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# Research in Autism Spectrum Disorders

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## Looking back and moving forward: The experiences of canadian parents raising an adolescent with autism spectrum disorder

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### ARTICLE INFO

Number of reviews completed is 2

#### Keywords:

Parent-professional  
Canada  
Qualitative research  
Adolescents

### ABSTRACT

**Background:** The aim of this study was to investigate parent experiences of raising a child with autism spectrum disorder (ASD) from early childhood and into adolescence.

**Method:** Semi-structured in-depth interviews were conducted with nine families of adolescents diagnosed with ASD with a range of cognitive ability. Thematic analysis was used to analyze the parents' narratives.

**Findings:** Four themes were constructed to represent the parents' narratives of their caregiving journey: 1) Rippling Effect of Loss; 2) Becoming a Parent-Professional; 3) One Size Fits None; and 4) Preparing for "The Future". Parental narratives reflect the tension they experience with the school system and the frustration with dealing with services that do not grow with their child's needs. Findings also indicate that, over the years, parents develop a specialized skill set that helps them navigate the ever-changing ASD landscape.

**Discussion:** The results of this study have several important implications, including the need for service and education providers to actively involve parents in the treatment of their child, as well as to increase appropriate services for adolescents that target both ASD and comorbid mental health challenges.

### 1. Introduction

Autism Spectrum Disorder (ASD) is a lifelong disorder with no known etiology or cure. Although this disorder is thought to persist throughout the individual's lifetime in most cases, much of the research has been focused on the experiences of families with young children and examines their journey from diagnosis to accessing early intervention and services. However, the experiences, needs, and outcomes of individuals and their families during the period of adolescence have been less well studied. Although minimal, the current research on adolescents with ASD suggests that many of the same difficulties experienced by families continue into adolescence (Mount & Dillon, 2014). These challenges are compounded by typical stressors related to hormonal changes, an increased need for independence, and the transition into high school (Hume, Boyd, Hamm, & Kucharczyk, 2014; Strunk, Pickler, McCain, Ameringer, & Myers, 2014).

The effects of raising a young child with ASD on the family system have been well-documented (Altiere & Von Kluge, 2009; Midence & O'Neill 1999; Woodgate, Ateah, & Secco, 2008). Families raising a child with ASD face unique challenges when compared to families of children with other developmental disabilities (DD) or families raising typically developing children (Hayes & Watson, 2013). Common areas of stress for families with young children with ASD include the delay in diagnosis, challenging behaviors of ASD, and worries about the future (Ho, Perry, Rourke, Weiss, & Weiss, 2014; Ho, Yi, Griffiths, Chan, & Murray, 2014). Unlike other

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DDs, such as Down syndrome which has a clear genetic basis and is diagnosed early in the child's life, ASD is often diagnosed several years after birth or even later (Mandell, Maytali, & Zubritsky, 2005). The delayed appearance of symptoms, the varying degrees of the condition, and the variable day-to-day behaviors are unique to ASD and contribute to parent stress (O'Brien, 2007).

Adolescence in typically developing children is often a tumultuous period as the child enters puberty and deals with physical, hormonal, mental, and social changes (Mulye et al., 2009; Orpinas, Home, Song, Reeves, & Hsieh, 2013). Children with ASD entering this transition period face the dual challenges stemming from their disorder as well as the typical stressors associated with transitioning into high school, increased independence, and bodily changes (Cole, 2008; Taylor & Seltzer 2011b). Several follow-up studies have indicated that some symptoms abate and improve as the child matures (Billstedt, Gillberg, & Gillberg, 2007; Lounds, Seltzer, Greenberg, & Shattuck, 2007; Mawhood, Howlin, & Rutter, 2000; Taylor & Seltzer 2011a). Studies on aggressive physical behavior indicate a much higher prevalence in early childhood and declines as the child reaches adolescence and adulthood (Mazurek, Kanne, & Wodka, 2013). Despite an overall trend in positive outcomes, these improvements are not seen across all individuals. For those adolescents who continue to demonstrate aggressive and self-injurious behaviors, these behaviors are even more difficult for their parents to manage due to the adolescents' increasing physical size and strength (Gray, 2002).

