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Parent Reported Impacts of their Disclosure of their Child's ASD Diagnosis to their Children

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Parent Reported Impacts of their Disclosure of their Child's ASD Diagnosis to their Children

by

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Abstract

The current study investigated parent-reported impacts associated with disclosing a child's autism spectrum disorder (ASD) to their child with ASD. This study addressed a distinct gap in the empirical literature, and findings have practical utility for individuals with ASD, their parents, and associated professionals and researchers. A qualitative design was used, whereby 15 semi-structured interviews were conducted with parents of a child with ASD, who had disclosed their child's diagnosis to their child, and were living in Alberta, Canada. Interviews were carefully transcribed. Data were analyzed using thematic analysis, with six themes arising: Communication about ASD; Understanding ASD; Awareness of ASD Features; Specific Child Reactions and Impacts; Views and Feelings Associated with ASD; and Magnitude and Valence of Impacts. Overall, current findings suggest that parental diagnosis disclosure to their child with ASD is associated with discernible positive impacts.

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List of Abbreviations

ADHD.....Attention-Deficit/Hyperactivity Disorder
APA.....American Psychiatric Association
ASD.....Autism Spectrum Disorder
CDC.....Centers for Disease Control and Prevention
LD.....Learning Disabilities
NAS.....National Autistic Society

Chapter One: Introduction

The present study examined the impacts of parental disclosure of their child's autism spectrum disorder (ASD) diagnosis to their child(ren) in an effort to address a distinct gap in the research literature. This chapter will provide a brief background and rationale for the present study in addition to an outline of subsequent chapters.

ASD is a neurodevelopmental disorder characterized by atypical/impaired social-communication and restricted and repetitive patterns of behaviour (American Psychiatric Association [APA], 2013). Recent research suggests that one in 68 children in the United States have an ASD diagnosis (Centers for Disease Control and Prevention [CDC], 2014).

Developmental abnormalities can become apparent in children suspected of having an ASD diagnosis as early as 12 to 18 months of age (Al-Qabandi, Gorter, & Rosenbaum, 2011). However, a recent review has indicated that the age of diagnosis is typically between 38 and 120 months (Daniels & Mandell, 2014). Parents tend to seek professional assistance upon noticing behavioural and/or developmental atypicalities in their child, which may result in a comprehensive and developmental evaluation of the child's functioning (Campbell, Ruble, & Hammond, 2014). A multitude of measures and approaches are used in the ASD diagnostic process (further described in Chapter Two; Klin, Saulnier, Tsatsanis, & Volkmar, 2005; Volkmar et al., 2014). Subsequently, clinicians typically communicate the results of the assessment (and potential diagnoses) to the child's parents.

Many researchers have focused on parental (dis-)satisfaction associated with learning of their child's ASD diagnosis (Abbott, Bernard, & Forge, 2013; Braiden, Bothwell, & Duffy, 2010; Brogan & Knussen, 2003; Chamak, Bonniau, Oudaya, & Ehrenberg, 2011; Chiu et al., 2014; Finnegan, Trimble, & Egan, 2014; Goin-Kochel, Mackintosh, & Myers, 2006; Midence &

O'Neill 1999; Moh & Magiati, 2012; Siklos & Kerns, 2007). Further, a profusion of literature has also examined parental impacts associated with their learning of the diagnosis (ranging from positive to negative; Abbott et al., 2013; Avdi, Griffin, and Brough, 2000; Calzada, Pistrang, & Mandy, 2012; Finnegan et al., 2014; Hutton & Caron, 2008; Nissenbaum, Tollefson, & Reese, 2002; Mansell & Morris, 2004; Midence & O'Neill, 1999). Specifically, parents report a range of impacts (positive and negative) and satisfaction (high to low) associated with the process of learning of their child's ASD diagnosis. In addition to this information, it is important to gain an insight into how individuals with ASD (as opposed to parents) are impacted by becoming aware of their ASD diagnosis, as this awareness may inform disclosure practices, beliefs, and feelings associated with having ASD. For some affected individuals, diagnosis disclosure has been found to be illuminating as it explained prior experiences and behaviour, and facilitated access to resources (Huws & Jones, 2008; Punshon, Skirrow, & Murphy, 2009). Conversely, some individuals perceived the learning of their ASD diagnosis as disadvantageous as it was believed to be discriminative, prejudicial, and/or stigmatizing (Calzada et al., 2012; Huws & Jones, 2008). Notably, the aforementioned studies did not explicitly state who informed individuals with ASD about their diagnosis, nor discuss associated impacts of diagnosis disclosure.

In sum, there has been a strong empirical focus on the impacts and satisfaction levels of parents upon being informed of their child's ASD diagnosis and some research on individual impacts associated with learning of their own ASD diagnosis. However, the link between professional-parent diagnosis disclosure and individual impacts/experiences, that is, the process whereby parents disclose their child's ASD diagnosis to their child on the autism spectrum, has not been fully explored.

The Present Study

The current study was developed to fill a gap in the empirical literature. Until recently, the topic of the impacts of parental disclosure of a child's ASD diagnosis to their child has remained relatively unexplored. Comparatively, there is an abundance of research examining the impacts of parental diagnosis disclosure to children with medical conditions such as pediatric cancer (e.g., Chesler, Paris, & Barbarin, 1986; Claflin and Barbarin, 1991; Clarke, Davies, Jenney, Glaser, & Eiser, 2005; Jithoo, 2010; Last & van Veldhuizen, 1996; Young, Dixon-Woods, Findlay, & Heney, 2002) and perinatal HIV (e.g., Bachanas et al., 2001; Butler et al., 2009; Domek, 2010; Vreeman et al., 2010; Waugh, 2003). However, ASD is qualitatively different to both aforementioned diagnoses (in terms of characteristics, symptoms, and prognoses), and thus may yield non-equivalent parental diagnosis disclosure impacts. Finnegan and colleagues (2014) reported several impacts associated with parental diagnosis disclosure of ASD in an Irish sample. However, the current study sought to thoroughly examine diagnosis disclosure impacts in a larger Canadian sample. Hence, the present study sought to identify impacts associated with parents disclosing their child's ASD diagnosis to their child.

Participants were parents of a child with ASD who were recruited via a web-based survey to provide demographic information and answer questions pertaining to their experience with disclosing their child's ASD diagnosis to their child (see Appendix A for survey items). Parents who indicated that they had a child with ASD; had previously disclosed their child's ASD diagnosis to their child with ASD; lived in the province of Alberta, Canada; and provided consent to partake in additional research on this topic were contacted. They were invited to participate in a semi-structured interview on the topics of experience with diagnosis disclosure to their child(ren), impact(s) of the disclosure, parent perceived child self-perceptions, and sibling impacts (see Appendix B for interview protocol). The present study represents a subset of the

larger project, and only diagnosis disclosure impacts were analyzed, reported, and discussed in this paper. The methodology, thematic analysis, was chosen to provide contextual qualitative accounts of parental diagnosis disclosure impacts.

Results of the current study consisted of six overarching themes (and subthemes within each main theme) pertaining to impacts associated with parental disclosure of their child's ASD diagnosis to their child, findings which have practical implications for families of children with ASD and associated professionals. Specifically, diagnosis disclosure facilitated parent-child conversations about ASD-related differences, difficulties, explanations, and problem solving strategies; understanding of ASD; awareness of ASD; specific child reactions and impacts associated with diagnosis disclosure; views and feelings associated with diagnosis disclosure; and magnitude and valence of impacts. Converse to prior research examining diagnosis disclosure to parents, most reported impacts were positive in nature.

This paper will be organized by chapters. Chapter Two will provide a description of ASD (e.g., characteristics, features, prevalence, and age at diagnosis), the process of diagnosis, professional disclosure of an ASD diagnosis to parents and subsequent parent perceived (dis-) satisfaction and impacts, experiences of individuals with ASD, and will conclude with a rationale for conducting the current study. Chapter Three will rationalize and describe the study's epistemological stance, chosen methodology and methods. Chapter Four will report results through the use of derived themes, subthemes, and participant excerpts. Subsequently, Chapter Five will analyze and interpret, and compare findings with related literature. The paper will conclude with an evaluation of the study's limitations, strengths, implications, and ideas for future research.

Chapter Two: Literature Review

Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by impairments in social communication and restricted and/or repetitive behaviours (APA, 2013). ASD symptomology is extremely variable and can be thought of as existing along a continuum, or spectrum of severity (Rapin & Tuchman, 2008). Researchers have focused efforts on: 1) best practice approaches to assessment and diagnosis of ASD, 2) the impacts on and satisfaction of parents when receiving a diagnosis for their child, and 3) the impacts and experiences of individuals learning about their diagnosis and living with ASD. However, a paucity of empirical literature has examined the parents' perceived impact of parental disclosure of an ASD diagnosis to their child. The current study examined parental disclosure of an ASD diagnosis to their child with a focus on parental perceived impacts of that event/process upon the child. This chapter will begin with an overview of ASD including the current clinical conceptualization, categorization, symptomatology, prevalence, age at diagnosis, and the diagnostic process. Next, parental satisfaction surrounding the disclosure process by professionals to parents and subsequent impacts of parents learning of their child's diagnosis will be discussed. Then, individual experiences upon learning of their diagnosis and living with ASD will be reviewed. Subsequently, given the paucity of parent-child ASD diagnosis disclosure literature, the impact of parent-child diagnostic disclosure for other medical and neurodevelopmental disorders will be reviewed. Finally, the current study will be outlined.

Conceptualization and Categorization of ASD

Currently, the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (DSM-5; APA, 2013) categorizes and describes ASD symptomology under two primary domains, as illustrated in Table 1. Specifically, an ASD diagnosis requires that individuals

Table 1

Autism Spectrum Disorder Diagnostic Criteria According to the DSM-5 (APA, 2013, p.50).

A. Continuing deficits in social interaction and social communication across several contexts. Examples include: 1. Poor social-emotional reciprocity. For example: Atypical social behaviour, lack of typical back-and-forth conversation, decreased communication about emotions and interests, and/or lack of initiations or responses to social interactions. 2. Poor use of nonverbal communication during social interactions. For example: impaired integration of verbal and non-verbal forms of communication, atypical body language, eye contact, gesture use, gesture comprehension, absence of facial expressions and/or nonverbal forms of communication. 3. Impairments in creating, maintaining, and comprehending relationships. For example: Challenges with modifying behaviour to align with particular social contexts, sharing, making friendships, and/or lack of interest in others.
B. Patterns of restricted and repetitive behaviours, activities and/or interests. Examples include: Repetitive or stereotyped motor movements, speech, or use of objects. 1. Maintenance of rigid routines, sameness, and patterns of behaviour. For example: Exhibiting strong distress due to small changes, challenges with transitions, adherence to routines, or inflexible patterns of thinking and following through with rituals. 2. Very fixated and restricted interests that are atypically intense. For example: Demonstrating a preoccupation or robust attachment with unusual interests or objects. 3. Hypo- or hyper-reactivity to sensory stimuli or exhibiting atypical interest in sensory components in their environment (e.g., seemingly indifference to temperature/pain, bad reaction to particular textures or sounds, visually attracted to movement/lights, and/or excessive touching or smelling objects.
C. Individuals must manifest symptoms in their early developmental time. They may not become apparent until particular social situations and/or can be masked by coping and learned strategies later in life.
D. Symptoms must result in clinically significant impacts across individuals' lives.
E. Symptoms must not be better accounted for by global developmental delay or intellectual disability (ID). Autism spectrum disorder and ID are commonly co-morbid, of which social communication should be lower than the expected typical developmental level.

Note: The information in the table above has been paraphrased. .

present with impairments in social communication in conjunction with stereotyped and/or restricted patterns of behaviour (APA, 2013). The first domain, social communication, can manifest as 1) impairments of social-emotional reciprocity such as absence of back-and-forth interactions during conversation, poor social initiations or responses, less sharing of affect, emotions, or interests; 2) impairments in nonverbal communication behaviours useful for social

interaction such as poor body language and eye contact, and an absence of nonverbal communication and facial expressions; and/or 3) deficits in creating, maintaining, and comprehending relationships such as modifying behaviour to suit particular social situations, difficulties in making friends, and/or disinterest in peers (APA, 2013). The second domain, patterns of restricted and repetitive activities, behaviours, or interests, is manifested by at least two of the subsequent symptoms/characteristics (either historically or currently): 1) Repetitive or stereotyped motor movements, speech (e.g., echolalia), or use of objects (e.g., arranging toys in a straight line); 2) insistence on rigid maintenance of routines, ritualized verbal (e.g., greeting rituals) and/or nonverbal behaviour (e.g., an insistence on eating the same food each day) patterns; 3) very restricted and fixated interests with atypical intensity (e.g., preoccupation with particular objects or perseverative interests); and/or 4) manifestations of hypo- or hyper-reactivity to particular sensory inputs or an abnormal interest in specific sensory stimuli (e.g., seemingly unresponsiveness to temperature or pain; disproportionate touching or smelling of objects (APA, 2013).

The manifestation, severity, and changes associated with ASD symptoms are extremely heterogeneous across affected individuals and over time (Richler, Huerta, Bishop, & Lord, 2010; Volkmar, Lord, Bailey, Schultz, & Klin, 2004). For example, distinct differences are observed across restricted and repetitive behaviours, which can vary from repetitive sensory/motor behaviours (e.g., spinning objects) to more sophisticated restrictive behaviours (e.g., insistence on eating the same food; Leekam, Prior, & Uljarevic, 2011). Similarly, the specific presentation and severity of social skills impairments vary across individuals (APA, 2013; Szatmari, Bryson, Boyle, Streiner, & Duku, 2003; Volkmar et al., 2004).

An ASD diagnosis entails long-term atypical development that affects individuals and their families (Abbott et al., 2013). Functional impairment may appear at different stages of an individual's life, and will differ based on individual characteristics and their environment (APA, 2013). There is variability in intellectual functioning levels across those with ASD, with 29.6% exhibiting average cognitive functioning, 29.3% with mild to moderate cognitive disability, and 38.5% with severe to profound cognitive impairments (median proportions used; Fombonne, 2005; Volkmar et al., 2014). A singular etiological cause has not been uncovered for ASD, and it appears that many genetic and environmental factors account for the emergence of ASD symptomatology (Betancur, 2011; Hall & Kelley, 2014; Happé, Ronald, & Plomin, 2006).

The prevalence of ASD has risen exponentially in recent years (Baio, 2012; Blumberg et al., 2013; CDC, 2014). Upon examining school and health records in Utah, Pinborough-Zimmerman and colleagues (2012) reported a prevalence rate of one in 77. Subsequently, Baio (2012) reported a nationwide prevalence of one in 88, followed by a more recent reported one in 50 (Blumberg et al., 2013). Most recently, the CDC (2014) examined a group of eight year olds across the United States in 2010, and reported a prevalence of one in 68.

In sum, ASD is a neurodevelopmental disorder that is characterized by impairments across social, communicative, behavioural, and sensory domains. Given its heterogeneous manifestation in affected individuals, many researchers and clinicians have focused on formal ASD assessment and diagnostic processes; for example, gaining a greater comprehension of core ASD features to more accurately identify them in affected individuals. Researchers have also attended to the communication process, whereby professionals disclose assessment results to parents in the form of an ASD diagnosis. The next section will provide a thorough description of the ASD diagnostic process from initial parental concerns to diagnosis disclosure and will review

associated satisfaction levels and impacts. Such a discussion will provide a foundation for the current investigation, a topic which until now has received little empirical attention.

ASD Diagnostic Process

The ASD diagnostic process typically commences when parents and/or individuals associated with the child (e.g., teachers or daycare/nursery staff) notice behavioural and/or developmental atypicalities in the child (Braiden et al., 2010; Hutton & Carron, 2008; Mansell & Morris, 2004; Midence & O'Neill, 1999; Osborne & Reed, 2008). Children with suspected ASD may demonstrate delays, display oddities, or lack skills in imitation, interest in others, empathy, language, communication, speech, social skills, sharing focus and attention with others, and/or orienting towards key stimuli in addition to stereotypical movements, restricted interests, and unwillingness to change (Dawson, Meltzoff, Osterling, Rinaldi, & Brown, 1998; Finnegan et al., 2014; Howlin & Moore, 1997; Osterling & Dawson, 1994; Stefanatos & Baron, 2011; Volkmar et al., 2014). Parents often seek professional advice concerning this atypical behaviour (Howlin & Moore, 1997; Midence & O'Neill, 1999; Siklos & Kerns, 2007).

A comprehensive evaluation is recommended when assessing the multiple and complex features of ASD to acquire a true sense of the child's capabilities and behaviour compared to both age-typical and ipsative levels (i.e., comparisons between the child's current and past developmental levels; Campbell et al., 2014). In alignment with this perspective, Volkmar and colleagues (2014) published best practice standards for completing ASD diagnostic assessments. Specifically, Volkmar et al. (2014) have recommended that ASD diagnostic assessments should include questions about ASD symptomology, include comprehensive diagnostic assessments when ASD symptoms are flagged during screening assessments, and coordinate and utilize multidisciplinary approaches (e.g., medical, psychological, communication, occupational, and

physical therapy assessments). A multidisciplinary approach facilitates communication between clinicians, which in turn may provide a more accurate portrayal of the child (Klin et al., 2005). Furthermore, the DSM-5 should be consulted when determining whether children meet ASD symptom threshold levels and/or whether other diagnoses can be ruled out (e.g., language disorders; APA, 2013; Volkmar et al., 2014). Subsequently, clinicians generally communicate the assessment results with parents and discuss treatment recommendations.

Many parents notice behavioural abnormalities prior to seeking a diagnostic assessment (Mansell & Morris, 2004; Midence & O'Neill, 1999), and sometimes as young as 12 to 18 months of age (Al-Qabandi et al., 2011). The earlier a diagnosis is made, the better, as children can then access early intervention opportunities that may in turn enhance their functioning, skills, and capabilities (Dawson, 2008). The diagnostic stability of earlier diagnoses seems robust, and Turner, Stone, Pozdol, and Coonrod (2006) reported that 88% of children in their study who received an ASD diagnosis at age two retained their diagnosis at age nine. However, an ASD diagnosis is not typically provided until somewhat later in development. Recently, Daniels and Mandell (2014) reported that the average age of diagnosis ranged from 38 to 120 months and that age at diagnosis is decreasing, hence recent diagnoses are being made earlier in development (Daniels & Mandell, 2014). Researchers investigated the age at diagnosis in four specific Canadian regions between 1997 and 2005 (Ouellette-Kuntz et al., 2009). The youngest median age at diagnosis was made in Newfoundland and Labrador (39 months), followed by Prince Edward Island (47.5 months), Manitoba (48 months), and Southeastern Ontario (55 months). Valicenti-McDermott, Hottinger, Seijo, and Shulman (2012) examined age of diagnosis in a sample of children in the city of New York, USA and reported a mean age of 38 months. Children who were born outside of the USA and born to foreign born mothers were referred for

assessment later, while children with language concerns, atypical mannerisms, or relatives of those with ASD were referred for assessment earlier (Valicenti-McDermott et al., 2012).

