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The Elephant in the Room: The Lived Experience of Talking to Children with ASD about their Diagnosis

Smith-Demers, Amanda D.

UNIVERSITY OF CALGARY

The Elephant in the Room: The Lived Experience of Talking to Children with ASD about their

Diagnosis

by

Amanda D. Smith-Demers

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Abstract

Autism Spectrum Disorder (ASD) is a complex neurodevelopmental disorder encompassing a wide variety of cognitive, communicative, behavioural and social abilities. Given the increasing prevalence of ASD, both clinicians and researchers are increasingly required to provide enhanced supportive services throughout the entirety of the diagnostic process. While many researchers have investigated parental experiences surrounding assessment and diagnosis of ASD, the relative oversight of diagnosis disclosure to children is surprising. As such, the current study focused on the lived experience of parents as they explored their decision-making process about whether to, and if so how and when to inform children about their ASD diagnosis. This decision-making process was explored through the use of semi-structured interviews conducted with both parents who had disclosed ($n = 20$) and parents who had not disclosed ($n = 20$) an ASD diagnosis to their child. This study initially set out to compare and distinguish differences between participant groups; however, much of the process revealed by both groups could only be differentiated by where these groups were situated on the timeline of disclosure. Consistent with previous research, results revealed that disclosure is often a gradual process that changes and develops over time. While many reflections and themes were highlighted by parents, the process of considering disclosure and/or disclosing to a child was seen as a unique and situational experience for each family and child; thus, emphasizing the complexity of the disclosure process and the consideration of unique factors specific to each family. In sum, many parents underscored the benefits and importance of disclosure, while also highlighting the experience of fear and wonder throughout the decision-making process. Research and clinical implications of the findings are discussed, along with suggestions for future research.

Keywords: Autism Spectrum Disorder (ASD), decision-making, diagnosis, disclosure, non-disclosure, parents

me through life's ups and downs, and I will always be there to support you in return. It means more than you know, that you were able to understand and support my pipedream of being in school for as long as I have been. I love you all to the moon and back!

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Friends are truly the family that we choose for ourselves.

Dedication

This research would have never been possible if not for all of the amazing families that took time out of their precious lives to share their experiences with me. I am more grateful than I could ever possibly express.

To all of the children that I have worked with, and currently work with:
> *Thank you for your kindness, affection, love, effervescent happiness, innocence and so much more. You have truly changed my life forever, and continue to teach me every day. Although you have taught me many things, above all you have shown me that everyone has amazing attributes that they offer this world, and without them the world would be so much less beautiful. You have all driven me to be the best that I can be, and have fueled my passion to complete this project.*

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I dedicate this dissertation to all of you.

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List of Symbols, Abbreviations, and Nomenclature

Abbreviation/Symbol	Definition
AD	Autistic Disorder
ADHD	Attention-Deficit/Hyperactivity Disorder
APA	American Psychiatric Association
AS	Asperger's Disorder
ASC	Autism Spectrum Condition
ASD	Autism Spectrum Disorder
CDD	Childhood Disintegrative Disorder
D	Disclosed
DSM-5	Diagnostic and Statistical Manual of Mental Disorders–Fifth Edition
DSM-IV-TR	Diagnostic and Statistical Manual of Mental Disorders–Fourth Edition–Text Revision
FS	Family Systems
GAD	Generalized Anxiety Disorder
GST	General Systems Theory
HIV	Perinatal Human Immunodeficiency Virus
ID	Intellectual Disability
IQ	Intelligence Quotient
ND	Non-Disclosed
NOS	Not Otherwise Specified
OCD	Obsessive Compulsive Disorder
ODD	Oppositional Defiant Disorder
PDD	Pervasive Developmental Disorders
PDD-NOS	Pervasive Developmental Disorder – Not Otherwise Specified
RRB	Restricted and Repetitive Behaviours
SCD	Social (Pragmatic) Communication Disorder
SLD	Specific Learning Disorder
n	Number of cases (subsample)
$\approx$	Approximately

Chapter 1: Introduction

Although researchers have explored the parental experience surrounding assessment and diagnosis for their child's Autism Spectrum Disorder (ASD; Mansell & Morris, 2004), there has been a limited focus on if, how, when, and by whom children are informed of their ASD diagnosis and the experience of that process. As research findings indicate that parents tend to be the individuals who disclose medical diagnoses to their children (Young, Dixon-Woods, Windridge, & Heney, 2003) and that self-awareness of a diagnosis has an important impact upon an individual's self-esteem and confidence (Bagatell, 2010; Davidson & Henderson, 2010; Huws & Jones, 2008; Huws, Jones, & Ingledew, 2001; Jones, 2001), the relative oversight of this topic is surprising. Further, the disclosure process has been seen as an important aspect of long-term management of clinical conditions (Vreeman, Gramelspacher, Gisore, Scanlon, & Byandiko, 2013) and can be a significant moment in children's lives where they are better able to clarify and understand prior life experiences (Huws & Jones, 2008). On the other hand, gaps in knowledge about such experiences and outcomes abound. Information about parental decision-making in the substantive area of ASD diagnostic disclosure, as well as the associated experiences of parents during this process, will enhance understanding about this issue within the ASD community with potential implications in terms of guidance for professional practice and family experience.

ASD Diagnostic Process

ASD is a complex and multifaceted spectrum disorder, with individuals exhibiting a wide range of cognitive, communicative, and behavioural symptoms (American Psychiatric Association [APA], 2013). Moreover, ASD often implies a pervasive pattern of atypical development that will impact both affected individuals and their families (Abbott, Bernard, &

Forge, 2012). Although the diagnostic process for ASD remains complex, researchers have investigated the typical process through which families work with professionals to understand the nature of atypical development and determine whether children have ASD (Mansell & Morris, 2004). If they receive a diagnosis, parents often meet with the diagnostic team to discuss the results of the assessment and subsequent diagnosis without children present (Austin, Katz, & Reyes, 2011). Subsequently, parents must come to terms with the diagnostic implications for their child (Pianta & Marvin, 1993). Moreover, parental reaction to the diagnostic process can vary from anger, to relief, sadness, or guilt (Nissenbaum, Tollefson, & Reese, 2002), and adjustment to the diagnosis may be challenging for some caregivers (Midence & O'Neill, 1999). As a result, parents often struggle to decide if, and if so how and when, to disclose the diagnosis to their child (Huws et al., 2001).

Disclosure of an ASD Diagnosis to the Individual Diagnosed

Although researchers have explored the topic of disclosure of some developmental or genetic disorders (i.e., Learning Disorders, Attention Deficit/Hyperactivity Disorder, and Turner Syndrome; Perry, Hatton, & Kendall, 2005; Sutton et al., 2006; Todd & Shearn, 1997) and chronic medical diagnoses to children (i.e., pediatric cancer or HIV; Vreeman et al., 2013; Young et al., 2002), the parallel subject of disclosure of an ASD diagnosis has received little attention. The aforementioned literature indirectly signifies the importance of gaining greater insight into disclosure of ASD as it suggests that parental diagnosis disclosure is positive for the diagnosed individual's well-being (e.g., Domek, 2010; Last & van Veldhuizen, 1996; Vreeman et al., 2010). Moreover, the literature suggests that parents consider many factors (e.g., benefits, hopes, worries, and risks) when deciding whether and when to disclose the diagnosis to their child.

Some researchers have described the positive impacts following diagnostic disclosure of ASD and the various aforementioned developmental, genetic, and medical diagnoses, which include an increase in self-esteem following disclosure (Huws et al., 2001; Jones, 2001) and an enhanced understanding of life circumstances (Bagatell, 2010; Davidson & Henderson, 2010). Conversely, other researchers have reported negative implications, including not coming to terms with their diagnosis and making an active effort to avoid awareness of it and/or disclosing it to others (Huws & Jones, 2008). Regardless, individuals with ASD may experience difficulties in a multitude of areas (e.g., social, cognitive, communication, etc.) and each of these unique difficulties could present challenges for which disclosure could have a bearing, and/or could affect elements of the disclosure process.

Present Study & Research Questions

The current study focused on a pressing issue of concern to many parents of a child with ASD; specifically, whether to, and if so how, to inform the affected child(ren) of their diagnosis. This study explored the lived experience of parents relative to their decision-making as it pertains to disclosure/non-disclosure of their child's ASD diagnosis to the child. Specifically, this study sought to illuminate the meaning and thought processes in relation to decision-making and results from this experience. This is an important area to consider as research has indicated that parents of children with ASD experience significant stress associated with their parenting and decisions associated with aspects of caregiving (Huws et al., 2001) even more than parents of children with other developmental disorders (Sanders & Morgan, 1997). A key concern of this study thus appreciates the complex process of decision-making surrounding whether, and if so how, to tell children with ASD about their diagnosis.

While best practice in pediatric health care suggests that parents are key members of the clinical team, family-centered care is often unsatisfactorily implemented within clinical practice (Kuo et al., 2012). As there is a great need to listen to and to hear the voices of parents on the issue of disclosure, this study valued how parents came to understand their decision surrounding whether to relay ASD diagnostic information to the affected child. Although researchers have explored the parental experience of assessment and diagnosis of ASD in children (Mansell & Morris, 2004), there has been little research focusing on if, how, when, and by whom children are informed of their ASD diagnosis. The current project was an Alberta-based investigation of parental experiences of diagnostic disclosure of ASD to their child(ren) with this diagnosis. Results have the potential to benefit the ASD community by expanding knowledge in this area through information guiding diagnosticians and other clinical support personnel, as well as the potential creation of an experience-based resource for families of children with ASD. Accordingly, it is hoped that the study will inform practice, diagnostic programming, and policy, with an aim of better serving individuals with ASD and their families. The following research questions were addressed:

1. What factors/considerations go into a parent's decision to disclose or not disclose their child's ASD diagnosis to the child?

2. How do parents navigate the disclosure process with their child?

3. How is disclosure experienced by parents who have a child with ASD?

4. What resources are perceived as necessary for supporting families in the disclosure process?

Following this introduction, Chapter Two provides a review of the literature surrounding ASD and how it relates to the notion of diagnostic disclosure. Chapter Two also outlines the

literature surrounding diagnostic disclosure from parents to children related to diagnoses beyond ASD, and the limited work that has focused on ASD in this area. Chapter Three focuses on methodology and the qualitative research design, including epistemological, ontological, and theoretical considerations. It outlines the descriptive phenomenological approach utilized in the study, including recruitment, data collection and analysis procedures, and an overview of ethical considerations salient to the study. Chapter Four encompasses the participant characteristics and study results – the product of data analysis – which entail the experiences of participants. Finally, Chapter Five reviews and integrates the findings pertaining to the decision-making process of parents related to disclosing or not disclosing their child's ASD diagnosis to their child. Lastly, the limitations, implications, and future directions of this research are presented.

