

RAISING AN ADOLESCENT WITH AUTISM SPECTRUM DISORDER:  
A QUALITATIVE STUDY

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## Abstract

The aim of this study was to investigate parent experiences of raising an adolescent with autism spectrum disorder (ASD). Nine families participated in semi-structured in-depth interviews.

Using thematic analysis, informed by grounded theory principles, 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.

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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. As the child matures, the research becomes sparser and the experiences, needs, and outcomes of individuals and their families during the period of adolescence have remained largely unexamined.

Although minimal, the current research on adolescents with ASD suggests that many of the same difficulties experienced by families continue into adolescence (Fong, Wilgosh, & Sobsey, 1993). These challenges are compounded by the typical stressors related to hormonal changes, increased needs for independence, and the transition into high school (Strunk, Pickler, McCain, Ameringer & Myers, 2014).

The diagnosis of ASD has recently been revised in the DSM-5. Previously in the DSM-IV-TR, ASDs were categorized as Autistic Disorder, Asperger Disorder and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS; APA, 2000). In the latest edition of the DSM-5, these three categories have been collapsed into the singular category of ASD. The DSM-5 criteria list those diagnosed with ASD as having 1) difficulty with social communication and social interaction and having 2) restrictive and repetitive interests and behaviours (APA, 2013). ASD is a separate diagnosis from Intellectual Disability (ID), which involves significantly below average intelligence and adaptive behaviour, but they are commonly associated with one another (Matson & Shoemaker, 2009). In a review conducted by Fombonne (2003), 30% of individuals with autistic disorder also had mild to moderate ID and 40% were in the severe to profound range. In addition to a comorbid diagnosis of ID, children with ASD tend to have other associated behavioural, medical, and mental health challenges, which may be

contribute to parent stress. Co-occurring behavioural issues include sleeping difficulties (Liu, Hubbard, Fabes, & Adam, 2006; Richdale & Schreck, 2009) and eating difficulties (Dominick, Davis, Lainhart, Tager-Flusberg, & Folstein, 2007). A high prevalence of medical disorders, such as seizures and epilepsy, have also been found in this population (Gabis, Pomeroy, & Andriola, 2005). Common mental health disorders include attention-deficit/hyperactivity disorder (Gargaro, Rinehart, Bradshaw, Tonge, & Sheppard, 2011), anxiety (Leyfer et al., 2006), and depression (Kim, Szatmari, Bryson, Streiner, & Wilson, 2000). It has been suggested that higher intellectual functioning in adolescents with ASD is associated with higher levels of depression (Fung, Lunsy, & Weiss, 2015). Given the recent change in the diagnostic criteria and the prevalence of comorbid disorders, this study sought to address the parents' own conception of ASD, and examine whether their own definitions have changed or remained the same as their child enters the period of adolescence.

Although individuals diagnosed with autism face similar challenges surrounding communication, social interaction, and repetitive interests, the severity of symptoms and outcome of individuals varies greatly. It has been suggested that, while most individuals diagnosed with ASD remain somewhere on the spectrum, a small minority eventually lose their diagnosis later on in life (Granpeesheh, Tarbox, Dixon, Carr & Herbert, 2009; Helt et al, 2008; Seltzer, Shattuck, Abbeduto, & Greenberg, 2004). The original Lovaas (1987) study compared three groups of children with autism under the age of 4, and at follow-up, found that those who received an average of 40 hours a week of Intensive Behavioural Intervention (IBI) for 2 years achieved significant outcomes in comparison to those who received the same treatment but less than 10 hours a week and to those who did not receive IBI at all. Furthermore, the study reported that 47% of the children in the intensive treatment group progressed to the point where their

post-treatment scores were indistinguishable from typically developing children. Other IBI studies have also reported positive outcomes but improvement to the extent of moving off the autism spectrum remains uncommon (Eldevik, Eikeseth, Jahr, & Smith, 2006; Howard, Sparkman, Cohen, Green, & Stanislaw, 2005; Perry et al, 2008; Sallows & Graupner, 2005). The reasons as to why certain children achieve better outcomes are unknown. However, there is a general consensus that improvement is a result of both child and treatment characteristics. Child characteristics such as early communication and language abilities, higher IQ, and lower autism severity are related to better outcomes (Howlin, Goode, Hutton & Rutter, 2004; Luyster, Qiu, Lopez, & Lord, 2007; Mawhood, Howlin, & Rutter, 2000; Perry et al., 2011). The available evidence highlights variability in outcomes and suggests a need to differentiate between good, medium and poor outcome groups. As such, it is reasonable to suppose that the experiences of the families within these separate groups are distinctly different from one another despite the common diagnosis of ASD. Based on the emerging theory in this study, parent experiences were compared to examine the similarities and differences between three child outcome groups (good, medium and poor outcome).

The effects of raising a young child with autism on the family system have been well-documented (Altieri & Von Kluge, 2009a; 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 (DDs) or families raising neurotypical children (Hayes & Watson, 2013). Common areas of stress for families with young children with ASD include the delay in diagnosis, challenging behaviours of ASD, and worries about the future (Ho, Perry, Rourke, Weiss, & Weiss, 2014; Ho, Yi, Griffiths, Chan, & Murray, 2014). Unlike other DDs, such as Down syndrome which has a clear genetic basis and is diagnosed

early in the child's life, ASD is diagnosed several years after birth or even later (Mandell, Maytali, & Zubritsky, 2005). Diagnosis often occurs after a long period of ambiguity and visits to many different professionals (Ho, Yi, Chan & Murray, 2014). The delayed symptoms, the varying degrees of the condition, and the variable day-to-day behaviours are unique to ASD and contribute to parent stress (O'Brien, 2007). Researchers have also pointed out that behavioural problems in children with ASD are the strongest and most consistent predictors of parenting stress (Hastings, 2003; Hastings & Brown, 2002; Tomanik, Harris, & Hawkins, 2004).

Adolescence in typically developing children is often a tumultuous period as the child enters puberty and deals with physical, mental, and social changes (Mulye et al., 2009; Orpinas, Home, Song, Reeves, & Hsieh, 2013). Children with autism 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). As discussed previously, ASD is an enduring condition that persists throughout one's lifetime and there is significant heterogeneity in developmental trajectories in adolescence (Levy & Perry, 2011). Several follow-up studies have indicated that some symptoms abate and improve as the child matures (Billstedt, Gillberg, & Gillberg, 2007; Lounds, 2007; Mawhood et al., 2000; Taylor & Seltzer, 2011a). Studies on aggressive physical behaviour 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 behaviours, these behaviours are even more difficult for their parents to manage due to the adolescents' increasing physical size and strength (Gray, 1994; 2002).

The family environment also plays an integral part in influencing the development of an individual with autism. Despite this, there is a dearth of research on experiences of families raising an adolescent with autism. The limited number of studies on parenting stress in raising an adolescent with ASD echo the findings from childhood. Abbeduto et al. (2004) found that mothers of adolescents with ASD reported higher levels of pessimism and depressive symptoms in comparison to mothers of adolescents with Down syndrome. 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 behavioural and social challenges as well as safety concerns related to the emerging sexuality of their adolescent (Fong et al., 1993). In a sample of 20 parents of adolescents with ASD in Singapore, parents explained that the challenging behaviours 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 behaviour 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. In another qualitative study, Gray (2002) examined the adaptation of parents

eight to 10 years after first receiving treatment at a centre for autism. The sample consisted of 20 parents whose adolescents ranged from 13 to 27 years old. Overall, the author found that the family experience improved during the adolescent and adult years. This improvement was attributed to increased manageability of autistic symptoms, accessibility to appropriate services, and changes in coping styles (Gray, 2002). The author notes however, that these improvements were not seen in all families. For families whose adolescent displayed aggressive behaviours, there were markedly different experiences.