In brief, the DSM-5 (APA, 2013) characterizes ASD as a neurodevelopmental disorder with a distinct categorization of behavioural symptomatology and a steady increase in prevalence over the past decade. Researchers have devoted significant attention to the diagnostic process to enhance the quality of ASD assessment (e.g., Klin et al., 2005; Volkmar et al., 2014). Considerable research and clinical efforts have focused on the ASD diagnostic process. Given the complex nature of ASD, the diagnostic process is best conducted through the use of multidisciplinary teams of highly trained professionals who assess for specific atypical patterns of behaviour (Klin et al., 2005; Volkmar et al., 2014).

In addition to the diagnostic process, the topic of diagnosis disclosure from professionals to parents has also been thoroughly explored. This topic will be reviewed to provide context for the purpose of the present study.

ASD Diagnostic Disclosure to Parents

The diagnostic disclosure process is a critical period in a family's life as they are presented with the potentially life-altering news that their child has ASD. Hence, researchers and clinicians have investigated how the results of an ASD assessment are disclosed to parents. Parental responses to the diagnostic process can range from relief to sadness, anger, anxiety, guilt, despair, grief, helplessness, confusion, surprise, shock, self-blame, denial, difficulty in accepting the child's differences, and distress (Abbott et al., 2013; Chamak et al., 2011; Chiu et al., 2014; Finnegan et al., 2014; Hutton & Carron, 2008; Mansell & Morris, 2004; Nissenbaum et al., 2002). Further, Reed and Osborne's (2012) review of diagnostic disclosure impacts on

parent health and child behaviour indicates that parental (dis)satisfaction associated with the diagnostic process varies across studies and is dependent upon a variety of factors.

Parents who reported greater satisfaction with the ASD diagnostic disclosure process were also positive about professionals who valued early parental suspicions pertaining to potential ASD diagnoses, received quality of information from the diagnosing professional/team, and written information about the diagnosis, being afforded "the opportunity to ask questions". (Brogan & Knussen, 2003, p.42). Parents were more also satisfied and less stressed when there was a stronger collaboration between parents and professionals and when parents were provided with sufficient information about early intervention programs (Moh & Magiati, 2012). Another study found that greater parental satisfaction was associated with children who were diagnosed with ASD at younger ages and when parents saw fewer clinicians (Goin-Kochel et al, 2006). Additionally, professional attitude, timing (most mothers preferred that diagnosis disclosure take place after an ASD diagnosis had been confirmed), and length of the meeting (longer length considered better) positively impacted maternal satisfaction (Chiu et al., 2014). Furthermore, parents were more accepting of the diagnosis when it was "repeated, clarified, and explained" in a straightforward way and when resource information was provided (Chamak et al., 2011, p.95). All ten parent dyads in Abbott et al.'s (2013) study were satisfied with the feedback session length (approximately an hour), while clinician positivity about the child and the caregiver's parenting seemed to impact general parental satisfaction. Also, some parents appreciated structured sessions, but also having opportunities to pose questions (Abbott et al., 2013).

Conversely, many parents indicated dissatisfaction with the lack of ASD information and/or support provided by professionals. Over half of the parents in one study were dissatisfied with the diagnostic process, and 80% of parents reported that receiving an ASD diagnosis was

stressful (Siklos & Kerns, 2007). Some parents reported that their child with ASD was misdiagnosed (e.g., as having hearing impairments, Fragile X syndrome, or predicting that the child would become visually impaired; Midence & O'Neill, 1999). A French study found that 93% of parents sampled were dissatisfied with how the diagnosis was disclosed to them, which was reportedly due to a blunt and insensitive professional approach, professional exacerbation of parental guilt, and delays in receiving an ASD diagnosis (Chamak et al., 2011). Similarly, Finnegan and colleagues (2014) suggested that some professionals reportedly lacked empathy during the diagnostic process. Some parents found the diagnostic process challenging to comprehend, found it hard to listen to verbal information about the diagnosis, and were concerned that they may have missed out on some information (Braiden et al., 2010). Parents in Braiden et al.'s (2010) study were generally satisfied with the information they received; however, they later relied on relatives, friends, and the internet to obtain and comprehend information. Additionally, six out of 11 parents reported dissatisfaction with diagnosis disclosure and provision of subsequent support, with three parents indicating that they had received no support upon being given the diagnosis, and had also not "been made aware of any services available to them" (Braiden et al., 2010, p.385). Another study revealed that most mothers were dissatisfied with the length of the feedback counselling session (i.e., too short; 71.5%); the timing of the diagnosis disclosure (77.9%); and that they received insufficient information about government/medical support and educational services (71.7%; Chiu et al., 2014). Subsequently, Chiu and colleagues (2014) concluded that parents would prefer to receive more information pertaining to resources, parenting, and intervention. In sum, inadequate provision of information and support, overly short session lengths, and poor interpersonal skills of professionals are associated with dissatisfaction with the diagnosis disclosure process.

Overall, parents report multiple factors associated with satisfactory and unsatisfactory diagnostic disclosure. Particularly, parents appear to appreciate additional information that educates them about ASD and directs them towards resources, services, and treatment, chances to ask questions, and when the clinicians exude positivity about their family. A lack of such information and poor interpersonal skills on the part of the clinician can result in a negative impression of the disclosure process. However, although the research describes parental experiences with receiving an ASD diagnosis for their child, the impact of learning of a child's diagnosis lasts longer than the actual feedback session itself and can influence parental behaviour and attitudes towards the diagnosis and their child (Abbott et al., 2013). A discussion of the impact of learning of their child's ASD diagnosis will provide additional context for the current research project.

Parental Impact upon Learning of Their Child's Diagnosis

For parents, receiving a diagnosis can be a highly emotionally charged time (Nissenbaum et al., 2002). Research findings have indicated that there are positive and negative impacts associated with receiving a child's ASD diagnosis. Indeed, Avdi and colleagues (2000) reported that an ASD diagnosis assisted parents in understanding their child, and "was represented as both a relief and terribly distressing" (p. 251).

Learning about a child's ASD diagnosis may be very positive and illuminating for parents. Some reported feeling relief when learning of the diagnosis as it provided an explanation for their child's challenges (Abbott et al., 2013). Several studies reported that an ASD diagnosis allowed parents to communicate and explain their child's challenges to others (Avdi et al., 2000; Calzada et al., 2012; Nissenbaum et al., 2002). In turn, this facilitated less blame and negativity about the child in Calzada and colleagues' (2012) study. Some parents

reported feeling very proud of their child despite the diagnosis (Nissenbaum et al., 2002) while others reported feeling relief upon receiving a diagnosis (Avdi et al., 2000; Finnegan et al., 2014; Mansell & Morris, 2004; Midence & O'Neill, 1999; Nissenbaum et al., 2002) as well as a greater comprehension and "acceptance of their child's behaviour" which subsequently aided them in adapting to their new family life, and facilitated access to assistance (Mansell & Morris, 2004, p.400). Receiving the diagnosis has aided parents in dealing with blame, guilt, and providing a label for their child's behaviour in addition to what parents can do to treat it (Midence & O'Neill, 1999). Overall, receiving an ASD diagnosis can be a positive event for parents as it answers questions and helps to explain child behaviours.

Conversely, research efforts have identified that many parents report experiencing adverse impacts from receiving an ASD diagnosis for their child. Some parents report experiencing negative emotions (e.g., surprise, helplessness, crying, devastation, disbelief, anger, or feeling sorry for their child; Nissenbaum et al., 2002). Other parents have reported the need to seek additional information about the diagnosis and the disorder, and even question the diagnosing professional's capability (Nissenbaum et al., 2002). Some parents were distracted from the session's content due to the disclosure's emotional impact (Abbott et al., 2013). Also, some parents worried about the child's future, struggled to comprehend which problematic behaviours demonstrated by their child were/were not due to ASD, and believed that others misunderstood their child's diagnosis (Mansell & Morris, 2004). Also, over time, parents were concerned about how to explain the child's diagnosis to their child (Mansell & Morris, 2004). Furthermore, many parents reported a grieving process whereby they mourned the loss of the child that they expected to have (Finnegan et al., 2014; Hutton & Caron, 2008; Mansell &

Morris, 2004; Nissenbaum et al., 2002). Distressingly, some parents described ASD as a "lifelong sentence" or "death sentence" (Nissenbaum et al., 2002, p.33).

Overall, it appears that parents experience a mixture of feelings, reactions, and experiences upon learning of their child's ASD diagnosis. Notably, parents report varying levels of satisfaction depending on the quality of information provided pertaining to ASD, resources, and services, in addition to clinician approach (e.g., Abbott et al., 2013; Brogan & Knussen, 2003). Furthermore, researchers have signified the multitude of positive (e.g., relief, explanatory) and negative (distressing) parental impacts of receiving a child's ASD diagnosis (e.g., Avdi et al., 2000). Undoubtedly, these studies have been fundamental for understanding the parental perspective of diagnosis disclosure, in addition to enhancing approaches for future clinician-parent disclosures. In turning towards the perspectives of those with ASD, the next section will examine individuals' experience of learning about their ASD diagnosis. This focus will assist in enhancing the framework for the current study. Notably, literature in the next section does not signify whether individuals learned of their diagnosis from their parents.

Experience of Learning of One's ASD Diagnosis

ASD diagnosis disclosure can lead to both positive and negative impacts on affected individuals' lives. As regards positive impacts, some individuals with ASD have reported that learning of their diagnosis served to clarify reasons for prior life experiences, legitimized behaviour differences, and provided them with access to support (Calzada et al., 2012; Huws & Jones, 2008; Punshon et al., 2009). Furthermore, 46.9% of participants in a recent study reported satisfaction with the diagnostic process and most participants felt relief (71.9%), were pleased (22.7%), and 29.2% were satisfied upon learning of their diagnosis (Jones, Goddard, Hill, Henry & Crane, 2014).

Additionally, research suggests that some individuals with ASD appeared to be aware that they had challenges despite being unaware of their ASD diagnosis. Specifically, numerous individuals seemed to internalize what other people said about them (e.g., "just odd" and "too lazy") without having an ASD framework with which to align their challenges (Punshon et al., 2009, p.276). Additionally, delays in diagnoses and misdiagnoses resulted in some individuals feeling blamed for their challenges (e.g., by professionals; Punshon et al., 2009). Three adults with ASD shared their life experiences in Hurlbutt and Chalmers' (2002) investigative study. Of note, one 61 year old participant who was diagnosed later in life (at 56 years of age) wished that he had access to more information about ASD as he "never knew what was wrong" (Hurlbutt & Chalmers, 2002, p.105). Hence, despite not knowing about their diagnosis, some individuals seemed aware that they had difficulties.

For some, learning of their diagnosis was detrimental as an ASD label was perceived to be stigmatizing, discriminative, and/or prejudicial (e.g., derogatory name-calling; fears that typical individuals would make prejudgements about those with ASD; Huws & Jones, 2008). Upon having an ASD diagnosis disclosed to them, some individuals felt "shock, disappointment, and disbelief" (Huws & Jones, 2008, p.104). Notably, the disclosure to some of these individuals was quite delayed (i.e., took place when they were older; Huws & Jones, 2008). Two of the nine participants in Huws and Jones' (2008) study seemed averse to having ASD (as thinking about his challenges put one participant "down too much" [i.e., made him feel bad]; p.104); and they avoided their diagnosis by steering clear of television shows or books about ASD. Similarly, some children and adolescents with ASD avoided information about their disorder, did not want others to know about their diagnosis, and did not identify benefits associated with their ASD (Calzada et al., 2012). In Jones and colleagues' (2014) study,

individuals with ASD reported feeling anxious (25%), upset (17.2%), angry (12.5%), and/or confused (24.2%) upon learning of their diagnosis, with 39.9% of participants reporting dissatisfaction with the diagnostic process (Jones et al., 2014).

In sum, the literature reviewed above highlights the distinct heterogeneity of experiences and impacts amongst individuals with ASD when learning of their diagnosis. Again, such heterogeneity speaks to the diverse nature, characteristics, and experiences of individuals with ASD, their families, and their support networks. Although the latter information provides a valued insight into individual experiences and impacts upon learning of their diagnosis and living with ASD, it does not address the particular parent-reported impacts of parental diagnostic disclosure to their children on the spectrum, which is the focus of the current study. A brief review of specific literature on this topic will emphasize some relevant and important findings as well as gaps in our knowledge pertaining to ASD.

Diagnostic Disclosure from Parents to Children

To date, researchers have focused on parental experiences with the diagnostic process for ASD, their satisfaction with the diagnostic process, and their perceived impacts of receiving the diagnosis for their child. Current clinical practice and research signifies that the diagnostic process generally concludes with professional disclosure of ASD diagnostic assessment results to the parent(s) of a child with ASD. However, the process of communicating an ASD diagnosis to the affected child has received very little empirical attention.

Attwood (2007) has recommended telling individuals about their ASD diagnosis, and specifies that they may be relieved to ascertain that they are not "weird" (p.330) insofar as their unique behavioural features are accounted for by ASD. Additionally, Attwood (2007) has recommended that the process of disclosure be age-appropriate and explain individual

differences (e.g., strengths and difficulties). A sole article by Finnegan et al. (2014) has reported on parental perceptions of lived experiences and impacts of seven Irish parents who had learned about and were adapting to their child's ASD diagnosis, and the process of disclosing the ASD diagnosis to their children (some parents had not yet disclosed). Parents reportedly sought to protect their child's self-image (i.e., to avoid having their child develop a negative self-view), waited to disclose the diagnosis until their children had developed a greater awareness of their ASD, communicated positive messages to their child, were scared that they would depict the ASD diagnosis in a manner that would define the child, and did not want to overwhelm them (Finnegan et al., 2014). It was concluded that parents' protective style in communicating their child's ASD diagnosis may have hampered children gaining a complete awareness of their diagnosis (Finnegan et al., 2014). As Finnegan and colleagues' work is the only investigation on this topic, the related area of parental disclosure of non-ASD diagnoses will be reviewed.

Parental disclosure of non-ASD diagnoses. An extensive literature search (e.g., through Google Scholar and PsycInfo) and review yielded only two published articles on the topic of parental disclosure of non-ASD psychological diagnoses to their children. Todd and Shearn (1997) reported on parental disclosure of a learning disability (LD; although the authors refer to individuals with intellectual disabilities) to their adult children and indicated that parents tended to avoid discussing the child's disability to protect the child from potentially strong and negative impacts on their sense of self. In an examination of Latino parental perspectives of Attention-Deficit/Hyperactivity Disorder (ADHD), some parents reported that talking with their child about ADHD was worrisome while others spoke with their children in simple terms (e.g., their brain works differently and does better when they take their medication) to alleviate child concerns and fears about ADHD-related stigma (Perry, Hatton, & Kendall, 2005).

Given the relative scarcity of parental disclosure of non-ASD psychological disorders, a discussion of parental disclosure of medical disorders may highlight important information relevant to the current research project. In this regard, it should be noted that the differences between ASD and medical conditions such as HIV or pediatric cancer are obvious and acknowledged; however, some insight into topics relevant for the current project may be gained from these research studies.

Parental diagnostic disclosure to children with pediatric cancer. Considerable research has been conducted on the process and impacts of parents informing their child about their child's pediatric cancer diagnosis. Clarke and colleagues (2005) found that parents who thought that the diagnosis was terminal were more likely to avoid informing their child and instead provided minimal information. Furthermore, parents who were shocked or upset by the diagnosis tended to inform their child with the information that the parents themselves had. However, other parents could not share information with their child until they themselves had dealt with the shock of diagnosis (Chesler et al., 1986). A sample of South African parents of children with cancer avoided using the word 'cancer' as they believed that the child would be too young to comprehend its meaning and were also fearful of the potential negative impacts of informing their child about the risk of death associated with cancer (i.e., "that the word cancer had the potential to 'startle' their children"; Jithoo, 2010, p.355). Notably, many parents opted for terms such as 'bad blood', 'growth', 'leukaemia' and 'tumour' instead of 'cancer' (Jithoo, 2010; Young et al., 2002). Chesler and colleagues (1986) found that age was a significant factor when deciding to inform a child of their diagnosis (i.e., younger children were less informed about their illness than older children). Similarly, Claflin and Barbarin (1991) concluded that many parents choose to not disclose the nature of the medical condition to younger children due

to their beliefs that children may not be able to comprehend their illness or that parents may not be able to disclose the diagnosis in ways that would facilitate child comprehension. Furthermore, in the long term, limited disclosure did not spare younger children from distress when compared to informed older children/adolescents i.e., that they experienced similar levels of distress whether they were informed or not (Claflin & Barbarin, 1991).

Conversely, Last and van Veldhuizen (1996) concluded that open parental sharing of diagnostic and prognostic information is advantageous for a child's emotional wellbeing. In particular, parental diagnosis disclosure during an early stage of the child's illness coincided with fewer anxious and depressive symptoms, as opposed to children who were told less information during a later stage of their illness (Last & van Veldhuizen, 1996). Within a sample of 42 participants, Clarke and colleagues (2005) reported that seven younger children (mean age of 6.45 years) showed positive behavioural changes upon being fully informed of their diagnosis by parents (i.e., that they had leukaemia or cancer). However, 16 younger children (mean age of 5.05) who were minimally informed of their diagnosis and 19 older children (mean age of 9.49) who were fully informed of their diagnosis showed negative behavioural changes (Clarke et al., 2005). It has been concluded that children's capability to understand information about their condition may be associated with maturity and competence as opposed to chronological age alone (British Medical Association, 2001; Clarke et al., 2005). Also, Clarke et al. (2005) suggested that children who are provided with more information concerning their cancer diagnosis may cope better as they can trust medical professionals and their family, comprehend the significance of medication, and are more free to talk with parents about concerns and worries. Most children in Last and van Veldhuizen's (1996) study preferred to know about their illness. Parents in the aforementioned study completed a structured interview, while their

children completed scales, questionnaires, and had their medical information reviewed by the researchers (Last & van Veldhuizen, 1996). Moreover, children who reported greater access to sources of information reported less negative self-esteem, anxiety, and depression whereas the opposite was observed for children who reported experiencing barriers to information (Last & van Veldhuizen, 1996). Last and van Veldhuizen (1996) recommended that parents inform children of their cancer diagnosis and potential implications "as soon as possible" (p.294) as many children learn about their illness from volunteers, peers, patients, and nurses (Jithoo, 2010; Last & van Veldhuizen, 1996). Also, parents reported finding it difficult to control discussions about their child's illness outside of the hospital environment (e.g., teachers informing the child's class about the child's diagnosis in front of the child; fears that siblings may inform the child with cancer about their diagnosis; Chesler et al., 1986). Therefore, parental disclosure to children about their diagnosis may ensure that children receive accurate information about their illness in addition to instilling a sense of hope about recovery (Last & van Veldhuizen, 1996).