Chapter 2: Literature Review

This chapter provides a review of the literature on Autism Spectrum Disorder (ASD) and its diagnostic process as it relates to the notion of diagnostic disclosure to parents by professionals. The limited literature on parental disclosure of an ASD diagnosis to a child is then explored to support the need for this emerging topic. Given the dearth of research in this area, literature addressing diagnostic disclosure in other pediatric non-ASD conditions, specifically developmental and/or genetic diagnoses, pediatric cancer, and perinatal human immunodeficiency virus (HIV), are also reviewed. This review of these diverse yet relevant literature bases offers emerging reflection and concepts that are not yet widely discussed within the ASD context.

Autism Spectrum Disorder

ASD is a pervasive neurodevelopmental disorder characterized by deficits in socio-communicative functioning in conjunction with restricted and/or repetitive patterns of behaviours, activities, and/or interests as described in the current edition of the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (*DSM-5*; American Psychiatric Association [APA], 2013). Specifically, individuals with ASD experience varying levels of impairment in the skills required for the healthy development of social reciprocity and peer relationships, along with delayed or atypical language acquisition, difficulties with pragmatic language use, and the presence of repetitive motor movements, fixations on routines, and/or intense preoccupations with certain topics or objects (Baron-Cohen et al., 1996; Haq & Le Couter, 2004; Kasari, Sigman, Yirmiya, & Mundy, 1993; Stephanos & Baron, 2011; Tager-Flusberg, 1999; 2001; Turner, 1999). These symptoms are present in early childhood and impair an individual's everyday functioning (APA, 2013).

It is important to understand that there is heterogeneity in phenotypic expression within ASD presentation (Szatmari et al., 2002) and that a diagnosis of ASD implies a lifelong pattern of atypical development that will impact not only the affected individual but also the family (Abbott et al., 2012). The severity and number of symptoms vary across individuals and, in some cases/diagnostic domains, across time (Richler, Huerta, Bishop, & Lord, 2010; Szatmari et al., 2002). There is also variability in intellectual functioning among those with ASD, with 44% exhibiting average or above average cognitive functioning (Intelligence Quotient [IQ] > 85), 25% presenting with borderline intellectual functioning (IQ score of 71-85), and 31% presenting with an Intellectual Disability (ID; IQ of ≤70; Baio et al., 2018). However, as it appears that there are several potential genetic and environmental factors that contribute to ASD symptomatology, a specific etiological cause has not yet been uncovered (Betancur, 2011; Hall & Kelley, 2014; Happé, Ronald, & Plomin, 2006).

Population demographics indicate a male to female gender ratio of 4.5:1 in ASD, ranging from 4:1 to 6.3:1 (APA, 2013; Baio et al., 2018; CDC, 2016; Newschaffer et al., 2007). Functional impairment may become obvious at different developmental stages and will vary according to environmental and individual characteristics (APA, 2013). Thus, ASD is considered a spectrum disorder with individuals demonstrating differential cognitive, social, language, and behavioural abilities (Johnson & Myers, 2007). Overall outcomes for individuals with ASD vary greatly and many individuals exhibit significant impairment over their lifetime (Howlin, Goode, Hutton, & Rutter, 2004).

Changes to diagnostic criteria. The diagnostic criteria for Neurodevelopmental Disorders in the most recent revision of the *DSM-5* (APA, 2013) encompassed major alterations to the previous diagnostic criteria from the *Diagnostic and Statistical Manual of Mental*

Disorders, Fourth Edition, Text Revision (*DSM-IV-TR*; APA, 2000; Kim et al., 2014). Within the *DSM-IV-TR,* criteria for Pervasive Developmental Disorders (PDD) included five sub-diagnoses: Autistic Disorder (AD), Asperger's Disorder (also referred to as Asperger's Syndrome [AS]), Rett's Disorder, Childhood Disintegrative Disorder (CDD), and Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS), which had been previously considered under the umbrella term of Autism Spectrum Disorders (APA, 2000). Within the *DSM-5*, diagnostic revisions included: (a) the removal of the PDD overarching category and the five subtypes; (b) the addition of a new diagnostic label of ASD to encompass four of the previous subtypes: AD, AS, CDD, and PDD-NOS; (c) a change from three previous domain categories of impairment (social interaction, communication, and restricted and repetitive behaviours [RRB]) to two (social communication and interaction, and RRB); (d) the inclusion of sensory differences or symptoms under the RRB category; (e) the inclusion of severity specifiers to further describe domain areas (requiring support [level one], requiring substantial support [level two], and requiring very substantial support [level three]), and subsequent specifiers to further outline presentation (e.g., pertaining to intellectual impairment, language impairment, etc.); and (f) a change around the age of onset, from before three years of age (*DSM-IV-TR*) to presentation in early development (APA, 2000; 2013; Kim et al., 2014). Lastly, within the *DSM-5* (APA, 2013) the newly related diagnostic label of Social (Pragmatic) Communication Disorder (SCD) was added for individuals presenting with impairment in the social pragmatic use of language.

Prevalence of ASD

Until recently, the prevalence of ASD has been estimated to be 2.47 percent (Xue, Strathearn, Liu, & Bao, 2018), a rate that is substantially higher than in previous studies (Baird et al., 2006; Baron-Cohen et al., 2009; Boyle et al., 2011; Brugha et al., 2009; CDC, 2016;

Chakrabarti & Fombonne, 2005; Fombonne, 2003; Fombonne, 2009; Kim et al., 2011; Kogan et al., 2009; Newschaffer et al., 2007). Though, the Public Health Agency of Canada's *National Autism Spectrum Disorder (ASD) Surveillance System* (NASS) just recently published Canada's first national report on the prevalence of ASD and indicates that among children aged 5 to 17 years, 1 in 66 have received an ASD diagnosis (approximately 15.2 per 10,000; Ofner et al., 2018). The *Autism and Developmental Disabilities Monitoring Network* (ADDM; Baio et al., 2018) has also just reviewed the data from 2014 in the United States and has indicated that among children aged eight, 1 in 59 have received an ASD diagnosis (approximately 16.8 per 1000). Moreover, the most recent *National Health Statistics Report* indicates that there has been a significant increase in the estimated prevalence of ASD in children ages 3 to 17 years in 2014 (2.24%) when compared to 2011-2013 (1.25%; Zablotsky, Black, Maenner, Schieve, & Blumberg, 2015). In fact, the first survey completed in 1966 indicated an estimated prevalence in young children at 4-5 per 10,000 (Lotter, 1966). In 2005, the United States Department of Education found that ASD was increasing at a rate of 10 to 17 percent per year; thus, it is no surprise that the current prevalence rate is substantially higher. As a result, researchers and clinicians are becoming more aware that enhanced and ongoing support for these individuals and their families through the diagnostic process is of utmost importance.

ASD Diagnostic Process

Raising a child is a difficult endeavor that can be made even more challenging when a child has a developmental disorder such as ASD. Indeed, this additional struggle can increase stress regarding parents' skills and decisions (Huws et al., 2001), and research has indicated that parents of children with ASD experience greater stress than parents of children with other developmental disorders (Sanders & Morgan, 1997). A source of this parental stress is the

process of receiving a formal diagnosis for one's child and the subsequent decisions that need to be made (Oswald, Haworth, Mackenzie, & Willis, 2017; Reed & Osborne, 2012).

Although clinical assessment and diagnostic practices for ASD continue to be complex and variable, researchers have investigated the typical process through which parents and their child work with professionals to obtain a diagnosis for the child (Mansell & Morris, 2004). Assessment and diagnosis of ASD most often occur before elementary school age (CDC, 2016; Oswald et al., 2017; Shea & Mesibov, 2009). Practitioners often strive to diagnose children as early as possible (e.g., at or before the age of two years). Although it has been reported that the age at initial diagnosis for ASD is decreasing, currently diagnoses are often made between the age of 38 and 120 months (Daniels & Mandell, 2013). Many families report that although they may seek an assessment as early as 18 months, the process of ASD assessment can be lengthy and arduous (Oswald et al., 2017). Moreover, despite earlier expressed concerns about development, children diagnosed with ASD receive a diagnosis approximately seven months later (on average) than children with alternate developmental diagnoses (Oswald et al., 2017). Formal assessment and diagnosis are considered important for enhanced prognosis as children are able to access interventions and supportive services at an earlier stage in development, thus improving developmental outcomes (Remington et al., 2007).

Although ASD diagnoses often are not made until two years of age, many parents notice atypicalities in development and behaviour prior to seeking out a diagnostic assessment (Mansell & Morris, 2004; Midence & O'Neill, 1999; Oswald et al., 2017). Thus, the diagnostic process usually begins once a parent, guardian, or other supportive individual notices developmental or behavioural atypicalities in the child such as delayed or lacking imitation skills, not sharing attention and focus with social partners, inability to orient to socially important stimuli, and/or

atypical language development, including delayed acquisition of single words and/or phrased speech, delayed or atypical expansion of abilities, or loss of previously developed skills (Dawson, Meltzoff, Osterling, Rinaldi, & Brown, 1998; Howlin & Moore, 1997; Osterling & Dawson, 1994; Stephanos & Baron, 2011). These concerns subsequently lead parents to seek professional opinion on the nature of the behavioural differences, during which a diagnosis is considered (Mansell & Morris, 2004). Although there are many domains assessed and many approaches to assess each (Klin, Saulnier, Tsatsanis, & Volkmar, 2005), best practice standards indicate that an assessment should be both comprehensive and developmental in nature so that an accurate picture of the child's functioning and behaviours can be established in relation to both normative (relative to same-age peers) and ipsative (relative to self, as a comparison between the individual's past and current developmental level) standards of development (Campbell, Ruble, & Hammond, 2014). In addition, the use of a multidisciplinary team (i.e., pediatricians, psychologists, speech-language pathologists, occupational therapists, etc.) is recommended so that professionals with specific training and experience can evaluate the child's skills and abilities across a variety of domains (Volkmar et al., 2014). Upon conclusion of this process, diagnostic conclusions are typically provided during a feedback meeting to parents who then seek support and services for their child.

Researchers have explored how clinicians provide feedback regarding an ASD diagnosis in an effort to understand how best to provide information and feedback to parents in a sensitive and informative manner. Parental reaction to the diagnostic process can vary from relief to anger or sadness (Nissenbaum, Tollefson, & Reese, 2002), and adjustment to the diagnosis can be challenging for some parents (Midence & O'Neill, 1999). Indeed, research has indicated that

parental coping with receiving an ASD diagnosis for their child is based upon a number of factors including satisfaction with the diagnostic process (Reed & Osborne, 2012).