The transition from childhood to adolescence also impacts the parent-child relationship. Taylor and Seltzer (2011b) found that while the mother-child relationship improved in early adolescence, the improvement tapered off upon the child's exit from high school. Youths with ASD, who did not have a comorbid ID, were at an increased risk for deterioration in the mother-child relationship. This group was also more likely to have unmet service needs post-high school when compared to those who also had ID.

Taken together, these studies suggest a need to examine family experiences based on the different adolescent outcomes. By grouping all outcome groups into a singular category of ASD, potentially important differences are obscured. In order to examine the variability of experiences within the context of ASD, this qualitative study compared parent experiences of raising an adolescent with ASD across three different outcome groups. By using a qualitative approach, this allows for researchers to better understand the perspectives of parents in a way that cannot be thoroughly examined through traditional quantitative methods. For this reason, qualitatively oriented approaches to analysis have become popular in attempting to elucidate the unique experiences of families raising individuals with disabilities (Altieri & Von Kluge, 2009b; Huws, Jones, & Indledew, 2001; Midence & O'Neill, 1999).

## **Objective**

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. Furthermore, the heterogeneity in the ASD category and the variability in the outcomes indicates a need to study these groups separately and examine the similarities and differences in the ways parents cope depending on the developing outcomes of their adolescent. The focus of this study was, therefore, to describe and compare the lived experiences of parents raising an adolescent with autism in three different outcome groups: low, medium and high – with the specific objective of examining how parents within and across groups conceptualize and understand autism as their adolescent matures.

## **Method**

### **Procedures**

This study was conducted as part of a larger study following the outcomes of adolescents who had previously received IBI (Perry, Koudys, & Ho, 2015). 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 autism treatment agencies in Ontario. In order to be included in the original study, participants had to have received 20 to 40 hours/week of IBI for one to three years; then been discharged for at least one year and been receiving less than 10 hours of IBI a week since discharge. Participants had been discharged from IBI for one to six years and were assessed on cognitive functioning, autism severity and academic ability where appropriate. Families were

also interviewed about the services their child was using. Participants were then categorized into one of the following three groups as defined by Prichard (2011).

Group 1 - Good: IQ estimate and/or Vineland adaptive behaviour composite (ABC) score above 84 and a Childhood Autism Rating Scale (CARS) score in the non-autism range (<30).

Group 2 - Medium: IQ estimate and/or Vineland ABC score from 40 to 84 and a CARS score not in the severe range (<37.5).

Group 3 - Poor: IQ estimate and/or Vineland ABC below 40 and CARS score not in the non-autism range (>30).

The present study was conducted approximately eight years after the data collection for the Prichard (2011) study. In the original study, these families provided consent to be contacted for future studies and included their contact information. This researcher contacted all of the initial participants via the mode of communication previously indicated by the participants. Of these 36 participants (32 families), eight (seven families) participants were lost to follow-up and seven (six families) participants declined to participate. 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 thesis study were purposively sampled based on their outcome groups outcomes (low, medium, high) from Prichard (2011). A subset of 10 adolescent participants (from nine families) were included in this study.

## **Participants**

A total of nine families, consisting of nine mothers and three fathers, participated in the present study. The majority of the parents ( $n = 10$ ) were born in Canada and had a college degree or higher ( $n = 11$ ). One family had two adolescents diagnosed with ASD, both of whom

were in the low outcome group. An estimate of the family's socio-economic status was calculated using the Barratt Simplified Measure of Social Status (BSMSS; Barratt, 2012). The BSMSS is based on the Hollingshead approach and generates a composite score from the participants' education level and occupation, which typically ranges from 8 to 66. The average BSMSS score for this sample was 42.2 ( $SD = 16.8$ ) and there was a wide range, from 16.5 to 63, indicating that our sample had a broad range of SES background.

The adolescent participants consisted of eight males and two females, between the ages of 13 and 20 years ( $M = 16.1$ ;  $SD = 1.9$ ). There were three adolescent participants from the good outcome group, three participants from the medium outcome group, and four participants from the low outcome group. For a summary of the adolescent participant characteristics, see Table 1.

### **Interview Structure**

Prior to the start of the study, this researcher clarified confidentiality and privacy issues, use and storage of collected information, and explained to the parents that they could withdraw at any time during the interview. Parents were then asked to sign an informed consent form (see Appendix A for Informed Consent Form).

Semi-structured in-depth interviews were conducted with parents at York University or at the homes of the families. Based on a critical literature review and personal clinical experience, specific domains of interest were targeted: The meaning of ASD, current experience with raising an adolescent with ASD, changes from childhood to adolescence, and expectations of the future (See Appendix B for Semi-Structured Questions). Although initial questions were standardized, open-ended probes were used to facilitate the parents telling their stories. Interviews typically lasted 1.5 hours.

## **Analysis**

All interviews were audio recorded and transcribed verbatim. N-Vivo software (QSR International Pty Ltd., Doncaster, Victoria, Australia) was used to store and manage the transcripts. Thematic analysis as described by Braun and Clarke (2006) was used to address the study's objectives. With this approach, the researcher suspends his or her beliefs and biases in order to allow the theory to be generated organically from the information obtained (Braun & Clarke, 2006). Using Glaser's and Strauss's (1967) constant comparative method, nine transcripts were first separated into 'meaning units' containing a complete thought, and then categorized or coded (Rennie, Phillips, & Quartaro, 1988). Through a process known as open categorization, codes were then grouped into categories and each unit could fall into more than one category. In the later stages of analysis, categories were modified and refined as these codes and categories were constantly compared to the existing data. These categories were then grouped together according to common themes in order to derive higher-order, more abstracted categories which yielded four broad themes.

Several validity checks were conducted to ensure the appropriateness of the categories and labels provided. First, the initial transcripts were analyzed and reviewed regularly by members of the thesis committee and any areas of disagreement were discussed with the intention of achieving consensus. Second, consensual validation was achieved by working with members of the Perry Lab (i.e., seven other graduate students). Lab members were asked to analyze certain blocks of text to see if the categories they generated were consistent with the ones I had. Furthermore, a 'reverse coding' technique was used whereby I provided the codes and asked team members to match the code with the appropriate text segment. We also approached one of the participating parents, several ASD providers and a few fellow

psychologists informally to gauge whether the category labels and supporting notions resonated for them, which they did.

## **Results**

A total of 246 lower order categories were collapsed into 13 higher order categories. From these categories, four main themes emerged to reflect the experiences of parents raising an adolescent with ASD: (1) Rippling Effect of Loss, (2) Becoming a Parent-Professional, (3) One Size Fits None, and (4) Preparing for “The Future”. The main themes and supporting sub-themes are summarized in Table 2. In general, these themes were representative of the parent experiences regardless of their adolescent’s outcome group. Each theme is reviewed below and differences between groups, if evident, are discussed.