Parental diagnosis disclosure to children with cancer may not be a static event. For example, some mothers reported the need to provide continuing information to their child after the initial disclosure, such as addressing the child's illness-related anxieties (Young et al., 2002). Parents may also need to instigate additional and open discussions by providing new information about the condition's treatment or prognosis, during normal interactions between the child and family after the initial shock of diagnosis has subsided, and during unpredictable social occasions that may require further disclosure decisions (Chesler et al., 1986).

In sum, although parents may avoid diagnosis disclosure due to potential negative impacts and fearing that children may be too young to comprehend, most research signifies that it is better to discuss a child's cancer diagnosis with them.

Parental diagnostic disclosure to children with perinatal HIV. An abundance of research has investigated the impacts (both expected and occurring) of parental diagnostic disclosure to children with perinatal HIV. Specifically, some caregivers expressed fear that diagnostic disclosure would lead to adverse psychological effects for their child (e.g., thinking a lot and/or being upset; Vreeman et al., 2010; Waugh, 2003). Parents and/or caregivers also worried that disclosure would lead to parents being asked challenging questions, children not being developmentally prepared to comprehend the ramification of their diagnosis, children being upset about death or worrying that their mother might die, children hating their mothers for passing on their HIV status to their children, and/or informing others of their HIV status (Vreeman et al., 2010; Waugh, 2003). Hence, parents believed that diagnosis disclosure should take place before their children became self-aware of their diagnosis, when their children were mature enough to understand their illness, cope, and not tell others (Waugh, 2003). However, Butler and colleagues' (2009) study reported that diagnosis disclosure did not impact quality of life scores in children, adolescents and young adults with HIV, and that disclosure should not be delayed due to fears of adversarial impacts on children and adolescents' quality of life.

Despite these fears and worries associated with parental disclosure of a child's HIV diagnosis to the child, the literature also highlights perceived positive impacts of parental diagnostic disclosure of perinatal HIV. Vreeman and colleagues (2010) conducted a study in Kenya whereby they examined the perceived impact of disclosing a child's HIV infection on the child's social relationships, treatment adherence, and wellbeing. Although most parents and/or caregivers had not disclosed the child's HIV status to their child, parents and/or caregivers reported potential benefits and risks related to disclosure (Vreeman et al., 2010). Benefits included a greater adherence and responsibility towards taking antiretroviral medication; further

children may ask why they were taking medication and not adhere to medication regimes if unaware of their diagnosis (Vreeman et al., 2010). However, some caregivers feared that disclosure to others would result in stigmatization, isolation, and discouragement from treatment adherence (Vreeman et al., 2010). Notably, Bachanas et al. (2001) reported that children who were not told of their HIV status demonstrated more psychological maladjustment and internalizing behaviour problems.

In a brief report of HIV disclosure practice studies, Domek (2010) stressed that children feel the "psychosocial stress" (p.441) of illness whether diagnoses were disclosed to them or not. Further, it was asserted that self-esteem, treatment adherence, behaviour challenges, bereavement, and fears about death and illness cannot be sufficiently attended to without diagnosis disclosure (Domek, 2010).

Summary of parental disclosure of diagnoses to children. In sum, the literature appears to indicate that parents consider many factors (e.g., worries, benefits, and hopes) when deciding whether and when to disclose their child's psychological or medical diagnosis to them. For the most part, the literature indicates that children fare quite well upon learning of their disorder. Although there are striking differences between ASD, HIV (e.g., concerns over transmitting HIV to others), and pediatric cancer (e.g., treatment and prognoses), the medical literature discussed above indirectly signifies the importance of gaining a greater insight into ASD disclosures as it suggests that parental diagnosis disclosure may be positive for an individual's wellbeing (e.g., Domek, 2010; Last & van Veldhuizen, 1996; Vreeman et al., 2010). However, it is critical to more fully explore the potentially unique impacts of parental diagnosis disclosure to individuals with ASD.

Summary

ASD is a complex and multifaceted disorder with affected individuals exhibiting a wide range of unique behavioural symptomatology (APA, 2013). Parents have reported positive and negative experiences when receiving information about their child's ASD diagnosis. Further, individuals with ASD cope with learning of/living with their disorder idiosyncratically. At present, there is a body of research examining the parental impacts of receiving their child's diagnosis, individuals with ASD learning of their diagnosis, and individuals' self-perceptions of having ASD. However, there is a distinct gap in the literature examining the impacts of parents communicating their child's ASD diagnosis to their child. To date, there have been two studies on this topic that indicate that some parents avoided talking about the diagnosis with their child as they sought to shelter the child's self-image or have them feel normal (Calzada et al., 2012; Finnegan et al., 2014). However, the Calzada article did not examine the impact(s) of parents telling their children about their ASD diagnosis. Moreover, Finnegan and colleagues' study is limited by its restricted and small sample size of Irish parents which may not be representative of Canadian cultural differences and parenting approaches. Humphrey and Lewis (2008) reported one affected individual's immediate reaction/impact upon learning of his diagnosis from his mother (i.e., that he "remembered thinking, 'Oh my God I'm a freak!'"; p.31). However, they examined the individual views and experiences associated with having ASD, not explicitly parental-diagnosis disclosure impacts. As such, there is a genuine need to uncover the impacts (both positive and negative) of Canadian parents informing a child of their diagnosis.

The Present Study

The current study investigated parental perceptions of the impact of disclosing their child's ASD diagnosis to their child. The study endeavoured to address the above indicated knowledge gap and provide much-needed insight on this topic. It is anticipated that parents will

benefit from disseminated findings by learning about disclosure impacts and advising them on how best to disclose an ASD diagnosis to their child.

Research Questions

The following research questions formed the basis for conducting the current study:

1. What are the parent perceived impacts of ASD diagnosis disclosure?
    a. What, if any, are the reported positive impacts associated with parental ASD diagnosis disclosure?
    b. What, if any, are the reported negative impacts associated with parental ASD diagnosis disclosure?

Chapter Three: Methodology

Chapter three will identify, outline, describe, and provide a rationale for the chosen methodology. The research design section will describe the reasoning for the chosen epistemology, current research paradigm, and in turn, highlight potential researcher biases. Second, the chosen methodology, thematic analysis, will be outlined, rationalized, and compared with competing methodologies. Finally, the methods section will include a discussion of the current study's participants, recruitment approach, research procedure, data collection and analysis method.

Research Design

This section endeavours to explain and rationalize the study's design with view to answering the specific research questions in a valid and reliable way. The study's epistemological stance will be outlined, evaluated, rationalized, and compared with competing epistemologies. Subsequently, the research paradigm subsection will evaluate and rationalize the adoption of a qualitative as opposed to a quantitative approach. Finally, researcher biases will be identified and discussed.

Epistemology. Epistemology can be defined as "the study of the nature of knowledge and justification" (Schwandt, 2001, p. 71) and "theory of knowledge" (Carter & Little, 2007, p.1317). The researcher adopted a realist epistemology, whereby data were considered and reported in a way that aimed "to capture and reflect as truthfully as possible something that is happening in the real world" and happens "independently of the researcher's, and indeed the research participants' views or knowledge about it" (Willig, 2012, p.11). Specifically, the realist perspective assumes that psychological or social patterns/processes impact individuals' thinking or behaviour and can in turn be discovered and reported by the researcher (Madill, Jordan, &

Shirley, 2000; Willig, 2012). The researcher was in favour of working via a realist epistemology as she believed that it would yield valid and somewhat realistic information about participants' and their children's unique experiences (i.e., reported impacts). Furthermore, in line with Braun and Clarke (2006), the researcher adopted a semantic approach to data analysis whereby the participants' statements were grouped into themes (rather than undertaking an interpretive process of attempting to determine what each participant 'meant' by their statements; please refer to page 33 for a further explanation). Hence, participant reports were accepted at face-value and determined to reflect their reality. A 'naive realist' (although Willig suggests that this should be termed 'direct realist') belief system aligned with the current study, whereby the data is assumed to reflect reality, albeit subjective to each participant (Willig, 2012). The semantic approach to data analysis aligns within a realist approach, and less within phenomenological or social constructionist epistemologies.

A phenomenological epistemology was not chosen due to its focus on participant subjective experiences as opposed to patterns within social processes (e.g., ASD diagnosis disclosure impacts; Willig, 2012). Further, a phenomenological approach values the participant's experience (and is unconcerned whether it is accurate or not; Willig, 2012). Finally, a social constructionism epistemology was not selected it did not align with the research approach (Willig, 2012). Social constructionists believe that concepts can be created and still represent objective realities, as opposed to be being discovered (Andrews, 2012). Further, social constructionism "is concerned with how knowledge is constructed and understood" (Andrews, 2012, p.44). Further, it focuses on making sense of phenomena as opposed to measuring phenomena via the scientific method (Andrews, 2012; Steedman, 2000). However, this approach is not without its criticism. Notably, it has been accused of being against realism in the sense

that social constructionism denies that knowledge is a product of directly perceiving reality (Andrews, 2012; Craib, 1997). Particularly, the current study sought to interpret parent reported impacts on a semantic level, and not socially create participant perspectives.

In sum, a realist epistemology was selected as it was deemed to portray parent-reported child ASD diagnosis disclosure impacts in a relatively realistic, participant-specific, and non-socially constructed manner. Furthermore, although it is believed that the interviewer may have impacted the manner in which patterns emerged (i.e., due to a semi-structured interview format), the current study sought to interpret data as being generated by participants.

Research paradigm. The current study utilized a qualitative design to adequately capture the personal, rich, situational, contextual, and unpredictable nature of participants' perspectives, views, and experiences (i.e., parent reported diagnosis disclosure impacts; Johnson & Christensen, 2014; Yin, 2011). A quantitative approach may have conflicted with the current design as it views human behaviour as predictable and objective (Johnson & Christensen, 2014). Second, given the distinct paucity of empirical studies in the current research area, a qualitative approach facilitated exploratory, inductive (data-driven) and deductive approaches (theory-driven; i.e., applying findings from non-ASD diagnosis disclosure studies and individual experiences associated with receiving an ASD diagnosis; Johnson & Christensen, 2014). However, a quantitative approach typically only gives rise to theoretical and quantitative approaches, which would be unsuitable with regards to answering the current research questions (Johnson & Christensen, 2014). Moreover, a quantitative focus on generating predictions and causal relationships would misalign with the current design (Johnson & Christensen, 2014). Third, participants in the current study may report and experience markedly different diagnosis disclosure impacts depending on family dynamics, contexts, and situations; hence, a subjective

(qualitative) ontology (i.e., truth) was deemed more applicable to answering the research questions than an objective (quantitative) approach (Johnson & Christensen, 2014). Additionally, given the idiosyncratic nature of ASD and sample selection criteria, it is acknowledged that study results may not be generalizable to all families of children with ASD. Fourth, quantitative research typically focuses on predefined and controlled variables and statistical relations, and therefore would not have adequately captured the rich and broad nature of data desired in the current study (e.g., categories, parental accounts of successes, difficulties, and interpretations of diagnosis disclosure impacts; Johnson & Christensen, 2014; Yin, 2011). Fifth, a qualitative design was more suited to the interpretive nature of inductive data within the current study. Specifically, data were primarily analyzed and interpreted by the current researcher. Subsequently, a research team member conducted reliability checks (please refer to page 40). Data interpretation was then evaluated by two faculty members. Notably, participants were uninvolved in analyzing or interpreting data.

Researcher biases. The researcher is aware that her personal beliefs and chosen epistemological approach may have impacted the nature and approach of data collection and subsequent interpretation. Specifically, while reading literature prior to commencing data collection, she developed the view that diagnosis disclosure may have positive impacts. However, while constructing her research questions, she sought to examine both positive and negative impacts associated with parental diagnosis disclosure so as to not bias participants' responses to these research questions. Also, she did not hold presumptions about what type of specific impacts (whether positive or negative) may be reported in the data. While coding the data, she took an inductive approach, and included codes that constituted potential diagnosis disclosure impacts. Further, when reporting the data, she aimed to describe and analyze both

positive and negative impacts. Also, the interviewer's (a research team member) personal biases may have impacted the manner in which the interviews were conducted. However, as she conducted all interviews, there was consistency across participants. Reliability checks on the derived themes were conducted to determine the reliability of codes and themes to further reduce the influence of potential personal biases. Specifically, the results and associated justifications were sent to and corroborated by two faculty professors and a research team member.

Methodology: Thematic Analysis

Thematic analysis (TA), as described by Braun and Clarke (2006), was chosen as the most suitable methodology with which to analyze and report findings. In order to determine methodology suitability, TA was compared with two other similar yet distinct methodologies, grounded theory (GT) and interpretative phenomenological analysis (IPA). Developed by Glaser and Strauss (1967), GT is somewhat similar to TA as it consists of an iterative and inductive form of analysis whereby concepts and categories are derived from text and in turn developed into theoretical models (Corbin & Strauss, 2008; Glaser & Strauss, 1967; Guest, MacQueen, & Namey, 2011). Further, GT requires concurrent collection and analysis of data and is conducted in a similar multistep process as TA (Cho & Lee, 2014; Glaser & Strauss, 1967). GT can consist of the following steps: Reading transcripts; noticing possible themes; comparing/contrasting themes and identifying related structures; and creating theoretical models (Bernard & Ryan, 1998; Guest et al., 2011). Strengths of GT are its meticulous analytical process and data supported interpretations (Guest et al., 2011). However, it is limited in the fact that GT is very time consuming and does not use quantification (i.e., it is non-mathematical and does not quantify findings; Guest et al., 2011). Due to the latter two limitations, GT was deemed unsuitable to use in the current study.

IPA was also evaluated as a potential methodology for the current study. IPA serves to investigate how individuals "make sense of their experiences" and the meaning that they attribute to particular occurrences and experiences (Chapman & Smith, 2002, p.126). Further, IPA endorses the view that the interviewer's own perceptions assist in making sense of what they are studying, and in turn, interpreting participant experiences (Chapman & Smith, 2002). The following strengths are associated with IPA: its suitability for smaller data sets, and its ability to facilitate exploration and interpretation of more than the text (Guest et al., 2011). IPA is also marked by limitations, notably its lack of a systematic approach, its focus on human experiences only (as opposed to perceptions, beliefs, etc), and propensity to encourage over-interpretation of the data that may give rise to erroneous interpretations (Guest et al., 2011). IPA was deemed unsuitable as its focus on human experience is inappropriate for the current study, insofar as the focus of the current project is on parental accounts of child impacts and does not examine actual experiences of the children with ASD.

Thematic analysis. Thematic analysis (TA) is defined as "a method[ology] for identifying, analysing, and reporting patterns (themes) within the data" (Braun & Clarke, 2006, p.79). This chosen methodology facilitated the identification and thorough analysis of parental accounts in an open, contextual, and non-restrictive manner (i.e., parents were not required to choose from a list of pre-determined response options; Yin, 2011). TA was deemed most suitable to adequately address the current research questions. Further, TA was believed to align well within a realist epistemology and qualitative paradigm due to the semantic nature of data analysis and interpretation (Braun & Clarke, 2006). TA allows for the use of inductive (data-driven) or deductive (theory-driven) approaches when examining data to identify, check, and/or modify codes in the data (Braun & Clarke, 2006; Fereday & Muir-Cochrane, 2006). It is

conducted by rigorously coding transcriptions to generate meaning and patterns from the data (Braun & Clarke, 2006). A code can be defined as "a label attached to a section of text to index it as relating to a theme or an issue in the data" that the researcher highlights as worthy of their interpretation (King, 2004, p.257). Thus, themes represent meaning and patterns within the data and can be examined in relation to research questions (Braun & Clarke, 2006). Several codes can exist under one theme (Braun & Clarke, 2006; King, 2004). Further, Braun and Clarke (2006) posit that data extracts can be coded "in as many different 'themes' as they fit into" (p.89), therefore suggesting that the same code can be used across themes. Themes can be identified via a semantic or latent lens (Braun & Clarke, 2006). The semantic approach focuses on deriving themes from the "explicit and surface meanings" of the data (Braun & Clarke, 2006, p.84). The latent approach strives to interpret data beyond the explicit meaning in order to determine "underlying" concepts and assumptions (Braun & Clarke, 2006, p.84). The current data will be analyzed using the semantic method.

Advantages of TA include its flexibility as a methodology, easiness to learn, accessibility to novice qualitative researchers, useful summarization of key features of large datasets, and capability to highlight similarities and differences within the data (Braun & Clarke, 2006). Indeed, TA is a methodology that facilitates solid structure (e.g., through analytical steps) while also being quite flexible (e.g., analyzing research questions while also examining unexpected patterns). However, there are also limitations associated with TA (Braun & Clarke, 2006). Specifically, it may be associated with inadequate research questions or analyses (which are considered research design flaws, and not necessarily an issue with TA itself; Braun & Clarke, 2006). Additionally, its interpretations can be very broad due to the methodology's flexibility. Further, conclusions may be limited if researchers do not use a pre-existing theory (i.e., they

cannot interpret their data on a deeper level; Braun & Clarke, 2006). Also, as codes from each interview are collated into one dataset, it is not possible to examine consistencies/contradictions across an individual transcript (Braun & Clarke, 2006).

