adolescent is in high school, he/she can count his/her participation in the study toward their school community service hours. In this case, a certificate attesting to his/her participation would be provided.

Your adolescent can also have the option of asking for a research report of their thinking and reasoning skills, social communication development, and their social and emotional functioning.

**Participation:**
It is your choice to take part in this study. Your adolescent will also sign a letter saying that she/he agrees to be in the study. You and your adolescent can stop participating in the study at
any time. The care your adolescent gets at Sick Kids hospital will not be affected in any way by whether your adolescent takes part in this study.

New information that we get while we are doing this study may affect your decision to take part in this study. If this happens, we will tell you about this new information. And we will ask you again if you still want to be in the study.

During this study we may create new tests or other things that may be worth some money. Although we may make money from these findings, we cannot give you any of this money now or in the future because you took part in this study.

**Conflict of Interest:**
Kelley Drummond and her supervisor, Dr. Brian, have no conflict of interest to declare.

**Consent:**
By signing this form, I agree that:
1) You have explained this study to me. You have answered all my questions.
2) You have explained the possible harms and benefits (if any) of this study.
3) I know what I could do instead of having my child take part in this study. I understand that I have the right to refuse to let my child take part in the study. I also have the right to take my child out of the study at any time. My decision about my child taking part in the study will not affect my child’s health care at Sick Kids.
4) I am free now, and in the future, to ask questions about the study.
5) I have been told that my child’s medical records will be kept private except as described to me.
6) I understand that no information about my child will be given to anyone or be published without first asking my permission.
7) I agree, or consent, that my child___________________________ may take part in this study.

______________________________________             _________________________________
Printed Name of Parent/Legal Guardian                    Parent/Legal Guardian’s signature & date

______________________________________
Printed Name of person who explained consent            Signature of Person who explained consent & date

______________________________________             _________________________________
Printed Witness’ name (if the parent/legal guardian does not read English)        Witness’ signature & date

If you have any questions about this study, please call Kelley Drummond or Dr. Jessica Brian at 416-813-8748.
If you have any questions about your rights as a subject in this study or injuries during a study, please contact the Research Ethics Manager at 416-813-5718.