The family environment plays an integral role in influencing the development of children, especially in the early years. For children with ASD, family factors such as parenting stress, have been found to impact the effectiveness of early intervention outcomes (Osborne, McHugh, Saunders, & Reed, 2008). In contrast, there is limited research on the experiences of families raising an adolescent with ASD. The research available suggests that many of the challenges experienced in childhood are magnified during adolescence. In addition to coping with the difficulties related to navigating the educational and healthcare systems, these families must deal with behavioral and social challenges as well as safety concerns related to the emerging sexuality of their adolescent (Chan & John, 2012).

In a sample of 20 parents of adolescents with ASD in Singapore, parents explained that the challenging behaviors were a barrier to their adolescent's future (Poon, 2013). Parents saw a bleak future with none of the parents expecting their adolescent to be able to live in the community independently (Poon, 2013). The imminent future of their adolescent maturing into an adult, compounded by the lack of formal supports available for adults, were a source of anxiety for this sample.

Similar results were found in a qualitative study conducted by Strunk et al. (2014). The findings of this study indicated that parents were frustrated with the healthcare services and were concerned with the increasing amount of prescription medication their son/daughter was taking. Parents also voiced concerns over their child's sexual development which could lead their child to engage in risky sexual behavior or be a victim of sexual harassment or abuse. Topics such as menstruation and masturbation were considered important but difficult subjects to discuss with their adolescent.

Although individuals diagnosed with ASD face similar challenges surrounding communication, social interaction, and repetitive interests, the severity of symptoms and outcome of individuals varies greatly. The reasons as to why certain children achieve better outcomes are not fully understood. However, child characteristics such as early communication and language abilities, higher IQ, and lower ASD severity are related to better outcomes (Howlin, Goode, Hutton, & Rutter, 2004; Luyster, Qiu, Lopez, & Lord, 2007; Mawhood et al., 2000; Perry et al., 2011). The heterogeneity within ASD and the variability in developmental outcomes suggest a need to include individuals from different sub-groups and examine parent experiences with adolescents of differing ASD severities.

The review of the extant literature on parent experiences of raising an adolescent with ASD reveals several fundamental gaps. The limited number of studies on this population suggests that adolescence is a challenging and resource-intensive time for families. Within the ASD population, there is also a large heterogeneity in terms of cognitive and adaptive abilities as well as developmental trajectories. In order to address the heterogeneity in outcomes, this study included parents of adolescents with varying degrees of ASD symptomatology and comorbid disorders. The focus of this study was to describe the lived experiences of parents raising an adolescent with ASD and examine how parents conceptualize and understand ASD from early childhood and into adolescence.

## 2. Method

### 2.1. Procedure

This study was conducted as part of a larger study following the outcomes of adolescents who had previously received Intensive Behavioral Intervention (IBI) as young children (Perry, Koudys, & Ho, 2017). The study protocol was reviewed and approved by the Research Ethics Board of Brock University and of York University. In the original Prichard (2011) study, 36 participants and their families were recruited from ASD treatment agencies in Ontario. In order to be included in the original study, participants had to have received 20 to 40 h/week of IBI for one to three years; then been discharged for at least one year and been receiving less than 10 h of IBI a week since discharge. Participants had been discharged from IBI for one to six years and were assessed on cognitive functioning, ASD severity, and academic ability where appropriate.

Of the original 32 families, seven families were lost to follow-up and seven participants (six families) declined to participate citing scheduling difficulties or otherwise, no reason was given. In total, 22 participants (19 families) consented to participate in the larger IBI follow-up study and have their child assessed. Parent participants for this current study were initially selected to represent a wide range of ASD outcomes (low, medium, high) as defined by cognitive ability and ASD severity of their child at the time of first follow-up with a mean age of 8 years old (see Perry et al., 2017 for further details about group categorization). Families were then purposively sampled based on characteristics that the researcher perceived would contribute to a different viewpoint on the topic. Including these unique perspectives helps to enrich the understanding of parent experiences. For instance, it was decided that an interview would be conducted with a family who was raising two adolescents with ASD. Another decision was made to interview a single parent raising an adolescent with ASD.

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