### **Rippling Effect of Loss**

Regardless of whether their child was in the high, medium, or low outcome group, the majority of the parents in this sample described their initial reaction to the ASD diagnosis as grieving over a loss. This meant a loss of dreams for the child as well as a loss of expectations for what the parent envisioned his or her own life to be. Such grief also entailed tangible losses like the end of friendships and financial costs. Like a ripple in the water, the initial diagnosis was where the loss was most greatly felt but the sense of loss continues throughout a lifetime. Although both tangible and intangible losses were ongoing, the types and degree of loss felt differed across the lifespan of the family. Subthemes for this Rippling Effect of Loss included: 1) Who is this child?, which focuses on the grief that surrounded the changing perception of their child’s identity as a result of the diagnosis; 2) Initial fearful view of ASD, which includes the misconceptions and assumptions parents had at the beginning of their journey; 3) Parent sacrifice, which characterizes both the sacrifices and the pervasive feeling of guilt that continued

even as the child became an adolescent; and 4) An isolating experience, which encapsulates both internal and external sources of isolation that severed friendships and family support.

**Who is this child?** Upon receiving the diagnosis, several parents noted that they went through a “grieving process” which lasted for quite some time after the diagnosis. It was important for the parents to let themselves feel sad about the loss of their dreams and many parents reflected that this grieving process was needed for them to “deal with it” and begin to move on. Initially, some felt that the diagnosis fundamentally changed who their child was. There existed a “typical” child whom they knew prior to the diagnosis and then a “different” child who emerged afterward. The grieving process gave them time to grieve the loss of the child they thought they had prior to diagnosis and to come to terms with who their child was after the diagnosis. As one mother reflected, “for the first 18 months, he was my baby, then at the point they were starting to question [whether he had ASD], I was starting to question - ‘now I don’t know this child, like this is not the child that I thought I knew’”.

Two of the families had suffered the death of another child prior to receiving a diagnosis of ASD for their other child. These parents explained that, although it was difficult to receive the diagnosis, the loss felt was qualitatively different. These parents felt an impetus to “hit the ground running” to search for services and treatments, which was something they could not do in relation to the actual, physical loss of their other child. As one father remarked upon comparing the diagnosis of autism with losing a child, “We've suffered a loss- this isn't a loss. This is just, you provided us with information, now how do we move on? How do we make this work in our family and in our lives?”. Another father responded that, while they grieved their current child, there was also “a sense of relief” because there were options available for them to pursue.

**Initial fearful view of ASD.** Most parents in this sample did not know much about ASD prior to their child's diagnosis. For some, they described their knowledge of ASD as "Tom Cruise in Rain Man," while others only learned about it during the diagnosis feedback session. Some parents were prepared for "some sort of a diagnosis," but regardless of the level of preparedness in hearing a diagnosis, it was "scary" for many. Coupled with their own preconceptions and misconceptions of ASD, many parents expressed that the diagnosing professional told them "the worst outcome". One mother was told that her son was "heading for an institution". As a result, most parents had a very negative view of what ASD meant for their child and for their family life.

The negative view of ASD also coloured their own expectations of what their young child would be like as an adult. Regardless of the outcome level of the adolescent, the normal developmental trajectory that most parents subconsciously assumed their child would follow was replaced by a series of question marks. Wondering what kind of career their child would have as an adult was replaced by whether he or she would ever be able to read. One mother, in preparing her adolescent son for "either college or university", recalled her initial feelings about her son's future:

I thought that because he was non-verbal --and he was for a while after the diagnosis, I'd never hear him speak or say anything meaningful. I didn't know what to expect as far as behaviour. Was he going to be, is he going to injure himself? Was that something that we would always have to be concerned about? Would it be constant care?

**Parental sacrifice.** In conjunction with the loss of dreams and goals they had initially had for their child, the parents also experienced a loss in relation to their own lives and future goals and expectations for the family. Some parents had wanted to have more children but,

because of the diagnosis, decided not to have any more children and to focus on their current child. The ASD diagnosis also meant that some parents had to reduce their work hours or quit their jobs in order to care for their child. For most of the families, this meant a reduction in the mother's work time specifically. This reduction in work hours was especially prevalent during the child's younger years as many programs required parent attendance. Although many of the programs were government-funded, parents noted that even "free programs" took a financial toll because it meant that one parent could not work outside the home. Mothers were generally the ones who put their career on hold to care for their child. Parents were often able to work once their child grew older and entered school but now, in adolescence, some parents found themselves again wondering whether it was time to stop work, and to concentrate on preparing their adolescent for adulthood.

Despite these sacrifices, parents also struggled with ongoing feelings of guilt. For some, it manifested as questioning the choices they had made with respect to the types of services and treatments for their child and whether they "did the right thing" or if they "should have done it sooner". For others, the guilt stemmed from not being able to be as involved with their child's typically developing sibling early on. As one mother remarked:

I know his first word, but it's also sad because I don't know my daughter's. Because she's younger...everything was on him. We [felt that] we had to fix him. And I have no idea what her first word was, or when she walked, nothing. I have no clue.

Parents understood that worrying about their child's life was a normal parent experience in raising any child and that a part of them would always worry about their child. Most parents remarked that, as their child's symptoms improved, they were able to step back and concentrate on other aspects of their life. It was important for parents to have their own life and to enjoy

themselves, but the feeling that they “needed to do something” still continued. Many parents were so involved in their child’s treatment and services that they felt guilty when they focused on other aspects of their life. For instance, one parent stated:

I've been taking time for myself and I know that I am allowed that, but my son has suffered for it. I think he could've really been using more attention - constant. You know? I don't think he's benefited in any way from me having a bit of a rest.

**An isolating experience.** While grappling with the feelings of grief surrounding the initial diagnosis, some parents reported temporarily drifting away from their friends and loved ones. One mother found it difficult to be surrounded by friends with typical children, because it made her feel “isolated” and “robbed” of the life that those friends were having. For others, however, the loss of friendships became permanent. One parent put it this way, “All my friendships from those days were gone because they just didn't understand why I couldn't go out and do anything. 'Just get a babysitter!’” Other parents expressed that, due to misconceptions about ASD, they did not have support from their extended family. One mother explained that her relatives were not close to her son because “they are almost nervous around him, they don't know what to do.”

### **Becoming a Parent-Professional**

Receiving the diagnosis of ASD shifted the parents’ career into becoming a ‘parent-professional’. From the childhood to adolescence of their children, these parents developed specialized skills which have continued to aid them in navigating the ever-changing system.

**Critical consumer.** Once submerged into the world of ASD, parents felt the need to learn more about it. All parents discussed going through a process of information gathering. Often times, parents felt overwhelmed with the volume of ASD literature and the technical terms used.

One father wondered, “A normal person reading that, would they digest [all of the information?]”. The internet was like a minefield for many parents to navigate as there were many good resources but also many poorly written ones. Parents had to learn how to differentiate “empirically peer-reviewed data from Jenny McCarthy<sup>1</sup>”. Several parents went on to take formal courses on ASD in order to understand more about the diagnosis and to learn how to work with their child at home.

Parents also faced an array of choices in regards to types of therapies and treatments available for their child. With time and money being limited resources, parents had to make informed decisions as to what services they wanted to pursue. The current best-practice guidelines state that early intervention is key for best outcomes in individuals diagnosed with ASD and, as a result, many parents felt they were in a race against time in seeking the best intervention for their child. One mother described her experience with working under the best-practice guideline:

They say the neuropathways are done when you are 6. But they start to solidify at 3 as far as my understanding was. So I wasn't looking at 6 as my deadline, I was looking at 3. So I was just in a panic, because I felt this self-imposed time crunch.

As their child matured into an adolescent, all of the parents in the high outcome group remarked that the information-seeking process continued but not at the feverish pace it did earlier since many did not feel the pressure of early intervention any more. One mother explained:

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<sup>1</sup>A celebrity advocate who supports a retracted science paper by Dr. Andrew Wakefield and continues to claim that vaccines cause autism and advocates disproven dietary treatments.