TA has been used successfully in similar studies. With specific regard to parental diagnosis disclosure, Clarke and colleagues (2005) used a form of TA to examine factors that influenced parents disclosing their child's leukemia diagnosis to the child, and child behaviours after receiving a diagnosis of pediatric leukemia. Mothers of children who were newly diagnosed with leukemia were interviewed (Clarke et al., 2005). The following themes were derived from parent interviewees: There were mood and behavioural changes following treatment; children demonstrated differing responses to their treatment, illness, and visits to the hospital; parents communicated information with their children via differing approaches (e.g., realism; optimism); there were varying parental communication approaches (e.g., providing full versus minimal information); parental perceptions of cancer (e.g., incurable); and parental responses to their child's treatment (Clarke et al., 2005). Methodological limitations included variability across participant accounts (i.e., complexity, length, and detail) and a potentially ungeneralizable sample (only 60% of those recruited participated in the study). However, Clarke et al.'s study had a respectable sample size by qualitative research standards (55 interviewees).

Ludlow, Skelly, and Rohleder (2012) used TA to examine difficulties experienced by parents of children with ASD. When asked about coping mechanisms and what makes things more difficult/easy for them as parents of children with ASD, the researchers generated themes on the stressful nature of attending to challenging behaviours, difficulties associated with others' judgments (e.g., while a child is having a tantrum in public), a lack of support (e.g., from organizations), the emotional impact of child's ASD on the family, and coping and support

pathways (Ludlow et al., 2012). Despite a lack of generalizability, their results were reported to somewhat align with similar studies (Ludlow et al., 2012).

Finally, Braiden and colleagues (2010) examined parental experiences of the ASD diagnostic process using TA. Identified themes surrounded initial parental concerns, the ASD diagnostic process, informing parents of their child's diagnosis, issues relating to how parents were equipped with information, communication concerns, parental comprehension of the ASD diagnostic process, and timeframe and degree of parental support from professionals (Braiden et al., 2010). Limitations of this study's findings surrounded the 17% participant response rate and small sample size (11 participants), thus impacting the study's generalizability. Furthermore, some of their themes appear to be derived from the interview questions themselves, which is unadvisable (for an explanation, please refer to Braun & Clarke, 2006). Given the aforementioned studies, there is support for the use of TA as a viable methodology when researching parents' experiences and perceptions of their child(ren) with ASD.

Methods

Methods can be defined as "research action" (Carter & Little, 2007, p.1318), and consist of the practical tasks associated with conducting research (Carter & Little, 2007). The following subsections will outline how the current study was conducted (i.e., participant recruitment, data collection procedure, and subsequent data analysis and interpretation).

Participants and recruitment. Purposive sampling was used. Twenty parents were recruited for the current study. Parents met recruitment criteria if they were the biological, adoptive, or foster parent of a child/children with a formal diagnosis of ASD, had disclosed their child's ASD diagnosis to their child with ASD, and were living in Alberta, Canada.

Recruitment was a two-step process whereby parents first completed a web-based survey that asked them to provide demographic information and answer questions relating to their experience of the diagnosis disclosure process. The survey (see Appendix A) was developed by an experienced research team in conjunction with informed parents and staff from several prominent ASD community-based organizations in a large urban Canadian city. Participants were recruited and directed to the questionnaire link by recruitment campaigns on social media networks, local ASD community events, news segments on local TV, and through recruitment posters placed around the city. Upon completion of the online survey, parents were asked to provide their contact information if they consented to be contacted by the research team for a follow-up interview for this research project. Subsequently, parents who had a child with an ASD diagnosis, had disclosed their child's diagnosis to their child, and were living in Alberta, Canada, and had opted to partake in further research were emailed by a member of the research team. After agreeing to partake in a semi-structured interview, a member of the research team scheduled a suitable date, time, and venue for the interview to take place. Of the 51 parents contacted, 20 interviews were conducted, as twenty (sets of) parents replied and consented to participate. Upon completion, transcription, and initial analysis of the 20 interviews, it was determined that five interviews would be precluded from data analysis. In three interviews, the individual with ASD attended the feedback meeting where a clinician informed them and/or their parents about the individual's ASD diagnosis. One interview was invalidated as the parents told the child that he had differences but did not explicitly inform him that he had ASD. Finally, one interview was excluded as the impact of diagnosis disclosure was not broached by the interviewer due to the situational nature of that particular interview. Within the final sample (15 interviews), parents spoke about 16 individuals with ASD (13 males and three females). For one

interview, a mother spoke about her two children with ASD. All other parents reported having one child with a formal diagnosis of ASD. For 13 interviews, the child's mother participated in the interview. For two interviews, both the child's mother and father participated. The age of individuals with ASD ranged from four to 34 years of age (median = 14). Age at diagnosis ranged from two to 26 years of age (median = nine). Age at diagnosis disclosure ranged from approximately three to 26 years of age (median = 10).

Procedure and data collection. Ethical approval was granted by the University of Calgary Conjoint Faculties Research Ethics Board prior to recruiting and interviewing parents. As this study was part of a larger project, data collection procedures were team based. The larger project is overseen by two faculty members who have expertise within the ASD clinical and research fields. These researchers had a significant role in project conceptualization, grant, funding, and ethical approval applications. All semi-structured interviews were conducted by one doctoral student in order to maintain consistency across interviews. The current researcher's role was to transcribe interview recordings, 16 of which she transcribed; the four additional interviews were transcribed by a second research assistant. Together, the research team scripted and selected questions pertinent to specific investigation areas (e.g., parent-child diagnosis disclosure impacts versus factors influencing diagnosis disclosure). Since there is a paucity of existing empirical literature in this particular area, questions were loosely influenced by associated prior research, but were primarily drafted to address the research questions of the project. Questions that were deemed to be directive or leading were eliminated or modified to be more non-assumptive and open-ended.

The interview protocol (Appendix B) reflected a larger set of topics, questions, and probes than the current study's research questions alone. Specifically, Questions One to Nine

examined the lived experiences and factors associated with parent-child ASD diagnosis disclosure practices. Question 10 sought to investigate ASD diagnosis disclosure impacts, and aimed to answer the current study's research questions. Questions 11 to 15 sought to examine parent-reported child perceptions of the child before and after diagnosis disclosure. And finally, Questions 16 to 25 were designed to examine the impacts/experiences of parental diagnosis disclosure to the affected individual's sibling(s).

Semi-structured interviews were conducted as they facilitated a richer insight into the potentially variable nature of impacts, while also affording the opportunity to probe and follow up on (in)congruent information. Further, semi-structured interviews allow researchers to explore research questions (i.e., deductive approach) while also facilitating versatility in the data collection process (i.e., inductive approach; uncovering and exploring unanticipated and potentially valuable data; Galletta, 2013). Each semi-structured interview consisted of a number of open-ended questions intended to stimulate discussion and description of factors and impacts of parental diagnostic disclosure to children with ASD and/or sibling(s). Parents provided informed consent to participate in the interviews (see Appendix C for the consent form), and upon obtaining participant permission, all interviews were audio-recorded. The interviewer adhered to the interview protocol and asked questions in a natural, conversational format. Follow-up probes were used throughout the interview, whereby the interviewer sought to obtain a greater insight into a particular phenomenon, impact, or experience. Follow-up probes were posed as clarifying questions (e.g., "And how old was he at that point?"). The interviewer also sought to confirm what she thought was being said (e.g., "sounds like you guys really gave him that time to process it after that initial conversation anyways, and waited till he brought it up again, or tried to facilitate") which was then confirmed by a parent (e.g., saying "yeah"). Probes

were unstandardized and served the purpose of helping to answer a given research question. It was not verified whether parental accounts were truthful or not. Parents were permitted to deviate from particular questions and provide as much or as little detail about their family, circumstances, experiences, and/or impacts as they wished. In turn, data were ready to be analyzed via a realist and semantic lens.

Interview duration ranged from 18:03 to 74:40 minutes (median interview length = 39:35). Interviews were transcribed verbatim in a rigorous manner. The researcher implemented the following transcribing practices: interviewer utterances (e.g., yeah', 'okay', or 'umhmm') were excluded from transcriptions if interviewees were mid-sentence (though they were included they occurred at the end of an interviewee's sentence). All other interviewer dialogue was transcribed (e.g., interview fillers such as "um", "like", and "you know"). At times, tenses or words were slightly modified to align grammatically or demonstrate correct spelling within a descriptive sentence, or when an individual's name was removed from the transcript. When the aforementioned occurred, the altered words were surrounded by square brackets (e.g., [going]; [son]). Additionally, some quotes or excerpts included three continuous dots (i.e., "…"). This was representative of an interrupted sentence whereby the interviewer may have said "yeah" (or something to that effect), which in turn was deemed irrelevant to the excerpt illustration. All transcriptions (i.e., full interviews) were checked for accuracy by the researcher. Audio recordings were compared to transcriptions, and any anomalies and/or inaccuracies were corrected. In order to enhance transcription accuracy, especially inaudible excerpts, the researcher sought further clarification from the interviewer when necessary.

Data analysis. Data were analyzed according to Braun and Clarke's (2006) step-by-step guide for conducting TA in a methodologically robust manner. The steps consist of: Becoming

familiar with the data; creating preliminary codes; looking for themes in the data; reviewing derived themes; naming and defining themes; and generating the report (Braun & Clarke, 2006). The steps are not necessarily meant to be a rigid sequential (linear) process; instead the researcher can move freely and recursively (forwards and backwards) between steps (Braun & Clarke, 2006). First, the researcher familiarized herself with data by transcribing, reading, and re-reading transcriptions in addition to noting early data interpretations. Transcribed interviews were read twice by the researcher, and all excerpts pertaining to parental diagnosis disclosure impacts were copied and pasted into a separate document for further analysis. All other interview data were considered inapplicable to the current research questions. Second, notable features of the data were coded by thoroughly reading each line of text in the transcription excerpts. Codes were clearly marked (e.g., by highlighting and making comments in an electronic document). Each code (section of text) was copied and pasted into a spreadsheet. Third, codes were analyzed for suitability and placed within certain themes. Fourth, themes were reviewed to ensure that they aligned with coded extracts and the remainder of the data-set. Fifth, themes were concretely defined and labeled by continued analysis of the data. At this point, a modified practice of Fereday and Muir-Cochrane's (2006) reliability check was applied. A second researcher (the interviewer) evaluated the adequacy, accuracy, and applicability of codes and themes. Although most codes and themes remained the same, several relatively minor modifications were made (i.e., several codes were moved to different themes/formed new themes). The current researcher and interviewer discussed the proposed modifications verbally, and then undertook decisions to makes such changes. Since the modifications were minor, the current researcher believed her data analysis to be quite adequate. Further, two university faculty members evaluated the results and related rationalizations. The sixth step involved selecting

appropriate data extracts (i.e., those that contributed to answering the research questions) and reporting findings, which can be read in the next chapter. Direct quotes from interviews are provided as support for the derived themes presented in Chapters Four and Five. The selection and inclusion of parent quotes was conducted in order to adequately depict and preserve parent meaning and perspectives.

Chapter Four: Results

Chapter four will identify, describe, and rationalize the results derived from the current study. Six themes and related subthemes were discerned from transcribed data. In line with Braun and Clarke's (2006) recommendations, data should align coherently and meaningfully within themes, but also be distinct from other themes. The data analysis confirmation stage was conducted by meticulously reviewing/modifying themes and the overall dataset (i.e., comparing codes with derived themes; Stages Four and Five in Braun & Clarke's [2006] TA guide). In turn, reliability checks were conducted (i.e., reviewers compared the adequacy of raw transcribed data with derived themes). Subsequently, derived themes will be described respectively:

1. Communication about ASD
2. Understanding ASD
3. Awareness of ASD Features
4. Specific Child Reactions and Impacts
5. Views and Feelings Associated with Diagnosis Disclosure
6. Magnitude and Valence of Impacts

Specific themes and subthemes were identified and reported as they were believed to represent distinct and valid patterns throughout the dataset. Please refer to Table 2 for a visual representation of each theme along with the frequency of interviews pertaining to each subtheme in brackets.

Theme One: Communication about ASD

Parental disclosure of an ASD diagnosis was reported to either promote or dissuade subsequent communication about ASD between affected individuals, and their parents, professionals, and/or peers. Specifically, this theme provides an insight into the nature and

function of ASD-related conversations between parents and their children with ASD, and the degree to which affected individuals self-disclosed their diagnosis to others and self-advocated for their needs. This theme was selected as distinct due to the core element of further discussion between affected individuals and their parents, peers, associated professionals, and others insofar as diagnosis disclosure facilitated or dissuaded further communication about ASD. Essentially, disclosure was associated with ensuing ASD-related communication.

Open communication. Parental disclosure of an ASD diagnosis facilitated more open communication with the affected individual about their diagnosis (12 interviews). This subtheme's distinctness surrounds the nature of parent-child conversations about ASD following diagnosis disclosure. Such discussions appeared to provide parents with an opportunity to discuss their child's ASD-related differences, difficulties, and solutions to problems with the child, and provided a learning or clarification opportunity pertaining to ASD features. Furthermore, discussions were sometimes initiated by the child.

Problem solving. Notably, eight of the 15 interviews referred to active problem-solving/advising that appeared to be mediated by parent-child communication (i.e., conversations). Specifically, parent-child conversations appeared to facilitate discussions of problems, potential problems, and solutions. Parents sought to teach their child how to overcome particular obstacles. For example, Participant One reported speaking with her son about how something was "hard stuff to learn" and proceeded to teach him how to learn the task in chunks, as illustrated by the following quote: "sometimes you learn a little bit now, and sometimes you take a break and don't learn that little bit right now, you learn it later." Participant One's quote suggests that she actively acknowledges ASD-related difficulties in

Table 2

Impacts of Parental ASD Diagnosis Disclosure: Primary Themes and Subthemes

Communication About ASD	**Understanding ASD**	**Awareness of ASD Features**	**Specific Child Reactions and Impacts**	**Views and Feelings Associated with Diagnosis Disclosure**	**Magnitude and Valence of Impacts**

• Open Communication (12 interviews)
  ○ Problem Solving (8)
  ○ Discussion of ASD Associated Difficulties (5)
  ○ Discussion of ASD Associated Differences (5)
  ○ Learning Opportunities (7)
• Disclosure to Others (7)
  ○ Disclosure to Peers (4)
  ○ Disclosure to Non-Peers (3)
  ○ Reluctance to Disclose (2)
• Self-Advocacy in Communication with Others (4)
	• Made Sense (5)
	• Understanding of ASD (11)
	  ○ Understanding of ASD Related Difficulties and /or Differences (6)
	  ○ Unsure of Understanding (1)
	  ○ Partial Misunderstanding of ASD Diagnosis (4)
		• Awareness of Themselves (6)
		• Awareness of ASD-related Differences (6)
		• Awareness of ASD-related Difficulties (7)
			• Thinking and Processing (4)
			• Information Seeking
			  ○ Questions (5)
			  ○ Research (3)
			• Access to Resources (6)
			• Excuse (5)
			• Self-Regulation Skill Development (2)
				• Views
				  ○ Part of Them (3)
				  ○ Matter of Fact (4)
				  ○ Label (2)
				  ○ Acceptable (2)
				  ○ Self-Image (4)
				  ○ Confidence (3)
				• Feelings
				  ○ Relief (3)
				  ○ Less Common Feelings (3)
					• Negative Impacts (4)
					• No Negative Impacts (6)
					• No Major Impacts (4)
					• Does Not Remember ASD Diagnosis Disclosure (2)

communication with her son and advises him about how to overcome such challenges. Similarly, Participant Seven spoke about solving problems and "figuring out how... [her daughter could] get along in life". Some mothers (specifically Participants 10 and 15) devised an anticipatory problem solving system that could address parent-child interpersonal problems (i.e., to address social or self-control challenges through the use of gestures). The following excerpt is an example of conversations pertaining to anticipatory problem-solving between a mother and her son with ASD.

> "And it's like me talking to him on Saturday night, '[son], these are the areas that you're not gaining self-control, and as you get older and move through junior high school, they're going to affect you, so we need to figure out how you're [going to], you're [going to] figure out how to control yourself.'" (Participant 10)

Participant 15 reported that her son experienced challenges with "social issues", for example, "read[ing] faces". In turn, she reported how she spoke with her son about problem-solving, as exemplified by the following excerpt:

> "Those are the ones I think you're dealing with. We take them over here then. This is who you are. It's part of who you are... How do we make it better?... How do we... you'll always have it, but how do we help you cope better with it, so you don't feel so out of it?'... And that was sort of how I put all of that." (Participant 15)

Again, diagnosis disclosure facilitated active dialogue about how to overcome social or behavioural challenges. Three mothers told their child about things that might happen to them and how they might address these issues in the future, therefore providing preparation in advance (e.g., peer relations; Participants Four, 10 and 11). Hence, it is possible that knowing about one's diagnosis facilitated preparatory parent-child conversations about how to address

hypothetical problems. The aforementioned excerpts illustrate explicit conversations between two mothers and their sons about ASD. Specifically, these participants acknowledge/address how to problem-solve within a hypothetical situation that the individual may experience, and potentially enhance outcomes for the affected individual and their social lives.

Discussion of ASD associated difficulties. Parents also discussed the child's ASD associated difficulties (five interviews) and differences (five interviews) with them. The current researcher chose to differentiate between 'communication about ASD-related difficulties' and 'communication about ASD-related differences' (please refer to next subsection) due to the fact that they are categorically unique insofar as a difference is not necessarily equivalent to a difficulty, and vice versa. For example, parents reported that their child may have difficulties (e.g., being "frustrated"; Participant Five [mother]). One mother reported gaining insight into her son's difficulties when she asked him about his challenges:

> "And I said to [son], I said 'okay, so what's the hardest thing about living with Asperger's?' And he said 'not seeing the grey'. So this kid who has supposedly an IQ of seventy five... said, realized that 'I see things in black and white. I don't see grey, and that life, a [lot of] life is grey.'" (Participant Two)

Discussion of ASD associated differences. With regard to differences, one mother reported reassuring her daughter that "it is okay to be different" and told her child that she didn't "have to be like everybody else" or "do it like everybody else" (Participant Four). It seemed as if this mother was explicitly communicating about ASD-related differences, and encouraged her daughter to embrace her differences. Further, communication facilitated conversations about children's differences in terms of not "really understand[ing] things in quite the same way" (i.e., his differences; Participant Seven) and validating that "there's a reason for it" (Participant 15).

As per the latter quotes, ASD diagnosis disclosure facilitated an endorsement of ASD-related differences and difficulties, and in turn provided affected individuals with a rationale for their differences.