ASD Diagnostic Disclosure to Parents

Once a diagnosis has been conveyed, parents typically engage in a process of coming to terms with the implications for their child, commonly referred to as diagnostic resolution (Pianta & Marvin, 1993). In essence, once a diagnosis has been communicated, parents typically proceed through a process of grieving for the loss of the life that they had envisioned for themselves and their child (Avdi, Griffin, & Brough, 2000; Wachtel & Carter, 2008). Resolution could involve parental acceptance of the diagnosis as demonstrated by parents incorporating it into their own reality without blame (to self or others) or guilt as the source of the child's developmental difficulties (Pianta & Marvin, 1993). A significant component of moving towards resolution of an ASD diagnosis is addressing the stigma often associated with the diagnosis (Huws et al., 2001). This stigma reflects the fact that children with ASD often do not differ physically from other children; rather, it is their socio-communicative and behavioural challenges that distinguish them. As such, children with ASD and their parents can be vulnerable to stigma from others who fail to understand how and why children are behaving the way that they are, often with erroneous blaming and/or assumptions of poor parenting (Birenbaum, 1992). Parents may often then be faced with the challenge of deciding if, how, and to whom the diagnosis is disclosed (Huws et al., 2001).

Researchers and clinicians have devoted substantial effort towards better understanding best practice standards for clinical assessment and diagnosis of ASD, including effective approaches to disclosing the results of a diagnosis to parents of an affected child. However, the disclosure of the diagnosis to the parent is often seen as the standard endpoint of the diagnostic

process, despite research suggesting that parents continue to experience challenges with the diagnosis well past the point of receiving it (Stuart & McGrew, 2009). Thus, continued support and the provision of follow-up services for families after receiving a diagnosis is an essential factor in helping families to adjust and continue to meet the needs of their family (Banach, Iudice, Conway, & Couse, 2010). Further, the topic of disclosure of the diagnosis to others has been relatively ignored, and the child is not often included in this diagnostic conversation. This notion is particularly important when considering the disclosure of the diagnosis to the child with ASD and its potential impacts on the family as a whole. Given the pervasive nature of ASD and the fact that many individuals are cognitively capable of understanding their personal challenges with social interactions, communication, and behaviours, it would seem to make sense that for a large portion of individuals with an ASD diagnosis disclosure to the individual could constitute a continuation of the diagnostic process. Thus, research and clinical work should focus on the disclosure process and potential outcome of that activity relative to the age and developmental level of the child.

Parental perceptions of disclosure. Parents may experience a variety of emotional responses, ranging from anger to relief to sadness, throughout the ASD diagnostic process (Finnegan, Trimble, & Egan, 2014; Nissenbaum et al., 2002). Research findings suggest that a number of factors can lead to greater parental satisfaction with the diagnostic process: a rapid diagnostic process; evidence-informed, practical, and clear information from the diagnosing professional; the receipt of written information about the diagnosis; the opportunity to ask questions; clear explanations from the beginning to the end of the assessment process; early parental suspicions pertaining to potential ASD being respected by professionals; and, sufficient information provided upon disclosure regarding next steps for support and early intervention

services (Brogan & Knussen, 2003; Crane, Chester, Goddard, Henry, & Hill, 2015; Howlin, 2008; Howlin & Moore, 1997; Minnes & Steiner, 2009; Moh & Magiati, 2012). Parents reported less stress and greater satisfaction when there was strong collaboration between parents and professionals (Moh & Magiati, 2012). Additionally, timing, attitude of professionals, and time spent to explain and answer questions during the feedback meeting positively impacted parental satisfaction (Bartolo, 2002; Brogan & Knussen, 2003; Chiu et al., 2014; Osborne & Reed, 2008).

Although best practice for professionals has been advocated within the literature, many parents still indicate dissatisfaction with the lack of information provided about ASD and the limited support given by professionals during the diagnostic process (Siklos & Kerns, 2007). For example, one study found that 93% of parents who were dissatisfied with the diagnosis disclosure process due to diagnostic timeframe delays, as well as an insensitive and blunt professional approach that led to increased feelings of guilt (Chamak, Bonniau, Oudaya, & Ehrenberg, 2011). It has also been reported that how professionals offer and explain the diagnosis can be difficult for parents to understand, interpret, and process (e.g., use of jargon, too much paperwork to interpret, unable to ask questions; Braiden, Bothwell, & Duffy, 2010).

Overall, parents have reported numerous factors associated with their perception of satisfactory and unsatisfactory diagnostic disclosure. Learning of a child's diagnosis may influence parental thoughts, feelings, and attitudes towards the diagnosis (Abbott et al., 2013) and subsequently how the parents respond to their child, thus potentially vicariously impacting their family. Learning about a child's ASD diagnosis may be very positive and informative for some parents. Abbott and colleagues (2013) indicated that some parents felt relief when learning of the diagnosis as it provided an explanation for their child's challenges. Other researchers have indicated that a diagnosis can provide the forum and language for parents to communicate about

their child's strengths and challenges within a supportive community (Avdi et al., 2000; Calzada, Pistrang, & Mandy, 2012; Nissenbaum et al., 2002). Moreover, it has been indicated that receiving their child's diagnosis has supported some parents to deal with their emotions (i.e., blame and guilt; Midence & O'Neill, 1999), as they no longer placed blame on themselves for their child's difficulties or deviation from typical development. Other studies report negative impacts, which are further addressed below.

While many parents have reported on the positive parental impacts of diagnostic disclosure, some have also indicated negative implications. Abbott and colleagues (2013) shared that the emotional impact of diagnostic disclosure negatively impacted some families' ability to absorb the information presented in the feedback meeting. For these families, this emotional impact often persisted through the final meeting and parents reported feeling mentally exhausted and lost (Abbott et al., 2013). Finnegan, Trimble, and Egan (2014) have also indicated that parents often experience challenges after receiving a diagnosis in their search for appropriate supports and fears while looking towards the future (e.g., uncertainty of how and what supports to access).

Overall, parents may experience a variety of initial reactions, emotions, thoughts, and experiences upon learning of their child's ASD diagnosis. Researchers have indicated that there may be both positive and negative parental responses to receiving their child's ASD diagnosis (Avdi et al., 2000; Finnegan et al., 2014; Nissenbaum et al., 2002), and parents have reported varying levels of satisfaction with the diagnostic process (Abbott et al., 2013). This research plays a key part in understanding parental perspectives surrounding diagnosis disclosure.

Individual Perspectives

ASD diagnosis disclosure may have a range of impacts for an affected individual's life. Some individuals with ASD have reported that learning about their diagnosis had some negative effects as the perceived label was stigmatizing, discriminative, and/or prejudicial (Huws & Jones, 2008; Mogenson & Mason, 2015). These individuals attributed some of their experienced stigma as *undesired* differentness (Mogenson & Mason, 2015). Upon diagnosis disclosure, some young adults in a college environment reported feeling "shock, disappointment, and disbelief" (Huws & Jones, 2008, p.104) as there had been a delay between the time of diagnosis and subsequent disclosure (e.g., age four at diagnosis and age 15 at disclosure; Huws & Jones, 2008). Correspondingly, some individuals avoided information about their diagnosis, did not want others to know, and could not identify any benefits associated with an ASD diagnosis (Calzada et al., 2012; Mogenson & Mason, 2015). Another study indicated feelings of anxiety (25%), upset (17.2%), anger (12.5%), and/or confusion (24.2%) upon initially learning of their ASD diagnosis, and many reported dissatisfaction with the diagnostic process (Jones, Goddard, Hill, Henry, & Crane, 2014). Some individuals who indicated negative feelings towards a diagnostic and labeling approach reported that they wanted ASD to be framed positively and conveyed in a pride-nurturing way (Linton, 2014).

For others, learning about their ASD diagnosis was positive and legitimized differences, provided necessary supports, and "in some instances… [helped] to clarify the significance of the individual's previous life experiences" (Huws & Jones, 2008, p. 105). Some individuals have described feelings of relief, happiness, and satisfaction upon learning about their ASD diagnosis (Jones et al., 2014). Furthermore, a recent study found that individuals expressed many significant benefits, including a sense of comfort and relief from being better able to understand

their challenges and having tools to help them move forward (Lewis, 2016). The study also

suggested that the transition from misunderstanding to acceptance could only occur through

receiving a diagnosis as many individuals already struggle to understand themselves regardless

of a diagnosis. Other individuals have described the diagnostic process and learning of their

diagnosis as liberating (Mogenson & Mason, 2015). More specifically, for these individuals,

receiving a diagnosis was a "means of situating themselves in relation to normative

experience…connected with their understandings of identity" (Mogenson & Mason, 2015, p.

259). The diagnosis then helped these individuals to reframe their difficulties, legitimizing their

experiences of being different and gaining insight into their own lives (Mogenson & Mason,

2015).

Overall, there is heterogeneity among individual ASD experiences and the impacts of

diagnostic disclosure. Such heterogeneity speaks to the diverse nature, characteristics, and

experiences of individuals with ASD, their families, other supportive individuals, and the

diversity of ASD itself. Although the above information has provided insight into negative and

positive impacts related to learning about one's diagnosis, there has been a paucity of work

exploring parents' disclosure of the diagnosis of ASD to their child with ASD.

Diagnostic Disclosure to Children

The process and effects of childhood diagnosis disclosure have not been well studied or

documented (Vreeman et al., 2013). For the purposes of this review and project, disclosure of a

diagnosis by a parent is defined as a child gaining awareness of their diagnosis/disorder from a

parent or guardian (biological, foster, or adoptive; Vreeman et al., 2013). Furthermore, the

disclosure can occur during a single instance or as a process that unfolds over time (Krauss,

Letteney, de Baets, Baggaley, & Okero, 2013). The disclosure process has been seen by some

parents as a significant event whereby children find some understanding or clarity about prior life experiences (Huws & Jones, 2008). Disclosure of a diagnosis to the child may also be important in the process of intervention and treatment planning (as the child can be an active member within the planning process and potentially better understand why they are being exposed to interventions), may allow for children to act as their own self-advocate, and aide in the creation of a support network (e.g., peers or other supportive people; Huws & Jones, 2008; Vreeman et al., 2013).

As noted earlier, most research in this area has focused on the process of diagnostic disclosure from professionals to parents. In contrast, parental disclosure of an ASD diagnosis to an individual and the means by which that disclosure is communicated has received very little empirical attention. As such, the limited literature on the parental disclosure of an ASD diagnosis will first be reviewed, and as there is very limited information, a broader discussion of psychologist and/or parent disclosure of other (non ASD) diagnoses will then be explored below.