You have your whole life to read those books, so don't think you have to read every book about everything about autism. Like it is overwhelming and you aren't going to absorb it. So think about it like this, it's there forever. You can pick one up and read a new one every once and a while. You don't need to know everything at once. It takes time. Yeah so, I haven't read one for a long time.

For parents of children in the low outcome group however, the pace of the information and service seeking intensified as their adolescent approached adulthood. These parents were faced with the looming presence of having to put their son or daughter into a group home which they perceived as the worst-case scenario. Parents reported that their adolescents had challenging behaviours, such as self-injury, and had difficulty with many basic self-care skills. These were barriers for their adolescent in staying at home with the family. Parents in this group explained that the next few years were pivotal in seeking appropriate services and treatment in order to lessen some of the problem behaviours so that their child could remain at their real home and not a group home.

We are really going to have to dig deep. We're going to have to try to do this for another 1-2 years-but really intense. Not just 'I'm going to still hang in there and be there', no, you're going to have to go further. You have to say, 'no, I'm not just going to be there, I'm going to actually go out and talk to whoever I have to talk to.' [...] I can't imagine just letting him go into a group home and then it's over. And after everything that we did- and I know we did that every single day of my life with the expectation that it was going to end up better.

**Manager of child's team.** The majority of the parents responded that they had a "team" for their child. This team was typically comprised of the school and service providers such as an

IBI therapist, an occupational therapist, and/or a speech-language therapist. While the roles of the team members generally remained the same, the team members themselves often changed from year to year. As a result, parents constantly had to adjust to the changing dynamic of the team, much like a manager with a rotating staff would.

One of the main roles as the manager of the team, was to facilitate communication with the team members and between team members. This was done in various ways such as organizing and attending meetings or having a daily communication book. In order for communication to be successful, it had to be “back and forth”, meaning that not only did the school and service providers have to communicate to the parents about the child’s progress, but the parents also had to be open about any issues occurring at home. For many parents, open communication was the key to maintaining a positive team environment but, unfortunately, this was also a source of struggle and stress. In this regard, parents expressed that they encountered the most difficulty when trying to communicate with the school. Sometimes the breakdown in communication occurred because there was no “back and forth” between the parents and teachers, so parents were left out of the loop. For instance, one mother responded that, despite her attempts to communicate with her son’s teacher, she only found out that her son had several assignments due two weeks before the end of the school term. Another mother thought that she had open communication with the school until she realized that they had stopped doing the programs they had previously agreed on without letting her know. In order to “be heard”, many parents felt a need to shed their “parent role” and assume the role of a professional when discussing the needs of their child. As one mother stated, “I try not to be emotional, because that really kills you. The first sign of emotion, they’re like ‘oh that’s the parent.’” In an attempt to distance themselves from being “just a parent”, several parents had asked other trusted service

professionals to represent them in team meetings as they felt that professionals trusted the opinion of other professionals more than they trusted the parents' opinions.

**Safeguarding the family.** Another important skill parents developed was becoming a gatekeeper for the family. Parents described that, in order to obtain services for their child, they needed to trade in a certain amount of privacy. Parents were constantly faced with the decision of whom to let into their team, and to balance both the need to obtain the best possible services for their child with maintaining privacy and normalcy for the family.

So now I'm at the point where I'm like, we have to make sure we have a circle of trust and anybody we can't trust is no longer in that circle and then we also want to ask ourselves- 'how big do we want this circle?' Because then it becomes too open and so that's a big problem. Yeah you really feel like you are under a microscope as a parent sometimes and it's hard.

For one family, in order to get their child into some of the government-funded services, they needed to make their story public by signing a petition.

If you go on the internet now [and] type in our names, you would see our names. Like you don't want to do all these things like that but [we did it] because of [our child]. We don't want to be labelled as well, right? But because of [our child] we had to fight for it.

In addition to protecting the family from outsiders, parents also talked about protecting the family from being "obsessed" with ASD. It was important for these families to not have their world revolve around their child's ASD. One mother stated, "Figure out what your family needs before medical professionals tell you what they think you should do. Figure out what's important to your family. Then those other decisions are so much easier." When talking about their family life, parents discussed the importance of maintaining a balance and making sure everyone's

needs were addressed at the appropriate time. For instance, one mother talked about how she made sure that the whole family attended her typically developing son's hockey games and would schedule her daughter's therapy sessions around her son's games.

### **One Size Fits None**

Parents often found that their child's abilities did not match with their own initial perceptions of ASD. As a result, their own definition of ASD has changed over time. Parents also found it difficult to find appropriate school settings and services to match the needs of their child. Often times, the responsibility was on the parents and their child to adapt to or find "a good enough fit" with the available resources. Broadly, this category highlights the tension of finding a "good fit" with the changing definition of ASD, with the school system, and with the available services for adolescents.

**Customizing a definition of ASD.** For many parents, the definition of ASD they held at the time of the interview was much different than what they had first imagined ASD to be like when their child was initially diagnosed. They found their own understanding of ASD changing based on their experiences with their child. One mother felt that the "earlier definition was very flat, in that it was one thing, where I think autism is a hundred thousand different things now." In general, parents felt that the original ASD label was very "limiting" whereas now, they saw it more as a "difference".

Within their own current definition of ASD, many parents highlighted the individuality of their child and, in many cases, individual traits that are not typically expected from a child with ASD. One mother described both her children who have a diagnosis of ASD as being "affectionate and social- much more so than I was led to believe, that they'd be in a corner rocking or always wanting to be alone." Another mother noted that her son, "considering his

limitations, he's quite empathetic. He does seem concerned about people, especially those close to him". Other parents described their child as "funny", "gregarious", and "creative".

In this current definition, many parents also discussed how difficult having ASD must be from the perspective of their child. One mother described ASD as being lonely:

I think that it must be very lonely because I see that he has such an interest in people, and I see that, at the same time, him saying that he has no interest in having friends and that kind of thing. I'm wondering if it's sort of his way of protecting himself.

Several parents explained that having ASD meant that their child had to "play the game according to rules we imposed", and that they were proud of their child for working hard to adapt to a world that often times, did not adapt to their needs. One father remarked that:

The only way I can liken [the experience of ASD to] is I know how I feel if I spend a day speaking French. I'm not really particularly good and it means a lot of effort. I'll come home and be exhausted, and I look at my child some nights and I think he is basically having to do the same thing. He is basically having to speak a foreign language for the better part of the day.

By re-defining what ASD meant for them and how it fit with their own understanding of their child, parents had a much more hopeful and positive working definition of ASD at the time of these interviews compared to what they reported in the past. In fact, for several parents, they viewed ASD as an integral part of their child's identity. Although it was difficult to receive the diagnosis, they now could not "picture" their child any other way, "because it makes him, him."

**Finding the "right" school at the "right" time.** For parents, one of the biggest obstacles was trying to fit their child within a rigid school system. Parents described their experiences with the school system as "frustrating" and that it was "completely the biggest stress

on our lives”. The first few years of school were especially difficult since the child had to transition out of government-funded IBI services and into the education system. One mother summed up the general sentiments of the parents by remarking that the gains her son had previously made “were reversed basically with public school”. Most importantly, parents were concerned with whether their child was learning at school and for many parents, they felt that their child’s potential was “wasted” in their initial school environment “with too many kids in the class and not enough support”. One mother described seeing her child at school, “in a little corner that they had made for him, with whale books, and that’s all he did all day, because he liked blue whales.” The child’s elementary school years were usually marked with multiple different attempts to find the best learning environment to fit the child’s needs.