Learning opportunities. Conversations with children and their parents also facilitated learning opportunities to teach children about ASD, available resources, and/or clarify misbeliefs (seven interviews). Diagnosis disclosure preceded explicit teaching moments between parents and their children with ASD. Specifically, Participant One asserted that it did not matter whether a person had a diagnosis or not. She stated "it's still the same person" when her son asked whether other people also had ASD. Such an ASD-related conversation may have sought to teach him that it did not matter whether others had an ASD diagnosis insofar as ASD did not define people. Participants Three and Five talked about answering their child's ASD-related questions. One mother informed her daughter that she would not be stopped from doing anything in life, but might "do tests in a slightly different way" (Participant Four). The latter mother-child conversation demonstrated an attempt to reassure the affected child that her ASD label would not serve as a life-barrier. For one family, learning about Temple Grandin (a well-known ASD advocate, author and Veterinarian Professor with ASD) served as "a catalyst for having lots of discussions" despite the child being informed of his diagnosis three years earlier (Participant 12; Mother and Father). It is possible that associating Temple Grandin's legacy and representation of ASD sparked and encouraged further discussion about the nature of ASD. Similarly, another child spoke "about his autism just in the last year and a half" (Participant 13), several years after being informed of his diagnosis. In sum, diagnosis disclosure appeared to facilitate parent-child learning opportunity discussions.

Overall, informing a child of their diagnosis facilitated open communication with parents. Within the Open Communication subtheme, a deeper analysis of communication topics surrounded open parent-child discussion about ASD-related problem-solving approaches (e.g., developing strategies), differences (e.g., validating differences), difficulties (e.g., frustration), and learning opportunities (e.g., conversations that facilitated enhanced knowledge about ASD).

Disclosure to others. The uniqueness of this subtheme surrounds individuals' self-disclosure of their ASD to others (both peers and non-peers) upon learning of their diagnosis (seven interviews). However, a third sub-theme evidences a reluctance to disclose one's ASD diagnosis to others (two interviews).

Disclosure to peers. Most commonly, the interviews revealed that affected individuals informed friends and/or peers about their diagnosis (Participants Four, 10, 11, and 15). Participant Four spoke about how her daughter was "very forthright about" her diagnosis, "explain[s] it very well", and specified that "all of her friends" knew that she had ASD. Another mother noted how her son had disclosed his ASD to a peer during a behaviour therapy group, to which the peer replied "so do I" (Participant 11). Participant 15 spoke about how her adult son openly disclosed his ASD to friends, and requested of them that if he didn't "figure somethin[g] out" that they were to "slap [him] in the face, and tell" him that he "didn't figure it out". Subsequently, Participant 15 concluded that his disclosure to peers "helped them figure out how to relate to him" (Participant 15). The aforementioned quotes suggest that parental diagnosis disclosure facilitated affected individuals with opportunities to disclose their ASD diagnosis to others.

Disclosure to non-peers. Additionally, three interviews touched on how parental diagnosis disclosure preceded individual self-disclosure to non-peers (e.g., interviewers, a

mother's co-worker, and an unknown other; Participants Seven, Eight, and 12). Notably, Participant Seven reported that her daughter openly disclosed her ASD when complaining about the loudness of music to an unknown other. In turn, her mother communicated her belief that this experience provided "an explanation", and that "it [gave] other people something to think about other than 'oh, she's just being rude'". Participant Eight reported that her daughter had disclosed her ASD to interviewers, who the mother believed to be "totally understanding" about her daughter's diagnosis, as illustrated by the following excerpt:

> "But now like even in job interviews and stuff, she's very open about it. Like, she'll say "I do have Asperger's", so she said "sometimes my brain doesn't always, you know, register the same as, as other people." And she, like I was totally impressed that she did that."

In sum, informing children of their ASD empowered them with the choice to disclose their diagnosis to others (non-peers).

Reluctance to disclose to others. Conversely, two individuals were reportedly reluctant to disclose their ASD to others upon learning of their ASD diagnosis (Participants 10 and 14). Specifically, despite being very open about his diagnosis in the past, Participant 10 stated that her son became more reluctant to tell others about his ASD, which she suspects was due to bullying or being "teased by a couple [of] kids" (Participant 10). Participant 14's son reportedly perceived ASD as a "stigma". Subsequently, Participant 14 reported that the family "respect[ed]" their son's preferences and let people (e.g., instructors) know "on an as-needed basis" only. Hence, some individuals with ASD may be reluctant to share information about the diagnosis with others, which may be due to the aforementioned reasons (ASD perceived as a stigma; disclosure associated with school based teasing).

In sum, affected individuals were empowered with the choice to disclose their diagnosis to others, or alternatively, to refrain from self-disclosing. Individuals experience a range of experiences from positive and supportive to negative (e.g., teasing) upon informing others of their diagnosis.

Self-advocacy in communication with others. This sub-theme was marked as distinct due to the ASD-related self-advocacy demonstrated by affected individuals in their conversations with others (four interviews) as exemplified by the following excerpt: "She will tell the teachers what she needs and what she doesn't need as far as how to, what she needs to cope and what she doesn't need, an, and that kind [of] stuff" (Participant Four). Following diagnosis disclosure, another individual was reported to be "more willing to ask for help" as other peers might not question the reason for them not getting extra help (i.e., other students would understand why he needed extra help; Participant Three). One student with ASD was reportedly more willing to advocate when she "need[ed] to take a break" at school (Participant Eight). Hence, diagnosis disclosure provided individuals with knowledge of their diagnosis, which in turn empowered individuals with the ability to communicate their ASD-related needs with others (e.g., teachers). Overall, it seems that knowing about one's ASD diagnosis can assist people in self-advocating for assistance when required and if the individual chooses to do so.

Theme Two: Understanding ASD

The second theme is distinct due to the common finding that parental diagnosis disclosure promoted variable levels of understanding amongst individuals regarding features of their ASD. The degree of understanding associated with diagnosis disclosure varied across families. Specifically, some parents reported that the diagnosis made "sense" to their children; in addition to facilitating a sense of understanding amongst their children as to why the child

behaves the way s/he does, and surrounding the child's differences and difficulties. One parent was unsure of the degree to which her son understood his diagnosis. Finally, some children exhibited a lack of understanding surrounding the nature of their diagnosis after disclosure. The following subthemes will provide a description of how disclosure impacts individuals' understanding of ASD.

Made sense. Five interviewees uniquely stated that disclosure or having the diagnosis made "sense" to their child, albeit for a variety of reasons. Parental diagnosis disclosure assisted with children making sense of their difficulties, understanding why "things were harder", and why one individual was "an incredibly black and white thinker" (Participant One). This excerpt suggests that Participant One's son derived a clear association/understanding between his difficulties and the ASD diagnosis. Participant Nine reported that her son "finally got something that made sense" upon learning of his diagnosis as he could also attribute ASD-related experiences to his newly learned diagnosis. Another parent stated that her child "enjoy[ed] knowing more" about her diagnosis and specified that it made "more sense to her... [as to] why it's... different for her" (Participant Seven). Indeed, learning of their ASD diagnosis assisted children with ASD to make sense of why they are the way they are (Participants Eight and 15), as depicted by the following quote from the mother of a child with ASD: "And that made sense to him, because of, because he knew that was part and parcel of who he was" (Participant 15). In sum, data suggest that learning of their ASD diagnosis engendered a sense-making phenomena for individuals on the autism spectrum. More broadly, it equipped some individuals with a sense of understanding about themselves relating to their diagnosis.

Understanding of ASD. This subtheme captures the apparent sense of individuals' self-understanding following diagnosis disclosure (11 interviews). Specifically, the affected

individuals understood why they were the way they were (five interviews), as portrayed by the following quotes: “It was just ‘I get it. I get myself. I understand myself now” (Participant 15) and Participant Nine reported that her son specified “okay, I’m this way”. Another mother said: “I think for him it was a bit overwhelming in the sense like ‘okay, now I know what’s wrong with me’” (Participant 14). These quotes suggest that learning of their diagnosis provided individuals with a new understanding of themselves and who they were.

Understanding of ASD related difficulties and/or differences. Disclosure also equipped children with an understanding of their ASD-related difficulties and/or differences (six interviews). For example, one mother believed that disclosure may have enhanced her daughter’s understanding of why teachers treated her differently, and that diagnosis disclosure “answered a lot [of] questions for” the child (Participant Eight). One mother reported that her child learning of his diagnosis “validated his efforts in the fact that there was something else that was going on” as opposed to being academically unmotivated (Participant Three). The interview data imply that ASD diagnosis disclosure stimulated a greater sense of understanding surrounding affected individuals’ differences and difficulties.

Unsure of understanding. However, an enhanced understanding of the self was not universally reported across interviewees. One mother was “not sure how much he understands” when speaking about her son’s awareness of his diagnosis (Participant Five). Furthermore, the mother made five references throughout the interview to her uncertainty of his ASD understanding. The following excerpt demonstrates the extent to which this mother was unsure of how much her son understood his diagnosis:

> “Um, a- and, y- you know, I, I, i-it’s [*sic*] hard to tell but I, but I think sometimes, you, you can see kind of a, a, a look of confusion, or a, that, that he, he knows, he can’t, that

he's, I don't wanna [*sic*] say the word trapped, cause I don't like that, but almost like he, that he knows he, he doesn't do things the way everybody else does. And he knows he's, he's different." (Participant Five)

Partial misunderstanding of ASD diagnosis. Another facet of understanding was prevalent amongst the data, that is, lack of understanding. Specifically, some parents signified that their child lacked an understanding about their diagnosis following disclosure (Participants One, Five, 12, and 13). One mother mentioned that her son with ASD thought that "everybody [had] autism or some disability" therefore potentially exhibiting a lack of understanding/awareness (Participant One). Similarly, Participants 12 and 13 implied that their sons demonstrated a misunderstanding of ASD. Specifically, Participant 13 exemplified this by quoting her son in the following excerpt: "If I have autism does that mean that I can, that I can race really fast?"

In sum, many interviewees reported a greater sense of ASD and self-understanding amongst affected individuals. However, some parents reported on their child's lack of understanding regarding facets of their diagnosis.

Theme Three: Awareness of ASD Features

Theme Three's distinctness surrounds its ability to capture how individuals are reportedly aware and/or unaware of their ASD features following diagnosis disclosure. The data collected from parents are represented by four discrete subthemes, each described below.

Awareness of themselves. This subtheme reflects distinct findings across six interviews (Interviews One, Three, Four, Five, Six, and Nine), and whereby parents implied that their children developed enhanced awareness of themselves following diagnosis disclosure. For example, Participant Four ("well yeah, that's just how I am") and Participant One ("knows where

he's at in some things") both reported this awareness in their children. One mother felt that her son exhibited an awareness of his skills and preferences and avoided tasks "because [they were] not interesting [or] motivating to [him]" (Participant Six). Interestingly, another mother suggested greater awareness with age, i.e., "the more he got older, he could see it" (Participant Nine). Conversely, Participant Five seemed unsure of the extent to which her four year old son was aware of his ASD diagnosis and asserted that "he could very much be really aware that he does have" ASD. Further, she "feel[s] that there is [an] acknowledgement in him that he is different". Thus, although diagnosis disclosure may proceed ASD-related awareness, this may not be observed across all individuals, as illustrated across Participant Five's interview. Hence, this subtheme suggests that individuals with ASD may exhibit varying degrees of awareness regarding themselves and ASD-related features.

Awareness of ASD-related differences. This subtheme captured parental-reports of their child's apparent sense of awareness regarding their ASD-related differences (six interviews). For example, Participant One said: "I think it has impacted them that, that they know that there are things that are different". Further, she went on to elaborate how her son evaluates social situations prior to going as there may be lots of people there, of whom he would not want to talk with as illustrated by Participant One quoting her son in the following excerpt: "Well, I'm thinking about going there, but I don't know if that's the best choice cause I don't, I don't really want to have to talk to a lotta people". Another parent reported that her son with ASD "knows [he's] different" from his twin sister (Participant Five; Mother). The prior quotes seem indicative of an awareness of ASD-related differences following diagnosis disclosure. Overall, this subtheme appears to reflect parental reported child awareness of their ASD-related differences.

Awareness of ASD-related difficulties. This subtheme was distinct due to the implied awareness of individuals' ASD associated difficulties. In total, seven interviewees revealed that their children were aware of their ASD-related difficulties following ASD diagnosis disclosure. Specifically, a mother of two sons with ASD often heard them say "this is my autism making this hard" (Participant One). Furthermore, she stated that "it's just a more a self-awareness, there are things that are more difficult for them". Hence, this mother suggested that her sons exhibited an awareness of their ASD-associated difficulties following diagnosis disclosure. Further, parents spoke about how their children were aware of challenges associated with their "motor skills", "social interaction" (Participant Eight), and "problem-solving" (Participant 14) difficulties, and having "worry-bugs" (i.e., worrying; Participant 12; Mother). Participant 15 said that her son "knew it was because he didn't read somebody's body language right when they were pissed off", therefore indicating an awareness of his difficulties. For three interviews, individual awareness of difficulties was associated with problem-solving, as illustrated by the following excerpts: "It's part of autism spectrum, that sometimes you have to chunk things down right, um, for them to be able to get them, or so it's not overwhelm[ing]. And so, he chunked it down for himself" (Participant Three).

> "But um, my older son, you know, he's very aware that 'I don't like to get in the car, and pay that much attention, and follow all those rules, and pay that level of attention that it takes to drive.' And he's aware of how much attention it takes to drive. And that he does not wanna [*sic*] maintain that kind of attention, ever... And so, he says 'I'm just better not doing that, so I'm going to have to learn how to take the bus.'" (Participant One)

Another mother reported that her daughter was aware of her social interaction challenges, and "tries to avoid crowds if she can" (Participant Eight). Hence, awareness of her social challenges

assisted her in avoiding/choosing particular situations depending. In sum, diagnosis disclosure was associated with affected individuals' awareness of ASD-related difficulties.

Theme Four: Specific Child Reactions and Impacts

The fourth theme was developed to illustrate particular reactions and impacts exhibited by children upon learning of their ASD diagnosis. Some subthemes seemed relatively common across individuals, ages, and familial contexts, while others appeared quite specific to certain individuals. The following subthemes justify inclusion within the overall theme, and provide an insight into the specific individual impacts and reactions: Thinking and Processing; Information Seeking; Access to Resources; ASD as Excuse; and Self-Regulation Skill Development.

Thinking and processing. This subtheme portrayed the extent to which four individuals reportedly thought about and/or processed the disclosure information for some time afterwards, as exemplified by the following quote: "The processing has taken a long... time" (Participant 12; Father). Hence, it is believed that the act of thinking and/or processing reportedly occurred for some individuals upon learning of their ASD diagnosis. Furthermore, it was noted that disclosure conversations served as "something to think about", and that "I think there was lots [of] thinking" (Participant One). Another mother reported that "a lot[of] stuff just percolates for a long, long time" (Participant 11). Further, two individuals were reported to experience a delay between learning of their diagnosis and initiating ASD-related conversations for (Participants 12 and 13). Notably, a seven year old boy was informed of his diagnosis three years earlier, and had only "spoken about his autism just in the last year and a half" (Participant 13). Similarly, the following quote depicts one mother's view about her son's later discussion initiation: "I think, opening the door and then just giving him the time to walk through it when he felt that he was ready" (Participant 12; Mother). Interestingly, Participant 12's son commenced

interest/discussion in ASD upon learning about Temple Grandin, a famous individual with ASD. The prior quotes and the overall subtheme suggest that diagnosis disclosure may be associated with a period of thinking/processing before some individuals address and/or engage with their ASD.

Information seeking. This subtheme was distinct due to the manner in which some affected individuals actively sought out ASD information following diagnosis disclosure. The actual act of information was believed to be a distinct subtheme that occurred subsequent to diagnosis disclosure. Typically, the interviews indicated that individuals tended to either ask parents questions about ASD or perform their own ASD research, as illustrated in the following subsections.

Questions. Five children were reported to have explicitly asked questions pertaining to ASD following diagnosis disclosure. For the most part, individuals tended to "usually" (Participant Eight) ask parents questions about their own ASD (Participants Two, Three, Eight, and 12). One mother found that "the biggest challenge in having this discussion with him [was] he want[ed] to know 'exactly what is my autism?'" and she felt that it was "not a literal answer" (Participant 12). One mother suggested that her son relay questions to his psychiatrist during his next visit with her (Participant Two). One individual reportedly tended to ask questions about whether others had ASD (e.g., "what kind of autism do you have?"; Participant One). In sum, disclosure preceded ASD-related questions for some individuals with ASD.

Research. This subsection was considered distinct as three individuals conducted their own research following diagnosis disclosure (Participants Two, Nine, and 15). Specifically, Participant 15 reported that her son "just looked it up" following the diagnosis disclosure. Similarly, Participant Two reported that her son went "online and [found] out what this thing

[was] and, and [read] some books" when engaging in ASD-related research. In one interview, the interviewer implied that the interviewee's son had done his research, to which Participant Nine confirmed that her son had conducted ASD-related research.

In sum, the overall subtheme indicates that some individuals with ASD actively seek information (through asking questions or performing research) following diagnosis disclosure.

Access to resources. The current subtheme captures an apparent access to resources following diagnosis disclosure to six individuals (Participants Three, Four, Eight, 10, 11, and 12). Specifically, one mother reported that her child knew that he could use accommodations, as exemplified by the following excerpt:

> "Um, I think again, knowing um, that he could use the accommodations, and that there were something, tools, and, and that the teachers knew, um, so using a laptop in class, and you know, having the headphones if they were just doing quiet study or during exams" (Participant Three)

In turn, this mother reported that her son's "marks improved... because of that" (i.e., having access to accommodations; Participant Three). The prior excerpt seems reflective of how ASD diagnosis disclosure equipped a child with the awareness that he could access particular resources (i.e., he now knew that these tools were accessible). Further, Participant Four felt that disclosure gave her daughter "the verbal tools to address it". Hence, although not a specific resource/support, learning of an ASD diagnosis facilitated one individual with verbal tools to address her ASD. Similarly, one child attended a supported camp for children with disabilities, whereby his mother implied that her son could be himself as illustrated by the following quote: "But you can, you can be yourself" (Participant 11). One daughter with ASD attended support organizations, whereby people "would sit down and talk to her" about particular information

(Participant Eight), hence providing her with informational resources. One mother "made" her son read a book about ASD (Participant 10), therefore facilitating access to resources following diagnosis disclosure. Another mother reported how watching the Temple Grandin movie had "showed some of the difficulties that [Temple Grandin] had that were directly related to her being... autistic" and "sort of brought [ASD] together" for their son (Participant 12; Mother). As such, access to ASD resources may have assisted affected individuals in conceptualizing their ASD. Participant 12 (mother) also mentioned that she, her son with ASD, and her typically-developing daughter read Temple Grandin books together as a family, therefore increasing ASD knowledge in the home. One mother reported that she began parent-mediated intervention with her daughter prior to attaining a formal diagnosis, that her daughter became more receptive to intervention upon learning of her ASD diagnosis, and that she (the mother) was a trained ASD practitioner prior to attaining her child's diagnosis (Participant Four). It is possible that Participant Four's daughter embraced her mother's intervention attempts following diagnosis disclosure or when she learned of her mother's experience. To conclude, for some individuals, diagnosis disclosure was associated with subsequent access to ASD-related resources (e.g., books and organizations).