Parental disclosure of an ASD diagnosis. Although researchers have explored the topic of disclosure from professionals to parents, the subject of parental disclosure of an ASD diagnosis to a child has received little research attention. A review of the existing literature suggests that many factors should be considered when deciding if and when disclosure is right for a specific family, regardless of the type of diagnosis. For the most part, the research findings indicate that children fare well upon learning about their diagnosis (Miller, 2015). Naturally, gaining insight into ASD diagnosis disclosure would be of vital importance as the process by which individuals with ASD are informed of their diagnosis is likely to have significant impact upon their well-being, receptiveness, and subsequent acceptance and understanding of the diagnosis (Domek, 2010; Vreeman et al., 2010). More specifically, individuals with ASD may

also experience difficulties in a multitude of areas (e.g., social, cognitive, communication, etc.) and each of these unique difficulties could present different challenges within the disclosure process. There is a need for ASD-specific literature informed by parents and children/youth pertaining to diagnostic disclosure as many social and interpersonal skills have been shown to develop over time for individuals with ASD with intervention in place (Huws & Jones, 2008; Mesibov & Handlan, 1997). Thus, it is critical to better explore the potentially unique impacts of parental diagnosis disclosure to individuals with ASD.

Results of the few published studies on the topic of disclosure of an ASD diagnosis to an individual with ASD indicate predominantly positive findings regarding outcomes. For example, some researchers describe the positive impacts of diagnostic disclosure, including an increase in self-esteem in affected individuals following disclosure of the diagnosis (Huws et al., 2001; Jones, 2001). It has also been suggested that individuals with ASD report a better understanding of their life circumstances (Bagatell, 2010; Calzada et al., 2012; Davidson & Henderson, 2010) and their behaviour and treatment by others when informed of their diagnosis (Huws & Jones, 2008). Additionally, some individuals report that ASD is something to be proud of and that the diagnosis disclosure positively affected their life (Davidson & Henderson, 2010).

Conversely, some researchers have reported negative implications of both receiving an ASD diagnosis and disclosing an ASD diagnosis to an individual. For example, Huws and Jones (2008) reported that some affected individuals reject their diagnosis and sought to avoid awareness of it and its disclosure to others. As well, these researchers reported that some individuals with ASD believe that the diagnosis provides a "stereotyping label that could be used by people without Autism to make prejudgments" (Huws & Jones, 2008, p. 103). Parents of individuals with ASD also reported hesitancy with disclosing diagnoses for similar reasons, as

they desired to protect their child from potential stigma associated with a clinical disorder, and what they viewed that disorder to subsequently entail (Finnegan et al., 2014; Todd & Shearn, 1997).

An unpublished dissertation by Duprey (2011) evaluated the parent disclosure process when sharing an Autism Spectrum Condition ([ASC]; a term used by the author to be synonymous with ASD) with a child. Duprey utilized a grounded theory methodology, and interviewed 10 parents (representing 10 children with diagnoses). Within this study, participants were recruited from both rural and urban areas, reflected some factors of family diversity (e.g., inclusion of single parent family, and step-parent household), and diversity in terms of developmental level and severity of ASC traits (Duprey, 2011). However, Duprey indicated that her sample size was small for grounded theory research in seeking maximum variation, and included a sample that was more homogeneous than had been initially planned (e.g., all participants came from the East Anglia region, largely consisted of two biological parent dyads, seven children had an Asperger's diagnosis, and all families were accessing support from a charitable organization).

Within this study, Duprey (2011) found three common themes expressed by participants: ambivalence (e.g., resources are too limited to consider sharing the diagnosis), inclination toward sharing the diagnosis (e.g., parents valued open communication and honesty with their child), and inclination toward not sharing the diagnosis (e.g., potential negative stigma and consequences associated with a diagnostic label). Duprey (2011) developed a three-stage theoretical model for parental disclosure to a child with an ASC: "consideration and preparation, disclosure, and consequence" (p. 106), with all stages influenced by parents' perspectives about potential risks and rewards of disclosing a diagnosis. This model described the process of

disclosure as cyclical such that parents are described to often revisit their initial thinking and orientation relative to ASD and disclosure, prior to sharing more information with their child.

Duprey further illuminated how parents described the disclosure process as "gradual and shifting over time, as their child becomes more aware of difference and their own strengths and limitations" (2011, p. 63). Duprey found that the disclosure process was more than "simply sharing the diagnostic label with the child" (p. 128), and further involved sharing its implications and parental concerns. Overall, Duprey's findings indicated that isolating the separate aspects of the disclosure process (e.g., parental acceptance of the diagnosis, weighing the pros and cons of diagnosis disclosure, etc.) appeared difficult to do, as it seemed to be a complex phenomenon interwoven within itself.

In an Irish study, Finnegan and colleagues (2014) reported on the process of disclosure versus non-disclosure in a study reflecting the perspectives of seven parents, using an interpretive phenomenological analysis (IPA) approach to data analysis. Participants within this study included a small sample size of six mothers and one father, all with a son with Asperger's syndrome or high-functioning Autism. Within this study, parents indicated that they wanted to wait for the right age and place for disclosure relative to their child, at which point learning about the diagnosis was viewed to nurture the process and information as useful rather than stigmatizing. Parents reported not wanting their child to develop a negative self-image and feared that diagnosis disclosure may overwhelm them (Finnegan et al., 2014). Overall, Finnegan et al. (2014) concluded that "open communication with the child regarding their disability seems necessary to provide them with the tools for dealing with their lives" (p. 11).

A second unpublished dissertation by Rossello (2015) investigated the process and effects of parental disclosure of a diagnosis of Asperger's disorder to adolescents. Rossello

utilized a descriptive phenomenological approach, and interviewed four adolescents with a diagnosis of Asperger's disorder (ages 13-17) and their parent dyads, for a total of 12 participants. Within this study, participants must have had their diagnosis disclosed to them at least one year prior to participation, were all located in the Los Angeles area, three of four adolescents attended private schools, and were recruited by a community organization that provides services to children with ASD.

Rossello (2015) explored parental preparation for disclosure, methods of disclosure, any changes parents would have made to the disclosure process, helpful supports, level of confidence during disclosure, and any observable changes in their child's behaviour or mood. Further to this, Rossello (2015) also explored the adolescents' feelings and reactions upon learning about their diagnosis. Participants expressed that their home was commonly the location where disclosure occurred, parents rated themselves as having an above average level of confidence during disclosure regardless of preparation, and they indicated that positive shifts in mood and behaviour were observed following disclosure. Rossello's study also indicated that parents often wished there were guidelines on how, when, and what to say during disclosure. Moreover, the reported feelings and reactions of adolescents varied following disclosure; however, most indicated that they wished they had learned about their diagnosis earlier.

Rossello's study found that fathers were more likely to report wishing they had received and disclosed the diagnosis sooner to their child; whereas mothers more frequently shared that they sought out an online community or support group during the disclosure process (2015). There were no reported correlations between age at time of disclosure and observable changes following disclosure. Moreover, it was found that parents often reported feeling more comfortable during disclosure if they had sought advice from a professional or done their own

research prior to disclosure occurring. Overall, Rossello indicated that more research is needed to better determine a best practice for disclosure, specifically surrounding timing, location, and methods for disclosure.

Although the limited literature base on the disclosure of ASD to a child has suggested potential parent considerations around the disclosure process, there is a paucity in the way of empirical evidence to support these initial considerations. Thus, much of the advice available to parents seeking guidance during this process is based on the clinical experience of professionals, and the personal accounts of parents and individuals on the spectrum (Whitaker, 2008). These sources of information, although not all contained within evidence-based studies, may prove useful for parents and thus selected non-peer-reviewed reports have been included below.

One clinician developed an adult-guided workbook for use with individuals who have ASD and average cognitive functioning to support them in understanding themselves and their diagnosis using the *I am Special* program (Vermeulen, 2013). Vermeulen describes this program as grounded in research, and "based on what scientific studies revealed about the self-knowledge of people with Autism Spectrum Disorders and the difficulties they experience when trying to understand their diagnosis" (2013, p. 20). Within this program, Vermeulen (2013) includes information on introducing Autism, with specific sections including explaining Autism to the person with ASD, why we should explain ASD, at what age should disclosure occur, who should disclose, the different stages of disclosure, special attention paid to the individual's self-esteem, and adapted communication. More specifically, the *I am Special* program outlines that disclosing and explaining ASD to someone who has ASD is a complex and difficult process. Vermeulen explains that many people with ASD have a difficult time understanding abstract concepts, engage in black and white thinking, and that the person who is disclosing must be careful not to

overestimate the individual's comprehension of the information being shared. Within this program, he outlines several reasons why the process of disclosure should begin: to ensure the people with ASD have realistic expectations for their future; as an awareness of their own behaviour to express, adapt, and protect themselves; to help individuals better find solutions to challenging situations (e.g., bullying); and, to better answer the questions that individuals are likely already asking (e.g., what's wrong with me?).

Vermeulen (2013) goes on to indicate that there is not a fixed age or point in time when disclosure should occur, but instead it depends on the cognitive functioning of the individuals, life circumstances, and how they react to their environment. However, he stresses that its best not to provide more information than individuals can understand and that explaining ASD should occur as a staged process over time. Vermeulen describes these stages as understanding about the human body, information about how the brain works, understanding that people are different (both inside and out), and then understanding the difference between illness, disorder, and disability. Hence, he explains that disclosure is a long-term process and should be started by a person who can guarantee continuity. Furthermore, he suggests that although parents can often assure continuity and that they are available to answer questions, he recommends that they are not the primary people in charge of disclosure. He instead suggests that disclosure should occur initially from a professional with knowledge about ASD and that parents assume a supportive role as their child understands ASD and what the diagnosis means for them. Lastly, Vermeulen discusses adapted communication, with special attention paid to the individual's self-esteem to ensure that disclosure occurs in a positive light without creating false hope. Vermeulen provides several strategies to help individuals understand and cope with the news of their diagnosis: provide information in small chunks, interspersed with breaks; adapt communication so that they

pay attention to the content of the message being communicated; emphasize that people are more than their limitations or disorder; create a healthy balance between affirmation and confrontation; allow for enough time to reflect and ask questions; and use a sense of humour.