Several parents discussed their own uncertainty about whether to put their child in a mainstream classroom or in a special education classroom. One child initially went to a mainstream school with special needs supports before her mother switched her to a special needs only school. Her mother explained that, originally, she and her husband “were kind of apprehensive for a while about bringing her to a school completely [for special needs] because we didn't know what other kind of behaviours were going to be here. I guess in the back of our heads, we were always kind of hoping that maybe she would mimic some of the behaviours of the other students in the regular classroom.” Other parents worried that putting their child in a special-needs-only classroom would mean that, because other classmates would also have a diagnosis or challenging behaviours, their child would have an even more difficult time learning and have poor peer models. One mother switched her son from a mainstream school to a private school for special needs and discussed her experience: “What happens when you get in to these private schools that will take your son, is there are a lot of ‘your sons’ in the class all of a

sudden... So you have that in the classroom, but 14 of them, that's even worse than 1 in 30 [for mainstream classes], so that didn't work". The mother ended up switching her child to another private school for special needs children that had even smaller class sizes which was a more optimal learning environment for her child.

Another source of difficulty, when it came to fit, was whether the school was supportive in working with the child and his or her challenging behaviours. These behaviours were anything that would be considered disruptive in a classroom environment and included repetitive or self-stimulatory behaviour (known colloquially as "stimming"), making loud noises, throwing tantrums and having "meltdowns". School environments were described as "not welcoming", with one principal even telling the parent that "there is no place for your son in my school." Many parents shared stories of receiving frequent phone calls from the school asking to take their child home whenever their child became upset:

Towards the last year she was there, we were getting a lot of phone calls about behaviours and then they would say, 'this is happening, come and get her- this is happening, come and get her.' I'm like, 'well, this is your job to figure out what to do in that case or remove her from the setting and keep her calm or whatever. I can't come and pick her up every time she has a tantrum'.

Oftentimes the school would address the behavioural challenges by "getting rid" of the child and sending him or her home or placing the child in a class where little or no learning demands were placed on them. One mother explained her frustration:

The thing about school is that the academic level and the behavioral level aren't separated and they need to be, so he wasn't being challenged. This even happened in private school

as well as like well, you know, we are a school for special needs, but he is really bright and is capable of these academic cognitive things and you aren't challenging him.

Parents tried a combination of different strategies from going to school with the child to shadowing him or her in the classroom, to switching to a private school, or homeschooling the child. One mother summarized her various attempts, "So the school he goes to, he's gone there since Grade 6. Before that, he went to [another school] where he had an extremely bad experience, and that's why we moved. In fact, I homeschooled him for a year and a half, or almost 2 years." Through trial and error, some parents were eventually successful in finding the elusive fit for their child's learning needs and happiness. One father and mother described their child's current school as "fantastic", and that the school "feels like a family":

The school is specifically designated for special needs children up until the age of 21. I believe that there's about 70 kids in her whole school and I think the ratio is 3 to 1 student teacher so it's fantastic. She swims every day, she's in the hot tub every day, she goes to the Snoezelen room every morning- I mean, I want to go to that school.

However, even when "a good learning fit" was found, parents explained that, due to a change in teachers or school administrators or even a change in their child's needs, they often had to restart the whole process of finding a good fit for their child. For children in the medium and high outcome groups especially, several parents found that as the child matured and ASD symptoms became less obvious, the less support their child received in school.

The more functional he becomes, the less people give him the time to process. Nobody gives him processing time anymore and he actually does require processing time- not a lot, but 15 seconds. It sometimes seems like [the teachers] are being deliberately obtuse but he actually requires processing time but no one give it to him.

One father explained that his son had a very good educational assistant for 3 years but, when the son went to high school, he was no longer eligible for it because he was able to transfer from a special needs class to a mainstream classroom. Overall, parents shared a similar difficult history as they tried to find the best schooling environment to optimize their child's learning.

**Outgrowing services and treatments.** The majority of parents found the government-funded IBI services, as well as speech therapy, and occupational therapy to be beneficial to their child during the early years prior to entering school. While early services were discussed in a positive light, the current treatments failed to grow with the needs of an adolescent with ASD. This was especially evident with adolescents in the medium and high outcome groups. For these adolescents, their needs have changed from focusing on primarily behavioural challenges to working on academics, social needs, and mental health issues. A general sentiment among these parents was that after the “essential” trio of IBI, speech therapy, and occupational therapy, there was nothing currently available for their adolescents. As a result, many of the adolescents in this sample were no longer utilizing services not because of lack of need, but rather, the services required “cannot be found and do not exist”. One mother explained that, when her son was young, he “was nonverbal- wouldn't eat food, he would stim like a crazy person, bashing his brains out” but, in comparison, the anxiety and depression her son deals with now as a teenager is “a million times worse because I could protect him against all that and I can't protect him now against the stuff that's in his own head.” Although she tried to seek mental health services for her teenager, she was turned away because “as soon as I said 'autism', it's like 'well our counsellors aren't qualified to handle that' because they seem to think that there's only one kind of autism and that's severe, nonverbal, whatever”.

### **Preparing for “The Future”**

Having gone through the initial journey of obtaining a diagnosis for their child and navigating through the services and school system pathways, all parents in this sample discussed “the future” to some degree. Parents tended to vary in discussing how far ahead this future was. For some, it was the next year while, for others, the future spanned a much wider net of time. In preparing for the next step, parents discussed having their adolescent becoming more involved with decisions, breaking down major goals into smaller steps, and remaining hopeful in the face of ambiguity.

**Parent-adolescent collaboration.** Previously when their child was young, parents naturally took on all the decision making but in adolescence, there was a shift for at least some adolescents to want more independence and to make their own choices. As a result, parents talked about discovering and developing their adolescent’s unique interests, trying to meaningfully involve their adolescent in decisions about his or her own care, and taking steps to support his or her independence.

Across all outcome groups, most of the parents remarked that, in recent years, it had become more important for parents to identify their adolescent’s own passion. For adolescents in the low outcome group, it was difficult for parents to either figure out their adolescent’s interest or to find ways to capitalize on it. One mother explained that she was still trying to get a sense of what her two children with ASD wanted to do, because “if you are following that, then you figure you are on the right path and it will be easier [once you know what they like].” For adolescents in the medium and high outcome groups, working with the adolescent to understand what his or her interests and goals are, helped in making decisions about attending future high schools or possible job prospects. For instance, one father remarked that, because his son liked to draw, they decided to enroll their son into a high school which focuses on arts and creativity, and

as a result, his son “flourished” with the curriculum. Another mother explained that she had always been vigilant about developing her son’s budding interests.

Once he wanted to be a garbage man because he was obsessed with recycling. So we'd stand out there waiting for the recycle truck and even though it's breaking every rule, the guy used to let my son whip the recycling into the truck. I was like- that's good money! That's \$25 bucks an hour! This is solid work! I mean if you like it- this is awesome! I never wanted to curtail what he was doing.