Excuse. Some parents specified that their son/daughter attempted to use ASD as an excuse after being informed of their diagnosis (Participants One, Three, Eight, 11 and 12). It is believed that this is a distinct subtheme associated with diagnosis disclosure impacts. Interestingly, all parents laughed while recounting their child's attempts at using ASD as an excuse, as illustrated by the following quote: "Yeah. [laughs]. 'I can't help taking an incredible long time in the shower because I have autism.'... 'Like, no, that's because you're a teenage boy... Get out [of] the shower!'" (Participant One). Further, some individuals reportedly used

ASD as a rationale for not completing "homework" (Participant Three), or an excuse "not to try" (Participant Eight). Perhaps some people viewed their diagnosis as a barrier to completing certain tasks or as a way out of completing undesirable tasks. It is also possible that some individuals used their ASD as an excuse, but may have not fully understood the nature of their ASD, as depicted by Participant 11:

> "'Can you hurry up?' cause he stops at every puddle, every rock, you know [inaudible] thing, and I said 'we, we have to get going. You need to hurry up.' He said 'I can't.' An' [*sic*] I said 'why?' 'I have autism.' So, it [inaudible; laughs] like, now that's the joke, right!"

Although parents laughed while recounting these occurrences, both parents in Interview 12 acknowledged that their son is hesitant to perform some activities as he has "worry-bugs" (i.e., tended to worry). Thus, Interview 12 illustrates that while some excuses may seem opportunistic, other individuals may be genuinely hesitant to perform particular tasks and/or activities. In sum, several interviews suggest that some individuals use their ASD as an excuse to avoid certain tasks following diagnosis disclosure.

Self-regulation skill development. This subtheme was distinct in that diagnosis-informed individuals developed self-regulation skills to implement when overwhelmed, as depicted by the following excerpt:

> "And if he didn't know that he had Asperger's, and he didn't know that that was part and parcel of it, he wouldn't have known, I mean, he had to learn, took him about three years to learn how to take himself out of a situation, sit in a corner with his Gameboy back then, play a few games, breathe, and then come back into it." (Participant 15)

This assertion was further corroborated by another mother who mentioned that if children are told of their diagnosis, "then that helps them self-regulate themselves as well" (Participant Eight). To that end, this was an interesting finding across two interviews, insofar as, knowing about one's diagnosis may be associated with self-regulation skill development.

Theme Five: Views and Feelings Associated with Diagnosis Disclosure

The fifth theme depicts a variety of views and feelings that proceeded from ASD diagnosis disclosure. The essence of the current theme is to portray the range of views and feelings that may be elicited by or associated with diagnosis disclosure. Across interviews, views and feelings were relatively heterogeneous. The following views were asserted amongst individuals: Part of them; matter of fact; label; acceptable; self-image; and confidence. Additionally, the interviews revealed a wide variety of feelings that were attributed to individuals upon learning of their ASD diagnosis (i.e., relief; and less common feelings).

Views.

Part of them. Two interviewees parents implied that their children with ASD viewed their diagnosis as part of themselves (Participants One and 13), and hence justified the current subtheme One mother asserted that she didn't "think [that her sons with ASD] view themselves as different, it's just a piece" and "it's just a fact, it's just a thing" (Participant One). Further, Participant 13 remarked "I think it's part of um, I think he identifies with it". Additionally, Participant 15's son was "raised to know [ASD is] nothing to be ashamed of, that it's nothing wrong with it. But it's just part of who he is" (Participant 15). In sum, some parents suggested that their children believed or were led to believe that ASD was part of them.

Matter of fact. Four parents explicitly used the term "matter of fact" when talking about their child's ASD (Participants Four, Seven, 12, and 13). For example, one mother mentioned

that her daughter was "very matter of fact about it" (Participant Four), suggesting that ASD 'was what it was'. Another individual was reportedly talking more about his ASD, and that it was "becoming more matter of fact" (Participant 12), insofar as, perhaps it was becoming more 'normal' in his life. Two parents reported that the ASD was "a matter of fact" (Participants Seven and 13). To that end, some parents asserted that ASD was (or was becoming) matter of fact for their children with ASD. Insofar as, they may be suggesting that their children were more accepting of their diagnosis, and normalized it.

Label. This subsection was formed as a result of two participants speaking to the concept of labels (Participants One and 14). Notably, Participant One believed that her sons did not hold ASD "as a label that they attach or even assign to themselves". Participant 14 reportedly sought to portray the "label" (i.e., ASD) to her son and not something that was "wrong with" him. However, she reported that her son views his ASD diagnosis as "a bit of a stigma". In turn, he appeared to view ASD via a negative lens, i.e., something that was "wrong with" him (Participant 14). Hence, learning of one's diagnosis was associated with labels, either the presence of ASD-related labels, or lack thereof. Notably, it was a concept that both participants endorsed as being a potential impact. Interestingly, Participant 14 reported that her son regarded ASD via a negative lens despite his parents framing ASD in a more balanced and positive light, as illustrated by the following excerpt:

> "Was 'okay, yeah, this is what's wrong with me, and now I also have ADHD too. An' [*sic*] that's what's wrong with me too.'... But, we've always framed it as 'you've got strengths and you've got areas of need that you need to work on.'"

It appears that the latter individual took his ASD information and framed it within a 'something wrong with him' label. In sum, ASD diagnosis disclosure appeared to be associated with the concept of labels (either negative or none at all).

Acceptable. One mother's account indirectly suggested that her son having ASD was more "acceptable" than obsessive compulsive disorder and anxiety disorder:

> "He... might say 'I have Asperger's'... He would say, he would say that now... You know, because, al- always before, 'Well, I have anxiety disorder' [flat low tone of voice], 'yuh [*sic*], haha, I have OCD' [flat low tone of voice], no but somehow he thinks having Asperger's is acceptable. [laughs]" (Participant Two)

Similarly, another mother implied that her son found ASD acceptable as she thought he didn't "wish [he] never had" ASD (Participant Three). To conclude, acceptability was associated with learning about one's ASD diagnosis.

Self-image. This subtheme touched on the concept of self-image following diagnosis disclosure. Specifically, two mothers implied that their sons' self-image improved, as illustrated by the following excerpt:

> "I think it helped him as far as his self-image, because he realized that it really wasn't a character issue, that this was something that was a brain issue, it was neurological... And so, therefore, um, you know he would have to work around it, but, you know, it validated him." (Participant Three)

For this individual, disclosure assisted "the way he was around friends, around the teachers improved too" (Participant Three). Hence, knowing about the nature of his diagnosis may have assisted in enhancing this individual's self-image. Further, Participant 15 recounted how her son asserted to his mother that he was "not stupid" upon learning of this ASD diagnosis. For these

two individuals, it appears that diagnosis disclosure impacted their self-image in a positive way. Notably, Participant One mentioned that her children's view of themselves was impacted in "sometimes a negative way and sometimes a positive way" but is "overall, more positive than anything", suggesting greater positivity associated with diagnosis awareness. Conversely, Participant Four implied that diagnosis disclosure did not impact her child's self-view by saying "yeah" when directly asked if her daughter viewed herself the same way following the disclosure. It is possible that learning of one's ASD diagnosis may impact self-image differently across individuals.

Confidence. Learning about an ASD diagnosis was associated with confidence levels for two individuals (Participants Four and Eight). Notably, one mother noted that awareness "has given her the confidence" as "she does things that [her mother] never imagined that she would ever do" (Participant Four). Participant Eight spoke of how her daughter "let[s] her diagnosis kind of hold her back from a few things", but in other regards she's "a little bit more confident" due to school awards. Further, Participant Nine reported that her son's confidence level is low, though did not specify if this was due to diagnosis disclosure or other factors. Confidence was another parent-reported child feeling following diagnosis disclosure.

Feelings. The following feelings reportedly followed from diagnosis disclosure.

Relief. This subtheme represents three individuals who were reportedly relieved upon learning of their diagnosis (Participants Four, Six, and Nine). Specifically, one teenager with ASD "was relieved" that he "got a real" diagnosis (Participant Nine). Notably, this individual had had many diagnoses up until that point. For another individual, receiving an ASD diagnosis was relieving, as "it took the pressure off her" (Participant Four). Participant Six believed that her son (who was non-verbal) was "relieved" as she believed he developed a sense of

"acceptance" (i.e., that his ASD was accepted, and that he could "feel safety and security"). To that end, diagnosis disclosure was associated with relief for some individuals.

Less common feelings. Some feelings represented one participant. However, their inclusion was deemed important in order to illustrate the array of feelings experienced by affected individuals following diagnosis disclosure. Specifically, Participant Seven reported that her daughter was "more comfortable... knowing that there's a name for... something that you know is different". Hence, for this individual, there was a sense of comfort associated with learning of her ASD diagnosis. Participant Nine indicated that her child "relaxed" upon learning of his ASD diagnosis (Participant Nine). And finally, Participant Seven suggested that her daughter was "happier knowing that there's, that there's a reason" for her ASD-related characteristics. In sum, several less common feelings were reported following diagnosis disclosure (i.e., comfort, relaxed, and happy).

To conclude, diagnosis disclosure was associated with a number of views and feelings. Notably, ASD was associated with being: part of the affected individual; matter of fact; attached to labels; an acceptable diagnosis; impacted self-images; and associated with confidence levels. Interestingly, some feelings were more commonly reported (e.g., relief), while others were representative of only one individual.

Theme Six: Magnitude and Valence of Impacts

Theme Six reported on impact magnitudes and valences across affected individuals. Interestingly, the vast majority of reported impacts were positive in nature, as implicitly illustrated by the prior five themes (e.g., ASD diagnosis disclosure provided a greater sense of understanding and awareness). Interestingly, Participant 11 seemed unsure whether diagnosis disclosure was impactful for her son with ASD. Specifically, she mentioned that "whether...

positive or negative", potential impacts of diagnosis disclosure or how her son thought about himself was "nothing he would verbalize". It is possible that disclosure impacted him in some way, but it did not seem apparent to her verbally. Further, there were some additional findings regarding the size and valence of impacts which will be described and analyzed in the following subthemes: Negative Impacts; No Negative Impacts; No Major Impacts; and Does Not Remember ASD Diagnosis Disclosure.

Negative impacts. This subtheme was justified for its identification of negative impacts associated with ASD diagnosis disclosure (Participants Eight, 10, 12 & 14). Although the vast majority of parents reported positive impacts, four parents identified some negative impacts. Notably, Participants Eight and 12 asserted that their children attempted to use their ASD as an excuse to avoid tasks, as previously discussed. This was highlighted as a negative impact. For another family, diagnosis disclosure led to the child experiencing suspected teasing at school as he openly disclosed his ASD in a way that annoyed his peers (Participant 10). One student on the autism spectrum viewed his ASD as a "stigma", and was also reluctant to discuss his diagnosis (Participant 14). And finally, one individual "internalized that [ASD is] not a good thing", but was "starting to see it as a positive thing" (Participant 12). In sum, although most impacts were positive in nature, learning about one's ASD diagnosis was also associated with negative impacts for some individuals.

No negative impacts. Six parents explicitly noted that diagnosis disclosure resulted in no negative impacts. Upon being asked if there were negative impacts/outcomes following diagnosis disclosure, five parents replied with "no" (Participants One, Two, Seven, Nine, and 15). Participant 13 asserted that she hadn't "seen any negative... impacts from [son] knowing

that he has autism." Hence, diagnosis disclosure appeared non-associated with negative impacts for many individuals with ASD.

No major impacts. Four parents implied that diagnosis disclosure did not have a major impact on their children with ASD, as depicted by the following excerpt: "I don't know, from what I saw, I don't think there was any big repercussions, or no internalizing and, and self-questioning from what I saw" (Participant One). Further, Participant One felt that her two sons did not see ASD as "a big deal" nor did they feel "negative about themselves" because of their diagnosis. Similarly, another mother thought that disclosing her daughter's ASD diagnosis had not "really made that much of a difference" as her daughter lived "a pretty typical life" (Participant Four). In sum, diagnosis disclosure appeared to result in no major impacts for some individuals on the autism spectrum.

Does not remember ASD diagnosis disclosure. Two individuals did not accurately remember the diagnosis disclosure conversation. In fact, Participant 12 reported that her son did not remember that his father informed him of his ASD diagnosis, but does remember pictures his father drew with him (which reportedly happened), and that his mother told him (which reportedly did not actually happen). Additionally, this child believed that "he remember[ed] some talks that" she had with him "later". Another mother recounted how her son explicitly didn't "remember that" (i.e., the diagnosis disclosure conversation; Participant 14). However, despite not remembering the disclosure conversation, both individuals exhibited resulting impacts (e.g., viewing ASD as a stigma, or displaying interest in ASD years after diagnosis disclosure). In sum, for two individuals, diagnosis disclosure was associated with not being able to remember the actual disclosure.

Chapter Five: Discussion

The current study sought to examine the impacts of parental diagnosis disclosure to children with ASD and has important implications for families of children with ASD, clinicians, and researchers within the field of ASD. There is a distinct knowledge gap in this domain, which the current study aimed to help address. All parents (17 parents; 15 interviews) in the current sample informed their child about his/her ASD diagnosis. It is believed that the current sample reached saturation (i.e., that there was no new forthcoming information in later interviews) as the addition of the last two interviews (14 and 15) did not yield any new codes or themes. In addition, researchers have indicated that saturation is often reached within 12 interviews when conducting TA (Guest, Bunce, & Johnson, 2006).

Overall, the results of the present study suggest that the positive impacts associated with diagnosis disclosure far exceed the negative impacts. Specifically, parental diagnosis disclosure to children facilitated open discussions between parents and children about the child's ASD. Subsequently, individuals with ASD were empowered with the choice of whether or not to self-disclose their ASD to others and/or self-advocate for their needs. Upon learning of their diagnosis, children were reported to exhibit understanding and awareness of their ASD-related differences and difficulties. Furthermore, individuals demonstrated a range of reactions and impacts subsequent to diagnosis disclosure. For example, thinking and processing diagnosis-related information, seeking information about ASD, gaining access to ASD resources, attempting to use ASD as an excuse, self-regulation skill development, and not remembering the diagnosis disclosure conversation. Following disclosure, parents reported that their children lived with a variety of views and feelings associated with their ASD (i.e., ASD is part of them; ASD viewed as matter of fact; ASD label views; an acceptable diagnosis; self-image

enhancements; confidence; and relief and less common feelings). Finally, diagnosis disclosure was associated with some negative impacts (i.e., using the diagnosis as an excuse to avoid/partake in particular activities; ASD viewed as a stigma/bad thing; and suspected teasing by peers). However, the majority of parents reported no negative impacts or implied that there were no major impacts associated with diagnosis disclosure. In sum, diagnosis disclosure is associated with an array of impacts for individuals with ASD. The following subsections will analyze the results, theme by theme, and compare current findings to related research. Subsequently, a discussion of limitations, strengths, implications, recommendations for future research, and a final conclusion will be provided.

Theme One: Communication about ASD

Parental diagnosis disclosure to children facilitated more open communication between individuals with ASD and their parents, peers, and professionals. Most notably, the parents sampled in this study engaged in open conversations about ASD topics with their children on the spectrum. Also, parents actively engaged in problem-solving conversations with their children to assist them with "figuring out" (Participant Seven) how to overcome obstacles and work through problems (e.g., improving self-control). Interestingly, two parents noted how they worked with their child to overcome interpersonal parent-child challenges (e.g., the use of gestures to inform individuals that their mother needed a break). It would be insightful to compare such problem solving conversations between individuals with ASD who know/don't know about their diagnosis.

Conversations also afforded the opportunity to identify, validate, and explain ASD-related difficulties and differences, and serve as learning opportunities for children, as parents taught them about ASD features and resources and clarified child misconceptions about ASD.

Parental diagnosis disclosure also empowered children with the choice to self-disclose their ASD to others. Four individuals self-disclosed their ASD to their friends/peers, which was associated with some positive impacts (i.e., peers learned how to relate to and help the individual with ASD). Social interaction and communication difficulties render children with ASD more vulnerable to social isolation and bullying (Humphrey & Lewis, 2008; National Autistic Society [NAS], 2006). Notably, prior studies report that positive relationships with peers and teachers serve as a protective factor against bullying (Hebron & Humphrey, 2014), and that lower social support is associated with greater bullying for students with ASD (Humphrey & Symes, 2010). Indeed, Hebron and Humphrey (2014) concluded that stronger social networks may result in less isolation and lower vulnerability to bullying, and greater peer advocacy for students with ASD at school. However, disclosure to peers may not always lead to positive impacts for individuals on the spectrum; one mother mentioned that her son's way of speaking about his ASD annoyed his peers. Additionally, this mother suspected that her son was teased by peers. In turn, this individual became more reluctant to disclose his diagnosis to others. Overall, two individuals were reluctant to disclose their ASD to others. Similarly, other researchers have quoted a participant who believed that peers "likely pick on" him as they were aware of his ASD diagnosis (Humphrey & Lewis, 2008, p.34). However, prior research has shown that "sensitively handled disclosure to peers in particular facilitated positive relationships, and reduced the ignorance that so often drives intolerance to difference" (Humphrey & Lewis, 2008, p.40). Therefore, it would appear that there are polarized implications associated with peers knowing about an individual's ASD diagnosis.

Moreover, several individuals reportedly disclosed their ASD diagnosis to explain their ASD-related differences and difficulties to others (as opposed to appearing "rude"; Participant

Seven). Another individual disclosed her ASD and associated differences in a job interview, whereby the interviewers seemed "understanding" (Participant Eight). Similarly, eight out of 10 adults in Punshon and colleagues' (2009) study could explain their ASD-related difficulties to themselves and others upon learning of their diagnosis, i.e., that they were not just being "unreasonable" (Punshon et al., 2009, p.277).