Another clinician shed light on when the disclosure process should be started for individuals with ASD through the use of the *All About Me programme*. Andrew Miller developed this program as a way to "explain and share the diagnosis with the child, with their parents present" (Miller, 2015, p. 79). Miller (2015) indicated that children should participate in the program when parents provide consent and a variety of criteria have been met. Miller identified these criteria as: the child having communication and cognition skills sufficient to understand shared concepts, ability to engage in the outlined sessions with the professional and parent, and awareness or a developing understanding of how all people are unique and different. Further, disclosure should be done at a time when knowing or learning about ASD may potentially improve the individual's everyday life (Miller, 2015). Overall, Miller indicated that for the four children (and associated parent) who participated in this program, learning about their ASD diagnosis appeared to be a positive experience based on informal evaluation (e.g., observation). However, this author suggests that even when children go through the disclosure process within this program, it is difficult to tell if they fully accept and understand their diagnosis after only three sessions. Therefore, Miller (2015) expressed the essential supportive role that parents play at diagnosis and over time, within the disclosure process.

Attwood (2007) recommends telling children about their ASD diagnosis, indicating that many children may experience relief when learning that they are not "weird" (p.330). Based on clinical experience, Attwood (2007) recommends that the process of disclosure be age-appropriate and explain individual differences (e.g., strengths and difficulties). This point can be

further exemplified, through one individual's self-reported lived experience, as discussed in the book: *Freaks, geeks and Asperger syndrome: A user guide to adolescence* (Jackson, 2002). Luke Jackson (age 13), a child with Asperger Syndrome, writes:

"I had finally found the reason why other people classed me as weird. It was not just because I was clumsy or stupid. My heart lightened instantly and the constant nagging that accompanied me all my life (not my mum) stopped immediately. I finally knew why I felt different, why I felt as if I was a freak, why I didn't seem to fit in. Even better, it was not my fault! So my final word on the subject is *get them told!"* (p. 34-37).

Further to this individual perspective, a parent's perspective of disclosure is described in *Coming out Asperger: Diagnosis, disclosure and self-confidence* (2008). The mother of a young person suggests that there is never a right or wrong time to tell a child about her/his/their diagnosis, but parents should use their judgment about the right time and way to inform the child (Jackson, 2008). Moreover, Whitaker (2008) emphasized that future research should investigate different disclosure approaches, shed light on developmental strategies, and provide guidance on how and when the disclosure process should be started.

This literature review has highlighted a range of experiences and perspectives among individuals with ASD and their parents when learning about and sharing an ASD diagnosis. Such heterogeneity speaks to the diverse nature, characteristics, and experiences of individuals with ASD, their families, and their support networks, and the likely variation in experience and preference related to diagnosis disclosure. Based on empirical evidence, the literature has not yet provided a guide for when and how families should disclose the diagnosis. Despite a range of considerations pertaining to diagnostic disclosure to an individual with ASD, limited research has been conducted to investigate this topic.

Although the subject of disclosure of an ASD diagnosis has received little research attention, some researchers have explored the topic of disclosure of other developmental, genetic (Gallo, Angst, Hadley, & Smith, 2005; Perry et al., 2005; Sutton et al., 2006; Todd & Shern, 1997), or chronic medical diagnoses to children (i.e., pediatric cancer or HIV; Vreeman et al., 2013; Young et al., 2003). While there are vast differences between these diagnoses and ASD (e.g., concerns over HIV transmission, and treatment for pediatric oncology), there are many connections that can be made between these diagnoses and thus will be explored in more detail below.

Psychologist disclosure of mental health diagnoses. There is limited research that has explored diagnosis disclosure to children; however, an unpublished dissertation by Allmon (2014) examined psychologist disclosure processes related to conveying mental health diagnoses (e.g., social-emotional diagnoses and/or cognitive diagnoses) to a child, using an online analogue mixed-methods approach. Allmon specifically explored the extent to which psychologists were likely to disclose a diagnosis to a child relative to client (age, cognitive ability, culture) and psychologist (years of service and type of clinical services provided) characteristics. Allmon recruited 47 psychologists for participation and found six common factors that were considered prior to a decision to disclose: "(1) child characteristics (i.e., age, culture, cognitive ability, maturity, developmental and functioning level), (2) support (family, social, therapeutic relationship), (3) personal beliefs about disclosure, (4) diagnostic characteristics (e.g., prevalence, public familiarity, current biological evidence, stigma), (5) how to provide a supportive disclosure (e.g., child friendly language), and (6) potential benefits" (Allmon, 2014, p. iv). Results revealed that psychologists were more likely to disclose a diagnosis to an older child (16 years of age or older), to a child with an American cultural background rather than

Chinese-American background (or other ethnicities), and to a child with an IQ in the superior range. Allmon also provided participants with an opportunity to share their current practice around disclosure, with common themes including: a supportive stance (i.e., indicated the significance of support from psychologists, family, or peers during the disclosure process for normalization or comfort); treatment implications (i.e., discussed the impact of disclosure on compliance with mental health treatment and treatment prognosis); child characteristics (i.e., consideration of the child's individual or demographic factors); the child's right to know about one's diagnosis (i.e., child deserves to have disclosure occur in an understandable way, so that they can better make informed decisions about their own treatment); and parental involvement (i.e., parental consent, preference, and choice in disclosure). Participants in this study indicated that they considered both the child's internal factors (age, cognitive ability, developmental and functioning level, diagnosis, culture, and maturity) and external context (i.e., is their home supportive?) prior to assisting in the disclosure process. Specifically, participants in this study shared that regardless of the professional's feelings around children's rights to know their diagnosis, parental preference was underscored as important and thus this researcher inquired about the role that psychologists should play in the disclosure process (Allmon, 2014). However, Allmon also indicated that "more prominent than acknowledging parent preference in participants' responses, was the examination of a child's desire and right to know their diagnosis" (2014, p. 114). Overall, this study suggested the need for future qualitative investigation on the decision-making steps and specific factors that psychologists consider in their decision to disclose a diagnosis to a child.

Parental disclosure of non-ASD diagnoses. There is limited research that focuses on parental disclosure of a non-ASD developmental or genetic disorder to children, with only four

articles found subsequent to a comprehensive search of the literature. These articles are discussed in more detail below.

Learning disability. One study reported on parental disclosure of a learning disability to an adult child (Todd & Shearn, 1997), using a grounded theory approach. Although the definition of learning disabilities has not remained static, the Learning Disabilities Association of Canada (LDAC) associates learning disabilities with a range of disorders that "result from impairments in one or more processes related to perceiving, thinking, remembering or learning" (LDAC, 2015, para. 2). Moreover, learning disabilities are lifelong, range in severity, and may interfere in the use or acquisition of reading, oral language, written language, or mathematics (LDAC, 2015). Todd and Shearn (1997) collected their data from a larger qualitative study in Wales and included the parents of 18 adult women, and 15 adult men with learning disabilities living in the family home. Data collection for this study involved three or four in-depth interviews over the span of 18 months.

Todd and Shearn (1997) found that "parents were important mediators of the relationship between their offspring and the wider world… (and) had extended the durability of Goffman's protective capsule," (e.g., a means to protect a child from potential stigmatization; p. 362); they further reported several stated consequences from a strategy of non-disclosure (Todd & Shearn, 1997). In fact, these authors referred to this non-disclosure strategy as *fictional identity building* and it was identified that parents in this study felt they had to deal with the continued distress of misleading their child. Moreover, these authors concluded that although breaking the news to a child may be emotionally charged and possibly painful, it is an essential step for individuals with a learning disability to build their own self-identity and to have control over their own lives (Todd & Shearn, 1997).

Attention-Deficit/Hyperactivity Disorder. In an examination of parental perspectives of

Attention-Deficit/Hyperactivity Disorder (ADHD), many parents stated that disclosing ADHD to

their child was a worrisome undertaking (Perry et al., 2005). ADHD is a neurodevelopmental

disorder described as "a persistent pattern of inattention and/or hyperactivity-impulsivity that

interferes with functioning or development" (APA, 2013, p. 59). Perry and colleagues (2005)

utilized a grounded theory approach and involved qualitative interviews conducted with 24

Latino families. Perry and colleagues (2005) found that a subgroup of parents who chose a

process of non-disclosure, as illustrated by one mother who reported that she "did not know the

best way to tell him [her son]" (p. 317). In contrast, other parents reportedly sought information

about ADHD and tried to offer an explanation of the diagnosis in child-friendly terms. Parents

who chose to disclose stated that they hoped to ease their child's fear, worry about potential

stigma, and difficulty adhering to medication and intervention regimes (Perry et al., 2005).

Genetic conditions. Another article discussed parental beliefs and strategies surrounding

the disclosure of a genetic condition to affected children (Gallo et al., 2005). Gallo and

colleagues (2005) utilized a qualitative narrative approach and the sample included 139

parents/caregivers (86 families) of children with various genetic conditions, including but not

limited to cystic fibrosis, hemophilia, sickle cell disease, phenylketonuria, and other conditions

resulting from single gene mutations. This study recruited their sample from a larger overarching

project, and examined the results of five questions from the larger 37-question semi-structured

interview protocol. Findings indicated that parents/caregivers initially focused on disclosing

information pertaining to the management of the genetic condition with a specific focus on

maintaining a positive attitude. Moreover, parents/guardians were more inclined to start

disclosing information to their child(ren) when the child displayed curiosity or began asking

questions, and to continue from that point forward. Some parents/guardians indicated that they had not (yet) disclosed, as they thought their child was too young or was not ready to understand and process the information. Overall, the authors expressed that parental disclosure was often situated in parents' aim of promoting positive adaptation, was based on the perception of a child's developmental readiness, and entailed a process that unfolded over time (Gallo et al., 2005).

In a qualitative study addressing diagnostic disclosure of Turner Syndrome, several women reported negative impacts later in life because their diagnosis was withheld from them (e.g., either by parents or professionals; Sutton et al., 2006). Turner Syndrome is a sex chromosome anomaly that transpires in one of 2,500 female births and is often characterized by short stature and infertility (Sutton et al., 2006). Sutton and colleagues (2006) utilized a qualitative semi-structured interview approach to data collection and included 97 individuals with Turner Syndrome, and 21 of their parents. Some of the mothers in this study indicated that they had withheld their child's diagnosis as they did not feel prepared for the disclosure process and did not want to share negative implications of the diagnosis (e.g., infertility). Some felt they had to process the diagnosis themselves before sharing it with their child (Sutton et al., 2006). Overall, study authors emphasized drawbacks of "secret-keeping" and stressed that a process of non-disclosure can lead to isolation, depression, fear, and mistrust of adults in authority (e.g., health care professionals, parents, etc.; Sutton et al., 2006). Moreover, researchers indicated that denying individuals the opportunity to learn about their diagnosis early in life left them vulnerable to learning about their diagnosis from an outside source in a potentially harmful way and left them unable to advocate for their own needs (Sutton et al., 2006).