In addition to identifying and developing the adolescent’s interest, parents also talked about providing their son or daughter with more choices and respecting their adolescent’s decision. The types of choices differed based on the outcome group of the adolescent, but all parents tried to provide opportunities for their adolescent to make decisions. The mother of one teenager in the low outcome group talked about respecting her daughter’s decision to eat with the family or not. Another mother discussed how her son, who is also in the low outcome group, no longer wanted to join some of the group programs for ASD, and so she had to look for other services that her son would be willing to participate in. For adolescents in the medium or high outcome group, parents were willing to let their adolescent take more of the lead and to have them make their own decisions. One of the mothers talked about how her son, by the end of grade 7, wanted to be able to walk home by himself instead of staying at an after-school care program:

He was like “Are you kidding me? I’m too big [for the after-school program].” So we kinda let the winter go by, because then, walking home in the winter was just so dark. So starting in the spring, his dad would come and would basically hide in the bushes [laughs] and watch him. And my son would, he would pay attention to the traffic, and he would

pay attention to the lights... then we got him a key, and he learned how to unlock the doors [and go home by himself].

Related to providing more opportunities for independent decision-making, it was important for parents to “keep lines of communication open” with their adolescent. The majority of the parents in the medium and high outcome groups reported that they had a very close relationship with their teenager. This relationship was based on mutual trust, where “he trusts us implicitly, [and] we trust him implicitly”. This foundation of trust began early on in the child’s life with all the parents in medium and high outcome groups disclosing to their child that he or she had ASD. In fact, several parents explained that it was a conscious effort to make sure that their child was always aware of his or her diagnosis and that it was nothing to be ashamed of. As a result, this trust and respect operated from parent to child and child to parent. This trust was especially important when discussing sensitive topics related to sex, puberty and drugs. For most of these teenagers, they did not have “typical peer role models” to discuss these topics with and, as a result, they often turned to their parents to talk about their concerns about puberty or with dating. One mother remarked that her son “feels that he [can] come talk to me about anything, so the puberty part of it wasn't that hard.”

**Take it step by step.** Many of the parents were happy with what their adolescent had achieved thus far and any future goals that could be accomplished were more than what they could have hoped for. For instance, one mother remarked that, for the longest time, she felt that, if her son could just do this “one thing”, he would be fine. Over the years, the “one thing” changed from being able to follow three-step instructions to learning how to speak, and now, “he’s just like any other kid, maybe he has learning disability-whatever. He’ll be fine. I know

that whatever I do now, he is fine. If I die tomorrow, he's fine. That's all I wanted." Another mother shared similar sentiments:

It's not like I'm having an issue with him where it's like 'our goal is now to work on this' because, you know, I don't want to say it's perfect, but you know what I mean? There's no issues. He's in a happy place, he's going to a place he loves to go to.

Compared to when the child was first diagnosed with ASD, the future seemed less daunting to these parents. Instead of viewing it as a series of question marks, parents now saw it as a series of concrete steps to get to a certain goal. Parents were cautious in making short and obtainable plans and "playing it one year at a time". For adolescents in the low outcome group, parents discussed continuing to improve self-care skills, with the "ultimate goal" as being able to keep the adolescent at home with the family instead of having to go to a group home. Parents were realistic with what their adolescent could and could not do:

We have no delusions of her working on any math or science or problems like that, but if she could feel some sense of accomplishment. If she could help me here, like maybe folding clothes or putting dishes away or things like that.

For many adolescents in the medium to high outcome group, continuing their high school education and going into post-secondary education was a possible next step. In order to prepare their adolescent, parents discussed taking a proactive stance in making sure their adolescent would be well supported in whatever future he or she decided on. Other parents have looked into putting their adolescent into either applied or academic streams in high school in order to prepare them for post-secondary education. Another father discussed saving up money so he could set up a store for his son to potentially work in. In contrast to the time pressure initially felt by these parents to get their child into early intervention and other services, the majority of parents

remarked that it was okay if their adolescent took a longer time to finish high school or post-secondary education. In fact, several parents commented that they would probably have to convince their child that “it’s not a bad thing for you to take that extra time”.

**Finding hope in ambiguity.** As noted earlier, when the child was first diagnosed with ASD, many parents went through a grieving process and found it difficult to cope with not knowing what the child will be like in the future. As the child matured and developed different skills, the future became filled with small but achievable goals that paved the way for a more concrete future. Although the future still holds some ambiguity as to what these adolescents will ultimately achieve, several parents now viewed this ambiguity as more hopeful.

If you have kids with Down's, that's what they are going to be. If they start off severely, that's how they're going to end up. If they start off mild, that's how they're going to end up. You can plan their life. Even if the kid's got, y'know, cystic fibrosis, you can say, 'well you know what, you are probably going to lose this kid by the time he is 25.' With Autism, you don't know. So, at first that was the heartbreaking point- I don't know. But then, that's your best part too, because it also means there's no limitations.

### **Discussion**

The current study sought to explore and investigate the parental experiences of raising an adolescent with ASD through in-depth qualitative interviews. Specifically, the narratives of parents caring for adolescents in three child outcome groups (high, medium, and low) were examined to understand differences and similarities. Overall, the four main themes were evident across parent experiences regardless of their adolescent’s outcome level. Differences among outcome groups were found in the subcategories related to school supports, service availability, and the types of future goals.

Parents in this sample discussed loss in numerous contexts and in varying severity. One of the biggest losses felt was the loss of dreams and goals they had for their child. Prior to the initial diagnosis, parents remarked that they knew very little about ASD and that the small bits of information they knew about ASD were mainly negative and false. Consequently, receiving the diagnosis of ASD for most parents was a devastating experience. The label of ASD led parents in this sample to perceive a change in who their child was prior to the diagnosis, and as a result, they mourned the loss of the child they thought they knew. Filled with misconceptions and a bleak outlook of their child's future, many remarked that they went through a grieving process but, for two families who had experienced a death of another child, this type of grief was markedly different. One theory that could help clarify these findings is the theory of ambiguous loss (Boss, 1999, 2004). Ambiguous loss is an unclear, externally caused, traumatic loss. Unlike a typical loss (e.g., death), part of the person still remains while the other part is gone. According to Boss, ambiguous loss occurs in two ways. The first is when the loved one is missing physically, but still present psychologically. This has been applied to instances of divorce, adoption, or missing persons (Carroll, Olson, & Buckmiller, 2007). The second type of ambiguous loss is when the loved one is physically present but is absent psychologically. It is this type of ambiguous loss that has been applied to the literature on Alzheimer's, dementia, and more recently, on the diagnosis of ASD (O'Brien, 2007). The pervasive nature of ASD, lack of biological markers, physical appearance of health, and variable outcomes, contribute to the ambiguity surrounding ASD. O'Brien (2007) conducted a mixed-methods study with 63 mothers of children with autism aged 2 to 13 years old to examine mothers' experiences prior to diagnosis and within a year afterwards. Similar to O'Brien's (2007) findings, parents in the present study reported that, when the initial diagnosis was given, they had difficulty adjusting

their expectations for their child because they did not know what to expect for their child's future. When discussing the child's future, O'Brien (2007) reported that the mothers tended to discuss their child's future while contrasting it with the expectation they had for their child prior to the diagnosis. While O'Brien's (2007) study was focused on the experiences of mothers of children who had received a diagnosis of ASD within a year, most of the parents in this study had received the diagnosis of ASD for their child at least a decade earlier. In comparison, a notable finding in this present study was the shift in the meaning of ambiguity. While parents explained that the ambiguity of the diagnosis and the unknown outcome of their child was initially frightening, now in adolescence, the future seems more manageable. Parents explained that it was helpful for them to break down larger goals into smaller goals and work towards them in a step-by-step manner. Parents also found it motivating to look back on their journey and see how far their child has progressed through the years. For some parents, the unknown future of ASD brought on a new meaning of hope. They explained that because there was such a larger range of outcomes, this could also mean that their child had limitless possibilities. One possible reason for this shift in the meaning of ambiguity from fear to hope could be that parents of adolescents with ASD have had more time to come to terms with actual impact of ASD. In contrast to studies that focused much earlier on in the parenting experience, these parents have seen the improvements and development of their adolescent throughout the years.