Upon learning of their ASD, some individuals were empowered with the choice to self-advocate for their needs (e.g., being more willing to ask for help and inform teachers about needs). However, one individual did not self-advocate about his higher-functioning abilities. Interestingly, self-advocacy was also common among individuals with ASD who partook in online forums (Bierer, 2013). Specifically, some affected individuals educated classmates about ASD and generated awareness about how some people with ASD were mistreated (Bierer, 2013). Similar to findings in the current study, other individuals self-advocated about required accommodations to professors, whereby some professors were supportive, while others were not (Bierer, 2013).

Overall, the first theme found that diagnosis disclosure facilitated open discussions about ASD. Parents and children on the spectrum could openly converse, rationalize, and problem-solve about ASD topics. Disclosure lead to choices surrounding self-disclosure to others and self-advocating for needs. For the majority of participants, communication seemed to provide a positive impact.

Theme Two: Understanding ASD

Parental diagnosis disclosure engendered varied understanding amongst children concerning their ASD. Specifically, learning of their diagnosis made "sense" to some children (e.g., disclosure made sense of their difficulties and why things were more difficult for them).

Also, disclosure provided individuals with a sense of understanding as to why they were the way they were. For example, one parent reported that her son's teacher attributed poor school performance with laziness despite his excess time and effort spent on carrying out his homework. Disclosure reportedly served to validate his efforts and in turn, rationalize his difficulties. Similarly, some parents in Finnegan and colleagues' (2014) study wanted diagnosis disclosure to result in validation for their child. Likewise, two other studies reported that knowledge of an ASD diagnosis equipped some individuals with a retrospective understanding (Huws & Jones, 2008) and explanation (i.e., "the missing part of the jigsaw"; Punshon et al., 2009, p.277) for prior life experiences. Conversely, individuals with ASD who did not have a "framework within which to explain their difficulties" internalized what others said about them, e.g., that they were lazy (Punshon et al., 2009, p.276).

In the current study, one set of parents were unsure of the extent to which their son understood his diagnosis. Notably, this child was four years old, and as such is potential lack of understanding could be due to the child's developmental stage or age. Four interviewees implied that their children exhibited a lack of understanding about their ASD. Specifically, individuals expressed misconceptions about ASD (e.g., that everybody has ASD and that ASD facilitates the ability to drive cars fast). Perhaps social skill deficits, developmental levels, intellectual functioning, and/or age may impede comprehension of one's ASD. Also, it is possible that some individuals typically do not understand the overall nature of their disorder, as indicated by Calzada and colleagues (2009) who found that young people with ASD tried to describe their main ASD-related difficulties but lacked "a sense of its broader meaning" (p.235). Additionally, Finnegan and colleagues (2014) have suggested that parents may be protective with regard to

how much information they impart about the child's diagnosis. In turn, this could also impede a child's awareness and understanding of their diagnosis (Finnegan et al., 2014).

Within the current study, diagnosis disclosure served to rationalize people's experiences, differences, and difficulties insofar as it made sense and gave rise to a greater understanding of one's diagnosis. However, understanding of one's ASD is heterogeneous, and it is possible that one's understanding may affect the extent to which they are impacted by diagnosis disclosure.

Theme Three: Awareness of ASD Features

Following parental diagnosis disclosure, individuals with ASD exhibited varying levels of awareness about themselves and their specific ASD symptoms. Additionally, awareness of difficulties assisted individuals with finding solutions to problems (e.g., feeling less overwhelmed by dissecting information into smaller chunks). Greater awareness of difficulties also assisted in advance planning for avoiding difficult tasks and using alternative means (e.g., taking public transit as opposed to driving a car). Correspondingly, most individuals with ASD in Punshon et al.'s (2009) study were aware of features that made them "stand out" from others (p.275).

Conversely, one set of parents were unsure of the extent to which their four year old son was aware of his diagnosis, whereas another mother mentioned that her son "could see" his diagnosis as he grew older (Participant Nine), suggesting that awareness may be enhanced with age, experience, and/or developmental levels. Although not explicitly examined here, research indicates that individuals with ASD exhibit some impairments in self-awareness regarding features of their diagnosis (e.g., self-ratings indicating that affected individuals have less autistic characteristics and more empathic features when compared with parent ratings; peer interaction skills, social cue challenges, and having narrow interests; Cederlund, Hagberg, & Gillberg, 2010;

Johnson, Filliter, & Murphy, 2009). Therefore, it is possible that disclosure enhances their awareness and that a lack of awareness may be associated with ASD-related impairments. In sum, individuals exhibit varying levels of awareness about their ASD features, associated differences, and difficulties upon learning of their diagnosis. However, it is also possible that differing levels of awareness are also idiosyncratically associated with affected individuals' capabilities and age.

Theme Four: Specific Child Reactions and Impacts

Specific child reactions and impacts occurred subsequent to parental diagnosis disclosure. Some children were reported to think about and/or process their diagnosis for some time after the disclosure. For some, it took several years between learning of their diagnosis and actively discussing it with parents. Following diagnosis disclosure, many individuals actively sought information about ASD. A subset of individuals asked their parents questions about ASD. Conversely, some individuals performed their own research on the internet or by reading books. In line with Huws and Jones' (2008) conclusion, Pinder's (1990) categorization of people with a diagnosis as information seekers, avoiders, or weavers is partially applicable for the current study. Notably, seekers are driven to uncover information about their diagnosis, regardless of what fearful information they might uncover (Pinder, 1990). Knowing about the disorder equips people with an appreciation of what the diagnosis "might mean for their lives" (Pinder, 1990, p.82). Weavers also seek out information, but are selective about the information that they maintain and discard, which could serve as a protective function for the individual (Pinder, 1990). Avoiders tend to steer clear of finding out more about their diagnosis whereas information is perceived as a "threat to their peace of mind" (Pinder, 1990, p.83). According to parent-reports within the current study, there were plenty of information seekers, no weavers,

and one avoider (Participant 14) who did not bring up the topic of his ASD nor appear to question it. Similarly, there appeared to be ASD information avoiders in several other studies (Calzada et al., 2009; Huws & Jones, 2008).

Parental diagnosis disclosure to a child with ASD facilitated access to resources (e.g., knowledge that one could use accommodations at school, verbal tools to label ASD, books, a movie, a support organization, and a summer camp for children with disabilities). Similarly, other studies found that learning of an ASD diagnosis granted individuals access to supports and/or services that they had not received in the past (Calzada et al., 2012; Huws & Jones, 2008; Punshon et al., 2009).

Furthermore, parents reported that children attempted to use their ASD as an excuse to avoid tasks (e.g., homework) or as an excuse to do particular activities (e.g., taking long showers). Again, all parents laughed after recounting this particular impact. Perhaps using ASD as an excuse demonstrates a lack of children's understanding about the nature of their ASD or that they learned that they could attempt to use their ASD diagnosis as a means to avoid undesirable tasks. Although, Finnegan and colleagues (2014) did not explicitly state that parental diagnosis disclosure resulted in excuse-making, one parent did not want it to occur and they believed that that "behaviour" would not be tolerated at school (p.8).

For two individuals, parental diagnosis disclosure preceded the development of self-regulation skills to assist them when feeling overwhelmed. Notably, both individuals practiced these skills to address challenging situations (i.e., removing themselves from a situation both physically and mentally). Hence, knowing about their diagnosis can aid individuals with recognizing activities/situations that they might find difficult, and in turn initiating problem-solving strategies before their challenges are exacerbated.

Theme Five: Views and Feelings Associated with Diagnosis Disclosure

The fifth theme depicts an assortment of views and feelings that children reportedly experienced upon receiving an ASD diagnosis. The purpose of this theme was to portray the distinct heterogeneity of views and feelings associated with diagnosis disclosure. While some feelings were somewhat common, others applied to only one or several individuals.

The following views were reported. According to parents, some children believed that their ASD was a "part of who" (Participant 15) they were, though it did not define them. Likewise, a sample of students with ASD in Humphrey and Lewis' (2008) study also viewed their ASD as "part of 'who they were'" and seemed to have "grown to accept and even celebrate their differences" (p.32). It would be interesting to determine whether the 'part of them' view was shared by individuals on the spectrum within the current study (i.e., whether the parent participants and their children with ASD shared the 'part of them' view).

Also, parents explained that ASD was "matter of fact" when discussing how their child viewed their diagnosis, and some parents viewed ASD as "matter of fact", insofar as, "it is what it is" (Participant 12). Hence, these particular parents implied that ASD was not necessarily "positive or negative, it just is" what it is (Participant 14). Similar to the previous paragraph, it would be interesting to determine whether these views were shared by the participants' children with ASD.

Two participants highlighted the nature of ASD labels. The majority of parents did not suggest that their children viewed their ASD differences in a negative light. However, one teenager viewed ASD via a stigma lens, saw ASD as something that was "wrong with" him, and was reluctant to talk about his diagnosis (Participant 14). Notably, some people may experience stigma when they possess "a characteristic of persons that is contrary to a norm of a social unit"

(Stafford & Scott, 1986, p.80). Huws and Jones (2008) also discussed the concept of stigma amongst the ASD community, whereby an ASD label could be viewed as stigmatizing. ASD stigma could comprise of felt stigma (i.e., there may be a fear of discrimination/prejudice although there may not be an actual experience of stigma) or enacted stigma (an actual experience of prejudice or discrimination; Huws & Jones, 2008). Further, Huws and Jones (2008) asserted that labelling somebody as having ASD can result in cessation of bad treatment by others (positive impact) or subjection to discrimination by others. Some participants in Huws and Jones' (2008) study did not like having ASD. Also, students with ASD in Humphrey and Lewis' (2008) study expressed negative connotations surrounding their ASD diagnosis, such as having a "bad brain" and being a "freak" (p.31). Similarly, some students wanted to appear "normal" (i.e., neurotypical; Humphrey & Lewis, 2008, p.31). Conversely, the current parent-reported child views appear to be more positive. This could either be that the current sample's families view ASD through a lens of positivity, or that parents are interpreting their child's views in an inflated positive manner. Indeed, diagnosis disclosure appeared to enhance three individuals' self-image, while leaving at least one other's self-view unchanged. Specifically, one student with ASD realized that his ASD was not "a character issue" but was a "brain issue" (Participant Three). Similarly, another individual realized that he was not "stupid" (Participant 15). Therefore, learning of an ASD diagnosis can improve an individual's self-image as they decipher what causes some of their difficulties.

There were a number of reported feelings associated with individuals learning of their ASD diagnosis. Relief was a commonly reported feeling (i.e., that there was a label for one's experiences). Prior studies have also reported that relief was associated with diagnosis disclosure (Huws & Jones, 2008; Punshon et al., 2009). Further, Finnegan et al. (2014) hoped

that relief would ensue following diagnosis disclosure. Moreover, several less common feelings were reported, which again speaks to the heterogeneity of feelings associated with receiving an ASD diagnosis. Notably, two individuals' confidence was reportedly impacted. Interestingly, disclosure adversely impacted one girl's confidence, while disclosure enhanced another individual's confidence. It was implied that ASD was an acceptable diagnosis for two other individuals. One individual was comfortable with knowing that her differences had a label, which was also reported in Finnegan et al.'s (2014) study. Another individual was relaxed upon uncovering why he was the way he was. Finally, one individual was reportedly happier that there was a reason, perhaps for her atypical characteristics. Overall, individuals appeared to experience a variety of mostly positive views and feeling following diagnosis disclosure.

Theme Six: Magnitude and Valence of Impacts

The final theme depicts the magnitudes and valence of impacts associated with informing individuals of their ASD diagnosis. Although the vast majority of impacts were positive in nature, four interviews reported negative disclosure impacts. Notably, two parents mentioned that their children attempted to use ASD as an excuse for avoiding particular tasks/activities upon learning of their diagnosis. Another mother mentioned that her son viewed ASD as a "stigma". One mother believed that her son was teased upon learning of his diagnosis. Interestingly, one individual was beginning to see ASD through a more positive lens, despite reportedly internalizing it as negative in the past (Participant 12's son). However, a number of participants explicitly stated that there were no negative impacts associated with diagnosis disclosure and many implied that there were no major impacts at all.

Two children were reported to not remember the actual disclosure, one of which recounted inaccurate details about the conversation (i.e., thinking his mother informed him when

it was actually his father who had done so). It could be theorized that diagnosis disclosure was not very impactful for these individuals. However, one of these individuals took three years before he initiated discussion and interest in his diagnosis, while the other perceived his ASD as stigmatizing. It is possible that individuals are distinctly impacted by learning about their diagnosis, but may not remember the disclosure conversation. Alternatively, individuals with ASD exhibit some memory impairments, which may also partially account for memory deficits (Goddard, Dritschel, Robinson, & Howlin, 2014).

In sum, this theme speaks to the overall lack of negativity associated with diagnosis disclosure whether it be no negative impacts or no major impacts, and is in contrast to prior studies who have reported greater negativity associated with living with ASD (e.g., Humphrey & Symes, 2010; Huws & Jones, 2008; Lewis & Humphrey, 2008; Punshon et al., 2009).

Limitations

There were a number of limitations within the current study. Specifically, impacts of diagnosis disclosure for the individual with ASD were parental interpretations and reports. It is entirely possible that individuals with ASD may report differences in magnitude and valence of impacts, and may even assert different impacts altogether. It appears that affected individuals are impacted differently, as described in Chapter Two, whereby some individuals embrace their diagnosis while others distinctly avoid it (Huws & Jones, 2008). Second, only parents who had disclosed their child's ASD diagnosis were included in the current study. Although parents who have not disclosed the diagnosis may have provided interesting alternative perspectives, the impacts of non-disclosure remain unexplored in the current study. This decision was primarily undertaken in order to complete the project in a required timely manner. It is anticipated that future projects will examine the impacts/outcomes and experiences of parents who have not

disclosed their child's diagnosis to them. Third, it is possible that the current sample may not be entirely representative of and generalizable to all families who have disclosed their child's ASD diagnosis. Parents in the current sample elected to fill out the online questionnaire and partake in a subsequent semi-structured interview. Therefore, parents who had not disclosed their child's ASD diagnosis to their child and those who chose not to participate in the research may experience different impacts and/or outcomes. Fourth, there was an overrepresentation of mothers' perspectives in the study (15 mothers; two fathers). It is possible that a greater sample of fathers may yield differing diagnosis disclosure impacts. However, the recruitment approach did not seek to discriminate across participating parent genders, insofar as, eligible parents who elected to participate were interviewed. Fifth, ASD is an extremely heterogeneous disorder. Although not explicitly evaluated, it seemed that a large proportion of affected individuals referred to in the current study had children without cognitive impairment. Therefore, it is possible that the current study may not be strongly reflective of families of children with lower cognitive functioning and ASD. Future research may benefit from examining disclosure impacts within a sample that is more representative of the broader ASD population. Sixth, it is possible that some impacts were not due to diagnosis disclosure, but ASD-related impairments (e.g., social skills deficits), comorbid diagnoses (e.g., ADHD), and/or developmental/situational changes in individuals with ASD. Therefore, it is paramount that a causal link not be assumed between parental diagnosis disclosure and subsequent impacts. However, it is possible that impacts are associated with diagnosis disclosure. Seventh, although this was a qualitative study, the researcher acknowledges that the interview protocol was adhered to, but not to the extent that questions were asked using the exact same wording, prompts, or order for each interview. Such an approach served to assist interviews in running in a smooth manner while also endeavouring

to maintain rapport with interviewees. Eighth, as mentioned and rationalized in Chapter Three, the researcher is cognizant that personal biases may have coloured methodology choices and data collection and interpretation. However, she took steps to limit the impact of personal biases (outlined on page 30). Ninth, the current methodology was analyzed on a semantic level (i.e., an assumption of what participants said was explicitly what they meant). It is possible that different results could have been generated had the data been examined via a latent lens. Hence, the current researcher acknowledges that differing approaches may directly impact reported findings. However, the researcher believes that the analyses and findings are a valid representation of parental accounts, experiences, and ASD diagnosis disclosure impacts. Notwithstanding, the findings are felt to represent a solid pilot research project, with the understanding that more research is required in order to develop a comprehensive insight into the impacts and experiences of parental ASD diagnosis disclosures to their children on the spectrum. Finally, the researcher cannot guarantee that parental accounts and memories were accurate.

Strengths

There were a multitude of strengths within the current study. Firstly, although a variety of studies have examined the extent to which individuals with ASD think about or are impacted by their diagnosis, this study examined the impacts associated with parental diagnosis disclosure to a child with ASD. Finnegan and colleagues (2014) conducted a similar study. However only one of their reported excerpts seemed to pertain to experienced impacts. It appears that impacts were of a 'could happen' nature. Therefore, the current study seems slightly different from Finnegan et al.'s (2014) study, and represents a unique contribution to the research literature. Second, Finnegan et al.'s study had a smaller sample size and explicitly interviewed parents of children with higher-functioning ASD only. Hence, to the author's knowledge, the current study

represents the largest sample used in an investigation of the impacts of parent-child diagnosis disclosure to date. Third, the current design afforded a richer, contextual, and inductive insight into the impacts of parental diagnosis disclosure to their child on the autism spectrum. Fourth, although unplanned, the current sample represented an appropriate gender ratio of males to females within the ASD population (4:1; APA, 2013). Fifth, all families were markedly unique in their experiences and perspectives. Hence, there seemed to be some heterogeneity (breadth) within the current sample. Finally, there was a large age range (four to 34 years of age) across individuals with ASD, therefore obtaining a variety of impacts across developmental and chronological age stages.

Implications

The current study contributes helpful and practical information for affected individuals, families of children with ASD, and clinicians and researchers in the ASD field. Specifically, results from the current study can assist with empowering parents who may be approaching the diagnosis disclosure dilemma, insofar as they have access to empirical information concerning the reported potential impacts of informing their child about their ASD diagnosis. It is hoped that the current findings can support the development of an accessible informational resource for both the ASD and general community. Until now, there has been limited information for parents who may be considering telling their children about their ASD diagnosis. Specifically, there is one notable ASD expert's book (i.e., Attwood, 2007) in addition to other informational websites. This study is amongst the first (with some input from Finnegan et al.'s study) to draft data-driven disclosure information from parents of children with ASD. This speaks to the validity of current findings, given that results are formulated by parents with experience in this particular process. Also, the current findings may be a source of relief for parents given that the findings suggest

that positive impacts exceed negative impacts following diagnosis disclosure. Interestingly, Finnegan and colleagues (2014) concluded that informing a child of their diagnosis had mixed implications. Also, although not entirely comparable, literature (see Chapter Two) highlights a mixture of positive and negative impacts associated with individuals learning about/living with their ASD. However, it was not explicitly stated whether parental diagnosis disclosure took place in the aforementioned literature. Further, the current results signify the distinctly heterogeneous nature of impacts associated with learning of an ASD diagnosis. Hence, prior research and current findings together strongly suggest that there is not a 'one size fits all' approach or set of impacts for individuals upon being informed of an ASD diagnosis. Hence, the current results are reflective of a small subset of families of children with ASD, and are not representative of all families.