Parental disclosure of medical conditions. Given the paucity of literature exploring developmental and/or genetic disorders, further discussion surrounding parental disclosure of medical disorders in other health areas is provided below.

Pediatric cancer. Medical researchers have begun to explore parental and professional decision-making regarding the disclosure of a clinical diagnosis to children, such as within the field of pediatric oncology (Bluebond-Langner, 1978; Bluebond-Langner, Perkel, Goertzel, Nelson, &McGeary, 1990; Parsons et al., 2007; Sisk, Bluebond-Langner, Wiener, Mack, & Wolfe, 2016; Wiener, Mellins, Marhefka, & Battles, 2007). For example, Sisk and colleagues (2016) completed a review of the literature on diagnostic disclosures to children using cancer as their illness model. The authors highlighted that over the last 60 years, the concept of diagnosis disclosure to children has dramatically changed. Although in the 1950s, a protective approach (shielding a child from bad news) was advocated by clinicians; the 1980s brought more acceptance and advocacy for children to be included in a more open and direct process of diagnostic disclosure – "always tell [the child]" (Sisk et al., 2016, p. 1). It was then identified that although children should always be told about their diagnosis, diagnostic disclosure is a complex process with many individual factors that need to be recognized and with many questions that need to be answered (e.g., When to tell? What are we trying to accomplish with disclosure?; Sisk et al., 2016).

Another study found that parents who deemed the diagnosis as terminal were less likely to disclose the diagnosis and only provide minimal information about the condition to the child (Clarke, Davies, Jenney, Glaser, & Eiser, 2005). Similarly, Jithoo (2010) conducted a study with 100 parents utilizing thematic content analysis, and reported that parents avoided using the word *cancer* as they felt their child would be too young to comprehend its meaning. These parents also

indicated that they were fearful about the potential for negative impacts (e.g., children assuming that the word cancer meant a terminal diagnosis; Jithoo, 2010). Additionally, when parents reported being upset and shocked about their child's diagnosis, they tended to only provide their child with limited information (Clarke et al., 2005). In another qualitative, interview-based study with 73 parents, participants reported that they only felt comfortable sharing their child's diagnosis with their child once they had dealt with the initial shock of the diagnosis themselves and had sought additional information (Chesler, Paris, & Barbarin, 1986). Other factors that were found to inform the disclosure process included the age of the child (Chesler et al., 1986), the child's ability to comprehend the illness, and the parent's ability to provide information in a child-friendly and understandable way (Claflin & Barbari, 1991).

Many studies that spoke to a limited disclosure process indicated that not fully identifying a diagnosis did not spare younger children from distress (Chesler et al., 1986; Claflin & Barbarin, 1991; Clarke et al., 2005). Specifically, a longitudinal mixed-methods study conducted by Claflin and Barbarin (1991) found that often less information was shared with young children under the age of nine. However, they indicated that children can identify emotional distress in their parents, and suggested that a lack of disclosure may have communicated the message that the diagnosis was too frightening or morbid to discuss (Claflin & Barbarin, 1991).

Conversely, there have been many studies that have highlighted positive aspects associated with informing children about their cancer diagnosis. For example, Last and van Veldhuizen (1996) utilized a self-report measure with 56 children and found that open communication and parental disclosure positively contributed to a child's emotional well-being and, when done at an early stage, coincided with less anxiety and fewer depressive symptoms.

Other research has emphasized that children in their capacity for understanding their diagnosis is related to their maturity level and not just their chronological age (British Medical Association, 2001; Clarke et al., 2005). For example, Clarke and colleagues (2005) conducted a qualitative study utilizing semi-structured interviews to describe parent reports of their child's behaviour and emotional reactions following diagnosis and potential disclosure. They found that children who were provided with more information were often older, more fully trusted their family and medical professionals, understood the importance of medication and treatment, and were more likely to speak openly with family about their concerns and worries than those children who were not told about their diagnosis (Clarke et al., 2005).

Research has indicated that parents should inform children as soon as possible about their cancer diagnosis as many children have reported learning about their diagnosis from an outside source (Jithoo, 2010; Last & van Veldhuizen, 1996). It was also indicated that children were provided with less information when informed by an outside source (an individual other than their parent/guardian; Last & van Veldhuizen, 1996). However, it was also the case that parental diagnosis disclosure was often not a static event and was often described as a continuing process over time (Young et al., 2002). Thus, as previously discussed in relation to developmental and/or genetic diagnoses, parents may initially avoid diagnosis disclosure because of perceived negative impacts even though much of the literature stresses the importance of parental sharing of information with the child as they are able to comprehend.

Perinatal Human Immunodeficiency Virus (HIV). Even more so than pediatric oncology, an abundance of research has investigated parental diagnosis disclosure of perinatal Human Immunodeficiency Virus (HIV). As more HIV-positive children gain access to antiretroviral therapy, they are surviving into adolescence and adulthood, and parents are faced

with the process of having to disclose the HIV-status to their children (Domek, 2010). However, research suggests that parents may fear or avoid disclosure for a number of reasons, including the potential of adverse psychological effects on the child, being unable to answer challenging questions about the diagnosis, their child not being developmentally ready to comprehend their diagnosis, parents' distress about death, and the various challenges or stigmatization attached to an HIV diagnosis (Vreeman et al., 2010; Waugh, 2003).

A qualitative interview-based study conducted with 20 families found that children should be informed about their diagnosis when they are mature enough to cope and not share their diagnosis with others openly and when they are able to understand what their diagnosis means for them (Waugh, 2003). However, diagnosis disclosure did not change the quality of life for children, and, thus, the disclosure process should not be delayed due to fears of adverse impacts on quality of life (Butler et al., 2009).

Multiple review articles related to HIV have also shown that disclosure can have positive effects such as improved self-esteem, less psychological distress, and decreased problematic behavior (Domek, 2010; Krauss et al., 2013; Vreeman et al., 2013). Specifically, it has been found that children are better able to make sense of the world around them, develop their true sense of self, and share their anxieties surrounding their illness as an outcome of being aware of their HIV diagnosis (Cantrell, Patel, Mandrell, & Grissom, 2013; Heeran, Jemmott, Sidloyi, Ngwane & Tyler, 2012; de Vinck-Baroody, Weitzman, Vibbart, & Augustyn, 2012). Reported benefits of disclosure also include greater adherence to treatment regimens and responsibility with taking medication (Vreeman et al., 2010). Despite the fear that disclosure would result in isolation and stigmatization (Vreeman et al., 2010), children who were not informed about their

HIV diagnosis demonstrated more psychological maladjustment and internalizing difficulties than children who were informed of their diagnosis (Bachanas et al., 2001).

Overall, there is substantial evidence surrounding the many benefits of disclosure and limited evidence of negative outcomes following disclosure to children with HIV (Cantrell et al., 2013). Two main factors relevant to the decision of whether and when to disclose an HIV diagnosis are age and developmental level (Cantrell et al., 2013). More specifically, as HIV is a chronic illness evolving over time and across developmental stages, it is important to appropriately tailor conversations to children's developmental level (Cantrell et al., 2013). Other factors that parents/caregivers considered included correct timing of disclosure, whether the children had previously asked questions about their illness or treatment/medication, the family situation or environment, enrollment in school, how prepared parents felt for disclosure, whether or not children would be able to keep their diagnosis a secret (e.g., concerns over transmitting HIV to others), and whether or not negative outcomes were anticipated due to disclosing/not disclosing (Bachanas et al., 2001; Cantrell et al., 2013; Domek, 2010; Vreeman et al., 2010; Waugh, 2003). Domek (2010) emphasized that children may feel the "psychosocial stress" (p.441) of their diagnosis regardless of disclosure and, therefore, the illness and well-being of the child cannot be sufficiently attended to without diagnostic disclosure (Domek, 2010).

Chapter Summary

The experience and effects of ASD diagnostic disclosure to children by parents are not yet well studied or documented (Vreeman et al., 2013); hence, further study is needed. Moreover, ASD is a complex and multifaceted spectrum disorder, with individuals exhibiting a wide range of unique cognitive, communicative, and behavioural symptomatology (APA, 2013). The disclosure process has been identified as an important aspect of long-term management for

clinical conditions (Vreeman, et al., 2013) and may play a significant role in the context of a

child's or adult's life (Huws & Jones, 2008). Parents report a variety of positive and negative

experiences when receiving and/or sharing information about their child's ASD diagnosis, and

individuals with ASD likely cope with learning about, and living with, their disorder

idiosyncratically. However, there is a substantial paucity of literature exploring the experiences

of parents communicating or disclosing their child's ASD diagnosis to the child. To date, there

have only been three studies on this topic (Duprey, 2011; Finnegan et al., 2014; Rossello, 2015);

however, these studies were limited by their small size and potentially homogeneity of their

sample, and they did not explore any cultural differences within the disclosure process.

Information about parental decision-making in the substantive area of ASD diagnostic

disclosure, as well as the associated experiences of parents with this process, are anticipated to

enhance understanding about this issue and offer potential guidance to the ASD community.

Ultimately, it is hoped that the current study will advance capacity and inform resource

development for parents who may be faced with a decision about disclosure.

Chapter 3: Methodology

It is important to recognize that there are multiple approaches that can be chosen in conducting research (Snape & Spencer, 2003). A qualitative researcher will select a qualitative design based on a variety of factors including:

"beliefs about the nature of the social world and what can be known about it (ontology), the nature of knowledge and how it can be acquired (epistemology), the purpose(s) and goals of the research, the characteristics of the research participants, the audience for the research, the funders of the research, and the position and environment of the researchers themselves" (p. 1).

This chapter describes the methodology of the current study, starting with an overview of qualitative research. This chapter also describes epistemological, ontological, and theoretical considerations; a historical and methodological overview of phenomenology, with specific information pertaining to the chosen descriptive phenomenological approach; information about how data collection was completed; ethical considerations; and information about the data analysis process. The chapter concludes with a section on evaluating qualitative research, with a focus on trustworthiness in the aim of supporting the rigor of the findings.

Research Design

A research design is a methodical plan used to organize a study; it consists of the "entire process of research from conceptualizing a problem to writing research questions, and on to data collection, analysis, interpretation" (Creswell and Poth, 2017, p. 5). To address the research questions, a descriptive phenomenological methodology has been utilized.