Other types of loss were also discussed by parents. Although most of the parents utilized government-funded programs, families experienced financial loss as attendance for these programs necessitated that a caregiver needed to be present to take care of the child. Mothers in particular, reported that they had to take time off work or even stop working entirely in order to provide care for their child which is consistent with the findings by Gray (2003). It is suggested

that mothers and fathers cope with ASD in different ways and often revert back to traditional gender roles (Gray, 2003). Although many of the parents were able to resume work shortly after their child reached school-age, many mothers in this study were also prepared to take a break from their career at this stage in their adolescent's life in order to address their needs. This present finding underscores an important area for future research on differences in mothers' and fathers' coping styles as well as how to best support parents, especially mothers, who choose to take a break from their careers.

Consistent with the current research on parent experiences early on in the diagnosis, is the theme of isolation (Woodgate et al., 2008). When parents first received the diagnosis, many explained that they went through a period of self-imposed isolation, in which they felt that it was difficult to be with friends and loved ones who were going through the 'typical' experience of parenting. For these parents, the isolation period was often temporary. Other parents however, experienced externally-imposed isolation. Often, this was a result of a lack of understanding about ASD from friends and family members, and in contrast to the self-imposed isolation, these fractures in relationships tended to persist into the child's adolescence.

A notable finding in this study was the development of parent-professional skills in response to the perceived tension existing between parents and professionals working in ASD services and school system. Often, parents felt that their role as a parent was undervalued and they had to shed their identity as a parent in order to have their voice heard by other professionals. Other studies have reported similar findings that parents felt they were not considered an equal partner in the care of their child (Brett, 2002). In response to this tension with professionals, the parents in this study developed skills that helped them advocate for their child as well as navigate the diagnostic and services system. All parents embarked on an

information-seeking journey at the outset of receiving the ASD diagnosis for their child which is consistent with the current literature (Ho et al., 2014; Woodgate et al., 2008). In Woodgate et al.'s (2008) study, they conducted a similar qualitative study but with parents of children between the ages of 3 to 9. They proposed the concept of 'vigilant parenting' which is similar to the 'parent-professional skills' theme discussed here. Taken together, it would seem that parents develop these skills early on and these skills continue to help parents find appropriate information and services for their adolescent.

Another major theme in this study was the concept of trying to find the "right fit". At a personal level, there was a mismatch between the traditional definition of ASD and the parents' own experiences with raising an adolescent with ASD, which led many parents to have their own personalized definition of ASD. Many parents eschewed the typical conceptions of ASD characteristics, specifically the notion that people with ASD lack affection for other people. In this new definition, parents used a variety of adjectives to describe their adolescent as the antithesis of ASD symptoms. The adolescents in this sample were described as "witty", "funny", "creative", and "affectionate". Although the ways that some of these adolescents showed their humour or affection differed qualitatively from what would be expected from typically developing same-age peers, parents nonetheless perceived their adolescent to have those characteristics. The majority of parents also focused on the strengths of their child in relation to their ASD, rather than a deficit-based approach. According to Boss (1999), this reconceptualization of what ASD means is an important turning point for parents as they move forward. Boss (1999) explained that, when dealing with ambiguous loss, the grief process is frozen because there is no clear end to the loss. As with ASD, the disorder is lifelong and the

symptoms are often pervasive with varying degrees. In order to “unfreeze” the grief process, a major step is to re-evaluate and re-organize what the disorder means to the family (Boss, 1999).

All parents in this sample shared experiences of dissatisfaction with the education system which is, unfortunately, consistent with the current research and seems to continue throughout the child’s schooling (Bitterman, Daley, Misra, Carlson, & Markowitz, 2008). Parents shared that their child was often excluded from the school environment as a result of their behaviour. In order to prevent challenging behaviour, the school often responded by not placing demands on the child or by asking parents to remove the child from school. This led to missed learning opportunities both academically and socially. As noted in another study on parents’ perspectives of the Ontario education system for children with ASD, the main concern for parents was that their child was not reaching their full potential (Starr & Foy, 2012). Parents also reported a mismatch between the educational setting and their child’s abilities. Often times, the onus was on the child and the parents to fit into the structure of the curriculum and school system, rather than the other way around. In response to this, many parents discussed strategies they used in order to find the best school environment for their child. Through a process of trial and error, some were successful in finding an appropriate environment for their child. For medium to high outcome groups however, finding a right fit was often a double edged sword, since the more improvements the child made, the fewer supports they were given. Overall, these heterogeneous experiences with the education system continue to underscore the importance of understanding the unique needs of each individual student.

It was positive to see that, overall, parents in this study found that the initial services offered were helpful. This is in contrast with an earlier Canadian study by Siklos and Kerns (2007) which point to a much bleaker picture. This finding could suggest that early intervention

services and treatment in Ontario are catching up to the needs of young children diagnosed with ASD. However, it is also important to keep in mind that this sample of adolescents and parents were ones who signed up for, and received, IBI prior to the age of 6. Hence, their satisfaction with the early services may be due to fact that they were the ones who actively sought services and may not reflect the current perspective on early services. As the child matured into adolescence, there was a notable shift in the reliance on services and treatment. While parents reported using a variety of services during their child's younger years, the parents in this sample explained that they no longer used as many services. Two plausible reasons exist for this shift. First, many of the adolescents in the medium to high outcome group have improved such that the nature of their needs have changed. As a result, the current services available are no longer suited for their changed needs. Parents with adolescents in the medium and high outcome groups mainly point to needs in the academic area as well as mental health needs that must be addressed. Another reason for the decreased use in services may be due to evolving coping strategies. Findings from Gray (2006) suggest that, over time, parents of children with ASD shift from problem-focused coping (i.e., service utilization) to focusing on the child's strengths and positive qualities.

Results from this study also provide insight into how parents perceive "the future" for their adolescents as they move on into adulthood. An increase in independence was discussed by parents of adolescents across all outcome groups. Based on the adolescent's abilities, parents provided opportunities for their adolescent to make decisions. For adolescents in the medium to high outcome group, the majority of parents explained that they had a very close relationship with their adolescent and as a result, topics like puberty and sex education were much easier to discuss than they had previously expected.

In comparison to when the child was first diagnosed with ASD, the nature of future goals has changed in adolescence. During childhood, parents focused largely on developmental milestones such as using meaningful speech and being able to read. In adolescence however, parents discussed the importance of discovering their child's interests and finding an appropriate environment to foster their growth. These findings are consistent with the perspective offered by Ruble and Dalrymple (1996), who propose that a successful transition into adulthood for individuals with ID/DD is marked by the degree of "person-environment fit." For many of the adolescents in the medium to high outcome groups within this sample, finding the appropriate "person-environment fit" meant the goal of post-secondary education which is supported by results from studies involving similar adolescents with similar abilities (Henninger & Taylor, 2014). For adolescents in the low outcome groups, the goal was to keep the adolescent at home with the family as long as possible.

### **Limitations**

Although this study provides a rich description of the parent experiences of raising an adolescent with ASD, it has several limitations that need to be acknowledged. First, this study was limited to the perspectives of parents of adolescents with ASD who were initially recruited from autism treatment agencies in Ontario and who took part in a long-term follow-up study examining IBI effectiveness. Therefore, differences may exist for parents who are not linked with autism treatment agencies, for parents from other regions, or for parents who declined to participate in the larger follow-up study. For these reasons, it cannot be assumed that this sample is representative of all parents raising an adolescent with ASD. However, a purposive sampling method was employed to describe a wide range of views based on evolving themes which reached saturation.