Individuals on the spectrum can analyze the current findings and examine parent-reported child impacts. Subsequently, they can determine where they fit in terms of potential diagnosis disclosure impacts, and whether it is a combination of positive or negative outcomes for them. Individuals may also learn/acknowledge that they have distinct (dis-)similarities with others on the autism spectrum. However, similar to individuals in Huws and Jones' (2008), some people with ASD may be reluctant to acknowledge or learn about their ASD, whereby the current findings may be a source of discomfort to them.

As a result of the current study, clinicians are now equipped with data driven findings (as opposed to sources of personal/expert opinion) and can analyze its findings and determine whether or not to incorporate them into consultations with parents who are considering if, how, and when to disclose their child's ASD diagnosis to their child. However, as mentioned in the limitations section, the current study is more representative of a pilot/foundational study and

more research is required in order to develop comprehensive informational resources for individuals, parents, and clinicians. For researchers, the current study serves to enhance the current body of empirical knowledge about ASD diagnosis disclosure, and will assist with refining future research question ideas, as the next subsection will outline.

Future Research

The following suggestions for future research are recommended. First, future studies could interview individuals with ASD to ascertain their perceived impacts associated with parental diagnosis disclosure to address the current study's limitations. Second, future research could examine the extent to which individuals on the spectrum exhibit self-awareness of ASD features, differences, and difficulties following parental diagnosis disclosure. Further, the impact of diagnosis disclosure and ASD characteristics (e.g., social skill deficits, intellectual and developmental functioning) on self-awareness could be analyzed and compared in order to determine their impact on self-awareness in the ASD population. Third, the current study's impacts included facilitation of subsequent open parent-child communication about ASD. Future research could examine the extent to which ASD-related conversations impact individuals (e.g., self-perception, self-esteem, self-efficacy, and social-emotional wellbeing). Fourth, the current sample evidenced a wide age range and varying developmental stages across affected individuals. Therefore, it would likely be helpful to more formally examine parental diagnosis disclosure impacts across age and developmental stages. In turn, such an examination might elucidate a variety of different impacts across groups.

Conclusion

To conclude, the current study investigated the impacts of parental disclosure of an ASD diagnosis to their child. The current study represented a much needed addition to the ASD

research domain, as many prior studies have focused on parental satisfaction and impacts associated with parents receiving their child's ASD diagnosis from a clinician and individuals' perceptions of living with ASD prior to, during, and after ASD diagnosis disclosure. However, there is a paucity of research surrounding parental disclosure of an ASD diagnosis to their child with ASD.

Results revealed that diagnosis disclosure facilitates more open communication about ASD differences, difficulties, learning opportunities, and problem-solving strategies; a spectrum of understanding and awareness of differences and difficulties; specific child reactions and impacts; child views and feelings associated with ASD; and a discussion on the magnitude and valence of impacts (i.e., negative impacts; no negative impacts; and no major impacts). Overall, it appears that positive impacts associated with parental diagnosis disclosure outnumber the negative impacts. The current results will be disseminated in the form of data-driven informational resources to individuals with ASD, their parents, clinicians, and ASD researchers alike so that all parties have access to informational supports when approaching, conducting, and concluding the diagnosis disclosure process. In sum, it is hoped that the current study will assist individuals with ASD in terms of understanding their differences and difficulties, and in living fulfilling and contented lives; supply parents and clinicians with data-driven information; and fill a gap in the ASD research domain.

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Appendix A

Diagnosis Disclosure Web-Based Survey

Discussing Children's ASD Diagnosis

You are being asked to be part of a research study. Parents of children with autism spectrum disorder (ASD) often struggle with the decision to talk to their child about their diagnosis. This study is asking parents of individuals with ASD, professionals who work with individuals with ASD, and individuals with ASD themselves about this important topic. You will be asked to fill out a survey containing questions about if you have spoken to your child(ren) with ASD about their diagnosis, as well as how, why, and when this discussion occurred. We also want to know how effective the discussion was, and what advice you would give to other parents facing this issue so that we can better understand what supports will help families with this important decision. There is a different survey for individuals with ASD to complete. If you agree to allow your child to complete the survey, please contact the primary researcher and he will gladly provide the link to it so that you may forward it to your child. The results from this study may be disseminated in journal articles, professional conferences, summaries to community agencies, and community presentations. Data will be stored on a password-protected computer and stored in a locked filing cabinet of the primary investigator for five years after the completion of the study. It will take 15-30 minutes to fill out the survey, depending upon the length and depth of your responses to the questions. This study is being conducted by _____, a faculty member in the Faculty of Education at the University of Calgary and has been reviewed by the Conjoint Faculties Research Ethics Board. If you have any questions about the study or your participation, please contact _____ at _____ or _____@ucalgary.ca. Participation in this study is voluntary. Participation in this study is not connected to any agency and will have no effect on any services you or your child receive. You may choose not to complete the survey without penalty by simply closing it prior to completion. However, should you decide to withdraw from the research project after you complete and submit your responses, the researcher will not be able to locate and remove your individual responses. Your responses will be anonymous and will only be used for research purposes. While it is not anticipated that you will experience significant distress through the process of completing this survey, the _____, _____ is a resource in the event that you do experience intense discomfort. Additionally, if you have any comments or complaints, you may contact an Ethics Resource Officer at _____ or _____. By submitting the completed or partially-completed measure, you are indicating your consent as a participant in this research study. The time and effort of your participation is greatly appreciated. Thank you for your consideration in participating in this research.

Sincerely Yours,
(Name and contact details of primary investigator)

I consent to participate in this research project.

- ○ Yes
- ○ No

Demographics

Please tell us a little about yourself and your child with ASD. If you have more than one child with ASD, please answer the questions on this survey in regards to only one at a time.

Which parental role best describes you?

- ○ Mother
- ○ Father
- ○ Step-Mother
- ○ Step-Father
- ○ Adoptive Mother
- ○ Adoptive Father
- ○ Foster Mother
- ○ Foster Father
- ○ Other, please specify... _____

How old is your child?

[ ]

What is your child's gender?

- ○ Male
- ○ Female

Where do you live?

Country [ ]

Province or state (if applicable) [ ]

What is your child's formal diagnosis?

Month and year of diagnosis Country of diagnosis

Autistic Disorder	☐		
Asperger Syndrome	☐		
PDD-NOS	☐		
Autism Spectrum Disorder (ASD)	☐		
Other	☐		

Does your child have any other formal diagnoses? (check all that apply)

☐ Intellectual Disability
☐ Anxiety Disorder
☐ Depression
☐ ADHD
☐ Tourette's
☐ Tic Disorder
☐ Epilepsy
☐ Obsessive Compulsive Disorder
☐ Specific Phobia
☐ Other, please specify... _____

Which professional(s) were part of the diagnostic process?

Please select all that apply

☐ Psychologist
☐ Pediatrician
☐ Psychiatrist
☐ Speech-Language Pathologist
☐ Occupational Therapist
☐ Physical Therapist
☐ Family Physician
☐ Social Worker
☐ Teacher
☐ Other, please specify... _____

☐ Unsure

Have you discussed your child's diagnosis with them?

○ Yes

○ No

How old was your child when you first had this discussion?

What prompted you to have this discussion?

Did your child find out about their diagnosis elsewhere and talk to you subsequently?

○ Yes

○ No

Did you struggle with making the decision to have this first discussion with your child?

○ Yes

○ No

If yes, what was difficult?

How did the first discussion go? What worked and what could have gone better?

Did your child appear to understand the nature of their diagnosis after the first discussion?

○ Yes

○ No

If so, what approach(es) or information appeared to be the most helpful in helping your child understand their diagnosis?

Did you seek any advice or guidance before having the discussion?

- ○ Yes
- ○ No

If so, what guidance did you seek?

What support(s) and/or resource(s) did you have in place that helped you with this first discussion?

What additional support(s) and/or resource(s) could have helped you with this first discussion?

What do you think are the potential benefits of discussing a child's ASD diagnosis with them?

How do you think this type of discussion will affect their social and emotional development?

What advice could you give to parents considering discussing an ASD diagnosis with their child?

Is your child aware of their diagnosis?

- ○ Yes
- ○ No

If yes, how did they find out?

Are you thinking about talking to your child about their diagnosis in the future?

- ○ Yes
- ○ No

If yes, please describe the factors that you will take into account to decide when and how you will talk to your child about their diagnosis.

If yes, what support(s)/resource(s) would help you with this discussion?

If no, what factors did you consider in making that decision?

What, if any, negative impact do you think that discussing a child's ASD diagnosis with them will have?

How do you think this type of discussion will affect their social and emotional development?

What advice would you give to parents considering discussing an ASD diagnosis with their child?

Thank you!

Thank you very much for taking the time to complete this survey. Your responses are valuable and will allow us to better understand the complexities surrounding the decision to discuss a child's ASD diagnosis with them, and possible effective approaches to having that discussion.

Are you interested in the results of the study upon its conclusion?
If you would like to be informed about the results of the study, please provide an email address.

Are you willing to participate in other research projects that we are conducting or will be conducting?
If you are interested in potentially participating in other research projects involving children with ASD and their families, please indicate your preference below, and provide an email address that we can contact you at. Please note, we WILL NOT provide your contact information to any other third parties, and all contact information will be kept secure and confidential.

Would you like to be informed of other research projects? ○ Yes ○ No

If yes, please provide us an email address:

Sorry, but you must provide consent to participate in this research project.
We appreciate you taking the time to consider this research project!

Appendix B

ASD Diagnosis Disclosure Semi-Structured Interview Protocol

Thank you for agreeing to participate in this research project and to talk with me today. I would like to talk with you about your experience surrounding deciding to tell, or not to tell, your child about their ASD diagnosis. Although I would like this to be more like a conversation than an interview, I do have a few questions written down to make sure I cover everything. If you feel uncomfortable with any of the questions, you can choose not to answer that question and you do have the right to stop the conversation at any point.

Interview questions:

PART 1

PREAMBLE: Can you reflect on your perspectives of telling or not telling your child about her/his ASD diagnosis?

1. Can we talk about your journey of deciding to share or not share about your child's ASD?
2. Have you told your child about his/her ASD?
    a. If so… "Can you describe that process?"
    b. If not, "Can you describe the process that has led you not to share that information?"
3. What considerations do you think have gone into your decision to disclose or not disclose your child's ASD diagnosis to the child?
    a. Probe: things that influence you in your decision?
4. Are there markers that might be indicators that it is the right time to talk about ASD to one's child?
    a. Probe: Age, development, functional level, etc.

5. Are there things that are helpful in moving forward towards disclosure?
6. Are there things that make disclosure of the diagnosis harder than it could otherwise be?
7. **If parent disclosed:**
    a. What do you think is the result/outcome of disclosing?
    b. What was the experience like for you as a parent?
    c. What was the experience like for your child?
8. **If parent has not disclosed:**
    a. How do you think it would be different if you (opposite of what they've done i.e., disclosed/not disclosed)?
    b. What do you think is the result of not yet disclosing?
9. What support(s), if any, might be helpful to parents and/or professionals in this process?

Continued Section for Parents who have disclosed:

10. Do you think that the decision to disclose the diagnosis had any impact on your child?
    a. How so?
    b. Tell me more about that
    c. Were there any positive impacts of disclosing?
    d. How about any negative impacts of disclosing?
11. I now want to talk with you about how your child thinks about him/herself. How do you think your child feels about him/herself right now?
12. What words do would they use to describe themselves?
13. Have they always felt this way?
    a. When did this change?

b. Why do you think it changed?

14. Tell me more about it.

15. We talked earlier about the potential impact of disclosure of the diagnosis. Did the impacts of disclosure affect how your child thinks about him/herself?

    a. How so?

    b. Tell me more about that.

PART 2

PREAMBLE: We talked earlier about your perspectives surrounding telling your child, or not telling your child about their ASD diagnosis. Now I want to change the focus a little.

16. Does your child (with ASD) have any siblings?

17. **IF NO:** Thank you so much for your time. I appreciate you sharing your experiences.

18. IF YES:

    a. How many siblings do they have?

    b. How old are they?

19. What considerations do you think have gone into your decision to disclose or not disclose your child's ASD diagnosis to their sibling(s)?

    a. Probe: things that influence you in your decision?

20. Have you told him/her/them about your child's ASD diagnosis?

21. IF THEY HAVE DISCLOSED TO SIBLINGS:

    a. Can you describe that process?

    b. When did you tell him/her/them?

    c. Did you tell them before or after, or at the same time, as your child with ASD?

d. Probe: tell me more about that. What let to that decision?

22. Were their markers that might be indicators that it is the right time to talk about ASD to your child's siblings?
    a. Probe: Age, development, etc.
23. Were there things that made that conversation easier, or more difficult?
24. What do you think was the result/outcome of disclosing to that sibling?
    a. Did they have a positive/negative/neutral reaction?
    b. What was the experience like for your child?
25. What was the experience like for you as a parent?

Thank you so much for your time. I appreciate you sharing your experiences.

Appendix C

ASD Diagnosis Disclosure Semi-Structured Interview Consent Form

Name of Researchers & Email:
_____, __ (_____)
Sarah Cadogan, B.A. (_____)

Supervisor:
_____
_____

Title of Project: The Elephant in the Room: Talking to Children with ASD about their Diagnosis

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This consent form, a copy of which has been given to you, is only part of the process of informed consent. If you want more details about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information. This study has been approved by the University of Calgary Conjoint Faculties Research Ethics Board.

Purpose of the Study:
You have been invited to participate in a research project investigating parental experiences and perspectives of disclosing an autism spectrum disorder (ASD) diagnosis to their child(ren). Parents of an individual with ASD often struggle with the decision to talk to their child about the diagnosis, yet this important topic has yet to be explored. The goal of this project is to better understand if you have spoken to your child(ren) with ASD about their diagnosis, as well as how, why, and when you made this decision. For parents who have discussed the diagnosis with their child(ren), we also want to know how effective the discussion was and what advice you would give to other parents facing this issue so that we can better understand what supports will help families with this important decision. Similarly, we are interested in knowing if parents have discussed their child's ASD diagnosis with their other children, and what that experience was like.

What Will I Be Asked To Do?
Participation in this research project is purely voluntary and involves commitment to complete a one-on-one semi-structured interview with a member of our research team. This interview is anticipated to last approximately 60 minutes, depending upon your responses, and will cover the topics of your potential experience with disclosing an ASD diagnosis to your child, your

perspectives on the impact of that decision on your child's personality and development, and if and how you may have disclosed your child's ASD diagnosis to your other children.

You will also be asked if you wish to participate and should you indicate unwillingness, you will not be required to answer any interview questions that you feel uncomfortable with.

What Type of Personal Information Will Be Collected?
Should you agree to participate, your name and email address will be collected on this form to document your willingness to complete this interview with us. You will then be assigned a participant number, and all information will remain anonymous. Data will be retained for a minimum of five years on an encrypted and password-protected computer (digital data) in a locked office in the Werklund School of Education on the University of Calgary campus.

Are there Risks or Benefits if I Participate?
It is expected that the information collected in this research project will provide us with an improved understanding of parental experiences with and perspectives of disclosing an ASD diagnosis to their child. There is very little research on this topic, and so many parents struggle to make an informed decision on this issue and have difficulty with navigating this challenge in their family life. The information gathered via this project has the potential to help other parents of an individual with ASD by providing information on this topic so that they may take advantage of it when faced with this issue.

The research project involves a simple semi-structured interview during which we will ask you questions about your experience with disclosing an ASD diagnosis to your child with ASD and/or your other children. Your responses to the questions will be audio-recorded so that we may transcribe the interview afterwards for analysis of the responses. There is the possibility that some participants may experience discomfort with some questions; however, this possibility is unlikely, and it is expected that participants will find their involvement in the interview to be rewarding and beneficial. Should any participants demonstrate distress regarding their involvement in this project, _____ will provide either brief intervention or refer the individual to a community agency where the participant may obtain longer-term services (such as Access Mental Health).

Participation in this research will have no effect on services you receive from any agency or organization.

What Happens to the Information I Provide?
All materials will be stored in a locked facility by the primary researcher, _____. While the information generated from this research project may be published and/or presented at academic conferences, you will be assigned a participant number when you arrive and the data will be reported as an aggregate, both of which ensures that individual participants are not identifiable. **Please understand that your participation will be kept confidential, and all reports will ensure anonymity.** Data from this study may also be used to inform graduate student research projects.

It is important to acknowledge that p**articipation is voluntary and participants may withdraw from the research project for any reason, at any time, without penalty of any sort.** If participants do withdraw from the research project, the data contributed will be destroyed. Furthermore, participants will be informed if any new information arises that may affect the decision to remain in the research project.

As the research questions we are interested in examining involve understanding the experiences and perspectives of parents of an individual with ASD as a group, **we will not have research project results for individual participants**. However, when the research project is completed and the data has been analyzed, participants should feel free to contact any of the researchers if they would like a summary of the group results.

Please return the consent form to the researcher. If you are interested in participating in this research project, please complete the form (see following page) and return it to the researcher that you have been in contact with regarding the study.

Signatures (written consent)

Your signatures on this form indicate that you 1) understand the information provided to you about your participation in this research project, and 2) agree to participate as a research participant. In no way does this waive your legal rights nor release the investigators, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from this research project at any time. You should feel free to ask for clarification or new information throughout your participation.

I, _____hereby consent to participate in this study.
(parent name)

Signature: _____ Date: _____

I give my consent to be contacted after participation in this research project should the researchers have further questions regarding this research project **(check one) Yes ____ No ____**

I give consent to be contacted for a follow-up research project should there be one **(check one) Yes ____ No____**

If you indicated "yes" to either of the above questions, please provide your email address so that the research team may contact you.

Email address: _____

Researcher's Name: _____

Researcher's Signature: _____ Date: _____

Questions/Concerns

If you have any further questions or want clarification regarding this research and/or your participation, please contact:

(Contact name and details of primary investigator)

If you have any concerns about the way you've been treated as a participant, please contact an Ethics Resource Officer at _____ or _____.

A copy of this consent form has been given to you to keep for your records and reference. The investigator has kept a copy of the consent form.