Qualitative research. As background to the qualitative inquiry, qualitative research methods consist of empirical processes that "collect and analyze data that cannot be represented

by numbers" (Brown & Lloyd, 2001, p.350). Various approaches can be used to elicit data; however, a qualitative interview commonly offers subtle nuances and first-person perspectives of participant experiences (Abbott et al., 2012). Psychology, and more specifically ASD research in psychology, has traditionally remained primarily within a quantitative realm (Bolte, 2014; Broome, 2011), but in doing so, researchers have often been unable to explore the depth of the experiences and perspectives of participants fully (Yin, 2011).

In general, qualitative research is a situated endeavor that locates and amplifies the *observers of their world* (participants) within their own world/environment(s) (Snape & Spencer, 2003). Qualitative research can consist of a naturalistic, descriptive, and/or interpretive approach to viewing the world; it is "concerned with understanding the meanings that people attach to phenomena (actions, decisions, beliefs, values, etc.)" (Snape & Spencer, 2003, p.3). Qualitative research has a long-standing tradition in an array of disciplines (Brown & Lloyd, 2001) and is well suited to studying human experience. It is ideal in addressing research questions eliciting understanding about a population and the social phenomena encompassed within that population (Snape & Spencer, 2003). Additionally, qualitative research can be used to explore complex processes occurring over time and provide a holistic and multi-layered perspective while also adopting a flexible approach (Snape & Spencer, 2003).

Given the distinct paucity of literature addressing parental diagnosis disclosure of ASD, an exploratory qualitative approach is well-suited to the aim of developing a deeper understanding of the inherently variable and context-imbued nature of disclosing/not disclosing, while also affording the opportunity to clarify contextual and process-related information of participating families. Semi-structured qualitative interviews appear valuable as a means to explore research questions systematically while also allowing versatility within the data relative

to the diversity of experiences and perspectives of participants who can offer a range of considerations and conclusions relative to the substantive focus of the study (Galletta, 2013).

Epistemological, Ontological, and Theoretical Considerations. It is important to consider the philosophical tenets informing both a qualitative approach and a substantive area, with both the researcher and the research approach(es) reflecting and contributing to theoretical understandings related to the area of inquiry. Accordingly, it is important that the researcher seeks to understand and articulate philosophical underpinnings; this offers evidence that findings are grounded in theory and that the researcher has carefully considered preconceived notions and ideas about the phenomena under study (McConnell-Henry, Chapman, & Francis, 2009).

Ontology. Ontology is the study of *what is*, or the study of beings or their action of being (Smith, 2013). Key ontological issues in social science research include whether reality exists outside of observation and whether there is a common reality that others share (Snape & Spencer, 2003). As an example, an ontological persuasion could presume that phenomena exist independently of the researcher's (or observer's) perceptions (Gallagher, 2008). Conversely, a researcher could view phenomena as a product and process of *co-construction* between participants (actively making meaning in and of their world) and the researcher (searching for lived experiences) through interpretation (Byrne-Armstrong, Higgs, Horsfall, 2001) and/or inherent subjectivity.

The researcher in this study aimed to capture and honour the lived experience of the participants as authentically as possible; however, it is acknowledged that a certain degree of researcher subjectivity will inherently be present. Thus, an idealist perspective was adopted. Idealism upholds the belief that "social reality is the product of processes through which social actors negotiate the meaning of and for actions and situations" (Uddin & Hamiduzzaman, 2009,

p. 658). Within idealism, researchers seek to identify their positionality including inherent biases and perspectives in the aim of accounting for, and supporting others in understanding unique biases and perspectives relative to the study and its findings.

In contrast to idealism, realism suggests that reality can exist largely independent of one's perceptions or awareness (Archer et al., 2016; Phillips, 1987). Accordingly, a realist position would posit that the world is *the way it is* and an ontological aim is to capture and reflect on participant experiences as truthfully and objectively as possible. It is important to understand, however, that there is often the denial that we can ever have a truly objective understanding of the world. An idealist approach is presumed in accepting "the possibility of alternative valid accounts of any phenomenon" (Maxwell, 2012, p. 5). Idealism encapsulates the notion that space and time are not independent of our sensibility, but instead exist in part because of our experience of them (Stang, 2016). Ontological reflexivity suggests that as researchers we must continually question which stories to tell, and how to tell those stories, while also remaining cognizant about who is telling those stories and their innate subjectivity (Ang, 1989). Therefore, as researchers we must be *ontologically reflexive* within, and about, our research (Archer et al., 2016).

Reflexivity and the role of the researcher. Descriptive phenomenological research (as discussed below) invites researchers to acknowledge personal and professional views, values, and biases, and to explore how these factors may have a bearing on their research. In this study, the researcher acknowledged her role as the primary research instrument. What this means is that as the researcher is key in the semi-structured interview process, individual researcher characteristics can theoretically influence the data that is collected and must be acknowledged (Pezalla, Pettigrew, & Miller-Day, 2012). Given this significant role in the research project,

elements of the researcher's personal and professional experiences and perspectives were deemed to be relevant to this study; hence, are included.

First, the researcher is a provisional psychologist who has worked within a variety of settings largely pertaining to assessment and behavioural interventions for children and youth, both prior to and during this study. The researcher also holds research, clinical, and personal experience working with children who have a diagnosis of ASD and their families. More specifically, this work has occurred at various stages throughout the diagnostic process, and the researcher has experience in disclosing the diagnosis of ASD to parents/guardians and to the individuals with ASD during this process. It is believed that these experiences have informed this study (and perspectives about the relative merits of this process) and piqued interest in the questions that are being addressed.

By identifying and dwelling on these experiences and their impacts, the researcher has endeavoured to ascertain and further bracket (or as much as possible, set aside) these values, experiences, and influences throughout the research process in an aim of remaining authentically open to the voice of participants. Bracketing is defined as the ongoing process of identifying and setting aside any assumptions that the researcher might hold (Fischer, 2009). The process of bracketing – deeply reflecting on personal/professional biases – relative to the area of inquiry, offered elements that contributed to the credibility of the data collection and analysis which is further discussed in later sections.

Epistemology. Epistemology is "concerned with ways of knowing and learning about the social world" (Snape & Spencer, 2003, p.13) and explores the basis of our knowledge as researchers or *how we know*. Epistemology in social science research is concerned with exploring human experiences, perceptions, and/or interactions (socioculturally contextualized),

and focuses on the people expressing the actions being explored (i.e., the participants; Cohen, Manion, & Morrison, 2000). From a post-positivist perspective, researchers are perceived to hold and need to seek to ascertain assumptions, prior knowledge, and values that they bring to the research; as such, the researcher can inadvertently influence the experience being observed or discussed (Ryan, 2006). This supports the view, as noted earlier, that researchers recognize the impact of their biases, values, and preconceptions (Ryan, 2006) by allowing the audience of the research a chance to account for the researcher's subjectivities; thus, situating itself nicely within an idealist perspective as previously outlined. Accordingly, this researcher adopted a post-positivist perspective, scrutinizing any personal assumptions, in order to best construct meaning from participants with as much objectivity as possible (Ryan, 2006).

In examining phenomena, the researcher needs an understanding of each participant's sense of identity to ascertain elements of lived experiences (de Gialdino, 2009). A person's identity may include characteristics that are common to all people in a group and also those characteristics that make that individual unique (de Gialdino, 2009). As researchers cannot isolate people from their environments, the epistemological approach is grounded in the parameters of context, yet varies as the researcher begins to uncover a phenomenon. Thus, it emerges as important that the researcher ensures that experiences are represented in a way that illuminates each participant's voice in context (de Gialdino, 2009).

Applying these notions specifically within this study, parents experienced and apparently navigated a decision-making process relative to disclosure of their child's ASD diagnosis to the child. In considering this process, theoretical underpinnings seemed cogent in informing this work. As an example, the researcher perceived herself to be influenced by a family systems lens which was perceived as helpful relative to perceiving parents and children in the context of the

family. Accordingly, this approach is believed to have informed the research in perceiving the multiple voices and perspectives of participants, in this case, parents and children, amidst the multiple locations and systems that comprise their experiences and contexts. This perspective is briefly explained below.

Family systems approaches. Systems theory (or referred here as Family Systems [FS]) is a broad overarching approach that is relevant to, and encompassing of, families in context (Cox & Paley, 1997; Cridland, Jones, Magee, & Caputi, 2014; Klein & White, 1996). Derived from General Systems Theory (GST), FS approaches underline the significance of exploring situations, individuals, and specific events within the context of one's social environment rather than in isolation (Becvar, Becvar, & Bender, 1982; Cridland et al., 2014; von Bertalanffy, 1950; von Bertalanffy & Sutherland, 1974; Whitchurch & Constantine, 1993). A focus of FS is the family, which can be seen as "unique interactive and reactive units, with their own basic social system of rules, values, and goals" (Cridland et al., 2014, p. 215). Families have also been described to include all who a family relies on over the course of their lives, for nurturance, support, care, comfort, and emotional closeness (Cridland et al., 2014). FS approaches have also described the family in terms of its *functioning positions* (Titelman, 1998). As noted by Titelman (1988), FS approaches suggest that as children are born into, or otherwise enter, a family, they fulfill a functioning position, indicating that each member of a family performs a specific role (e.g., caregiver, child, etc.; Titelman, 1998). Each position is believed to have an influence on both the family and each individual therein in terms of values, beliefs, attitudes, behaviours, and feelings (Titelman, 1998).

FS approaches have several basic assumptions: (1) the family is a system and is impacted by the relationships among family members; (2) individual and/or family characteristics are

considered within the system, which in turn generates family responses and subsequent outcomes; and (3) boundaries exist between different family subsystems (e.g., parental, marital, etc.) and the external environment (Angell, Meadan, & Stoner, 2012). These approaches are inclusive of both positive and negative aspects of family functioning, and vary regarding their scope and focus on the family (e.g., macroscopic and microscopic; Cridland et al., 2014). A macroscopic approach puts emphasis on the way a family interacts with other external systems (e.g., schools, other families, etc. within the larger community); whereas, a microscopic approach focuses on the relationships and interactions internal to the family (e.g., maternal or paternal subsystems; Cridland et al., 2014).

Within disability research, many of the more recent conceptualizations of the family have embraced a FS perspective (Cridland et al., 2014; Haefner, 2014; Keen, 2007). By situating the child with a disability and her/his/their family within this theoretical framework, researchers recognize the interrelatedness of family members and amplify the strengths and needs of family members within the context of the whole (i.e., the family unit; Brown, Nolan, & Davies, 2001; Keen, 2007; Knox, Parmenter, Atkinson, & Yazbeck, 2000; Murray, 2000). A FS approach also acknowledges "the heterogeneity of families and ASD" and "recognizes that family functioning changes across time and in response to life events" (Cridland et al., 2014, p. 217); accordingly, the changing system of the family amidst dynamic external contexts and systems yields a broad and shifting orientation to understanding family experience.