## **Implications**

The findings from this study offer several implications for practice and research. In terms of practice, understanding and labeling the experience of ambiguous loss is important for both professionals and parents. This will help parents make sense of their feelings and allow them to come to terms with what ASD means to them and their family. Based on the experiences of parents in this sample, it seems that the meaning of ambiguous loss changes as the child matures. Further research could examine how ambiguous loss is reconceptualized later on as the child transitions into adulthood.

In addition, the findings underscore the importance for ASD service providers and educators to focus not only on the child, but on the needs to the parents as well. Over and over again parents have rightfully insisted on being an equal member of their child's team, and it is vital that their position on the team be respected. It may also be suitable for ASD information workshops to target parent-professional skills by teaching parents how to critically analyze the information given to them in the media, on websites, and so on.

This study also highlights the paucity of appropriate services for adolescents in the medium to high outcome groups. Specifically, services that target both ASD and comorbid mental health issues, such as depression and anxiety, must be available and easily accessible. Mental health professionals need to be trained in how to adapt to and customize treatment methods suitable for the needs of adolescents with ASD. For adolescents in the low outcome group, services could work with the family in helping to meet the goals they have for their child. Depending on the needs of the family and the adolescent, this could include focusing on self-help and behavioural skills with the goal of keep the adolescent at home with their family.

Although I attempted to recruit both mothers and fathers in order to understand their potentially different experiences, the majority of participants were mothers. For future research, it would be useful to recruit fathers specifically to explore their perspectives of raising an adolescent with ASD. In this limited sample, some differences in the coping styles between genders were discussed. Mothers were more likely to put their career on hold and assume primary caregiver responsibilities to address the needs of their child. It would be beneficial for workplaces to provide internal supports for parents who decide to temporarily pause their careers. Other strategies such as working part-time or working from home could also be presented as options for parents with children diagnosed with ASD.

Through the use of semi-structured in-depth interviews, this study provides a unique insight into the experiences of parents raising an adolescent with ASD and contributes to the limited knowledge about the needs of these adolescents and their parents. To the best of my knowledge, this is the first study which examines the experiences of parents of adolescents with ASD in three different outcome groups. 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.

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Table 1

*Adolescent Characteristics (N = 10)*

Participant	Sex	Age	Full Scale IQ (Prichard, 2011)	Vineland ABC (Prichard, 2011)	Outcome Group	Parent Participant
1	Male	15.08	95	76	Good	Mother and Father
2	Male	13.25	96	89	Good	Mother
3	Male	16.33	109	84	Good	Mother
4	Male	15.17	62	75	Medium	Mother
5	Male	16.25	79	81	Medium	Mother and Father
6	Male	14.33	83	103	Medium	Mother
7	Female	17.50	18	48	Poor	Mother and Father
8	Male	20.17	33	47	Poor	Mother
9*	Female	16.00	22	57	Poor	Mother
10*	Male	17.17	20	50	Poor	Mother

\*Participant 9 & 10 were siblings

Table 2

*Summary of Main Themes*

<i>Main Themes</i>	<i>Subthemes</i>
Rippling Effect of Loss	Who is this child? Initial fearful view of ASD Parental Sacrifice An isolating experience
Becoming a Parent-Professional	Critical consumer Manager of child's team Safeguarding the family
One Size Fits None	Customizing a definition of ASD Finding the "right" school at the "right" time Outgrowing services and treatments
Preparing for "The Future"	Parent-adolescent collaboration Take it step by step Finding hope in ambiguity

## Appendix A: Informed Consent Form

**IBI FOLLOW-UP STUDY****PARENT CONSENT FORM**

I agree to participate in the IBI Follow-up Study being conducted by Dr. Adrienne Perry and Dr. Julie Koudys. I understand that the purpose of the study is to find out about the development and behaviour of adolescents and young adults with autism who had received Intensive Behavioural Intervention (IBI) as young children.

I understand that my son/daughter and I would be required to participate in a Psychological Assessment at York University (or in another agreed location) of about 4 hours duration. This will include psychological testing of my son/daughter, questionnaires for me to complete, and an interview about services we have received and my experience with my son/daughter. **Portions of the interview will be audio recorded to facilitate later thematic data analysis.** I understand that, if I give permission, a teacher or staff member who works with my son/daughter will also be asked to complete a questionnaire about his/her behaviour at school. Further, I understand that the researchers would like to compare the assessment results from this new assessment to the information they have on file from the previous study my son/daughter and I participated in.

I realize that participation is totally voluntary and I know that it will make no difference to any services my son/daughter or family receive if we participate or not. I understand that there are no known risks to participation. I will be offered a \$50 honorarium to cover transportation and parking. I understand that I will receive a written report of the findings of the assessment and may come for a feedback session.

I am aware that all information collected in the study will be stored securely, in a locked cabinet in a locked office at York University and will only be accessed by people directly involved in the research under the supervision of Dr. Perry and/or Dr. Koudys. Files will be kept for 10 years or until 10 years after my son/daughter's 18th birthday. In computer data files, I understand my name will be replaced with a code number and that the **audio recordings will be transcribed into a written document which will not include my name, but only a code number, and the audio recordings will then be deleted.** I understand that all information collected will be kept confidential, within the limits of the law. I understand there are rare exceptions involving serious matters such as child abuse, sexual abuse by a health care provider, imminent risk of harm, and legal situations, where confidentiality cannot be guaranteed.

I have had a chance to ask questions about the study and they have been answered to my satisfaction. I may have a copy of this form to keep if I wish.

- I agree to participate in the study, bringing my son/daughter for the assessment and myself completing questionnaires and interviews.
- I agree that the researchers may conduct a Psychological Assessment on my son/daughter (if the adolescent is 16 or over and has the capacity to give consent him/herself, this will be done as well).
- I agree that the researchers may audio record portions of my interview for the purposes of data collection and analysis.**
- I agree that the researchers may contact my son/daughter's teacher or a worker who knows my child well to ask them to complete one questionnaire (which will take about 20 minutes).
- I agree that the researchers may use the previous information they have on file from the earlier study to compare to the new assessment.

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Parent/Guardian Name (print)

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Signature

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Date

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Researcher who Obtained Consent

---

Signature

---

Date

## Appendix B: Semi-Structured Interview Questions

### Meaning of Autism

1. Describe your adolescent
2. What does autism mean to you?
  - a. Has this changed over the years?

### Current Experience

1. Describe a typical day in your household
  - a. What roles do your family members play?
2. What is your experience with your adolescent's school?
  - a. Positive? Negative?
3. What is your experience with your adolescent's healthcare?
  - a. Positive? Negative?
4. What is/has been your experience with your adolescent's therapy/treatment program?
  - a. Positive? Negative?

### Future

1. Where do you see your adolescent in 5 years?
2. What goals do you have for your adolescent? What are some barriers that might prevent him/her from achieving this goal?

Changes from childhood

1. How has your adolescent changed from when he/she was first diagnosed with autism?
2. When you think back to those early years, was there anything you found helpful at the time but, looking back, you now believe was not helpful? Was there anything particularly helpful?
3. What advice would you give to parents who have just received a diagnosis of autism or ASD for their child?

Other

Is there anything more you would like to share about your experiences that I have not asked?