Application of the theoretical approach to the parent/child dyad. The parent/child subsystem that is intersected with ASD is important as the family plays an integral role in the life of the child and the potential parental view of and response to ASD (Angell et al., 2012); accordingly, the child with ASD "presents pervasive and bidirectional influences on the entire

family system" (Cridland et al., 2014, p. 213). Within this view, the family is observed as a group of interconnected individuals who act together to produce a unique yet cohesive unit that reflects and impacts the feelings, thoughts, and behaviours of all members (Paylo, 2011). Parents have acknowledged that having a child with ASD poses many distinct challenges and opportunities for a family, and raising a child with ASD has been described as stress-inducing for these families (Cridland et al., 2014; Myers, Mackintosh, & Goin-Kochel, 2009; Yamada et al., 2007). Of note, parents of children with ASD experience significantly higher levels of stress than parents of children with other disabilities (Mugno, Ruta, D'Arrigo, & Mazzone, 2007; Myers et al., 2009; Pisula, 2007). Such challenges can include inflexibility, unique intolerances, sudden mood shifts, limited (or difficulty with) social interactions both inside and outside the family unit, difficulty with self-care, and limited communication skills (Attwood, 2007; Australian Bureau of Statistics, 2011; Heiman & Berger, 2007; Macks & Reeve, 2007; Pakenham, Samios, & Sofronoff, 2005; World Health Organization, 2005). Having a child with ASD has also been described within the literature as burdening, in some instances, to the family unit (e.g., financially, emotionally, and socially; Montes & Cianca, 2014). However, research also highlights positive influences of ASD on the overall functioning of a family, with reported positive outcomes of emotional strength, increased patience and empathy, and improved communication skills (Bayat, 2007; Davis & Gavidia-Payne, 2009; Pakenham, Sofronoff, & Samios, 2011). Overall, the literature seems to position raising a child with ASD as a life-changing experience, prompting family units to re-evaluate their beliefs, values, and perspectives on the world (Gray 2006; Myers el al., 2009).

FS approaches seem germane when considering families that are impacted by ASD, as it is not just the child but also the parents and siblings who navigate and cope with this

diagnosis/disorder (Hartmann, 2012). Moreover, how parents view ASD in conjunction with the child's presentation, could differentially impact their decision about whether or not, and if so how, to disclose the diagnosis to their child. As briefly described here, it is presumed that the intersecting systems/subsystems (e.g., parent, child), their various influences, and the internal decision-making process associated with this context may have a bearing on decisions around disclosure.

Rationale and Approach to Qualitative Inquiry

Beyond theoretical tenets, as outlined above, that inform the researcher's approach to this substantive area of study, this study reflects a research framework espoused in a descriptive phenomenological approach. As there are a substantial number of qualitative methodological approaches, it is important that a rationale for the use of descriptive phenomenology in this study is provided. Within qualitative research, Creswell and Poth (2017) have identified five major qualitative approaches to inquiry: phenomenology, narrative research, grounded theory, case study, and ethnography. Phenomenology focuses on the lived experience of individuals and the common meaning that these individuals attach to their experiences of a phenomenon. Moreover, phenomenology seeks to understand the essence of lived experience or meaning among a group of individuals and does not focus solely on documenting the individual experience (Creswell & Poth, 2017; van Manen, 1990). Similarly, narrative research allows the researcher to explore lived experience; however, unlike phenomenology, narrative research describes an event or series of events in chronological order through *life course stages*, and seeks to tell stories of individual experiences rather than describing the essence of the phenomenon (Clandinin, 2013; Creswell & Poth, 2017).

Grounded theory moves beyond a description of lived experiences to formulate or

uncover a theory or model around a shared process in providing a framework or explanation for the process (Corbin & Strauss, 2007; Creswell & Poth, 2017). While grounded theory aims to develop or uncover a theory based on a group of individuals who share an interaction, action, or process, ethnography focuses on the patterns of behaviour, language, and beliefs that depict elements of a *culture-sharing* collection of people (Creswell & Poth, 2017). Within ethnography, the researcher seeks to determine how the group works and does not focus on an underlying problem utilizing a single case as a specific example (Creswell & Poth, 2017). Case study as an approach seeks to describe a case(s) within a real-life *bounded system* (e.g., a specific context or setting) over a specific period and involving several sources of information in the data collection process (e.g., interviews, observations, and other documents; Creswell & Poth, 2017; Yin, 2014).

Given the plethora of qualitative approaches, it seems important to carefully weigh these relative to research aims and questions in ultimately determining the appropriate approach based on the type of research problem, focus, unit(s) of analysis, and optimal approaches of data collection and analysis (Creswell & Poth, 2017). As noted earlier, the purpose of this study was to explore the lived experience and decision-making of parents relative to the disclosure or lack of disclosure of their child's ASD diagnosis to the child. Given that the primary research focus was to discern the phenomenon of disclosure versus non-disclosure among parents who share this experience of determining a response to diagnosis relative to informing/not informing their child, a deeper understanding about this phenomenon was sought. This included depth of understanding relative to inherent meanings that lie beneath decision-making and action, which seemingly imply the essence of parents' decision-making. A phenomenological approach appeared most suited to addressing these queries; this approach is further examined below.

Phenomenology. Phenomenological researchers "focus on describing what all

participants have in common as they experience phenomenon" and attempt to "reduce individual experiences with a phenomenon to a description of the universal essence" (Creswell, 2007, p. 58). Moreover, phenomenologists attempt to put aside their own experiences and knowledge while exploring a phenomenon, to approach the lived experience of participants with a sense of newness (Creswell & Poth, 2017).

Beyond the methodological aim of phenomenology, it is important to consider and discuss the philosophical underpinnings of this approach (Creswell & Poth, 2017). Phenomenological research evolved out of a positivist paradigm, offering researchers a method to explore participants' reality (Reiners, 2012). This paradigm often assumed some level of objectivity as knowledge or reality was affirmed as rational, logical, and independent of human interaction (Reiners, 2012; Sokolowski, 2000). Yet various approaches and perspectives have emerged with a range of perspectives about objectivity versus subjectivity of knowledge that can be generated by phenomenological inquiry.

Approaches to phenomenology have stemmed from the works of Edmund Husserl (descriptive; 1963) and Martin Heidegger (interpretive; 1962). In determining one's phenomenological approach, researchers can consider which of these approaches (or various others that have emerged from differing persuasions) is/are most congruent with their positionality, the proposed research questions, and their underlying philosophical tenets (Bloomberg & Volpe, 2012; Lopez & Willis, 2004; Reiners, 2012). Husserl believed that phenomenology was based on the meaning of the individual's experience and developed descriptive phenomenology whereby preconceived opinions were set aside (bracketing), and an individual's everyday experiences were described (Reiners, 2012). In contrast, Heidegger believed that bracketing was not necessary as he was interested in interpreting and describing the

human experience (Reiners, 2012). As this study sought to describe the unique experiences of parents, rather than interpret those experiences, it was essential that any biases were bracketed to the best extent possible. Evidence from the phenomenological literature has also indicated that a descriptive approach should be used to explore and illuminate poorly understood facets of an experience, or where a paucity of experiences exists (Matua & Van Der Wal, 2015). In contrast, an interpretive approach would be best utilized to explore the conceptual qualities of an experience, where literature is already in existence (Matua & Van Der Wal, 2015). The current study most closely aligns with, and hence is reflective of, a descriptive phenomenological approach as there is a significant paucity in the literature surrounding child diagnosis disclosure; accordingly, Husserl's work is described in greater detail below.

Husserl and phenomenology. The philosophy of phenomenology emerged from the work of Edmund Husserl who believed that consciousness is grounded in the meaning of individual experience (Creswell & Poth, 2017; Lopez & Willis, 2004). Experiencing thoughts, memories, imagination, perceptions, and emotions were outlined as involving *intentionality*, which is "one's directed awareness or consciousness of an object or event" (Reiner, 2012, p. 1). Subsequently, Husserl developed descriptive phenomenology whereby a person's everyday experiences are uniquely described (Dahlberg, Drew, & Nystrom, 2008) and the importance of the *life-world* is explained (Overgaard & Zahavi, 2009). The life-world has been defined as "the world we ordinarily take for granted, the pre-scientific, experientially given world that we are familiar with and never call into question" (Overgaard & Zahavi, 2009, p. 4). Husserl considered science to be founded on the premise of the life-world and theoretical assumptions may become a part of the life-world as they are consumed into everyday practice (Overgaard & Zahavi, 2009). Thus, scientific study is something that people do and can be considered as a way of relating to

the world (Overgaard & Zahavi, 2009).

One primary assumption within the descriptive approach is that "experience as perceived by human consciousness, has value, and should be an object of scientific study" (Lopez & Willis, 2004, p. 727). Reportedly, Husserl also believed that this type of subjective information is extremely important as individual actions are heavily influenced by what that individual perceives to be real (Lopez & Willis, 2004). This method then has ultimately emerged into a scientific approach exploring the lived experiences specific to a group of people. Husserl spoke to the concept of *phenomenological reduction* as a method to describe a phenomenon as free as possible from cultural context and assumptions (Dowling, 2005). An important assumption within this approach is that researchers need to seek to dispose of, or set aside (bracket), their personal biases and prior knowledge "to grasp the essential lived experiences of those being studied" (Lopez & Willis, 2004, p. 727). Thus, the intent of the researcher is to bracket preconceived notions as much as possible to explore and reflect upon the unique everyday experiences of the participants more fully (Lopez & Willis, 2004). Moreover, the process of reflexivity "becomes a process of continually reflecting upon our interpretations of both our experience and the phenomena being studied so as to move beyond the partiality of our previous understandings" (Finlay, 2003, p. 108). Within this assumption, the objective of the researcher is to achieve *transcendental subjectivity*. This Husserlian concept suggests that the researcher continually assesses personal biases and preconceived notions and neutralizes them with the aim of not impacting or minimally impacting the experiences reported by a participant (Lopez & Willis, 2004).

Another assumption encompassed within this method is that essential features of lived experience emerge across individuals who have shared that experience, referred to as *universal*

essences (Lopez & Willis, 2004) – "commonalities in the experience of the participants must be identified so that a generalized description is possible" (Lopez & Willis, 2004, p. 728). The common essences, or similar collective descriptions, are then explored as a representation of the phenomenon being studied (Lopez & Willis, 2004).

Descriptive phenomenological approach. The descriptive phenomenological approach is useful for illuminating the meaning(s) ascribed to a phenomenon (Giorgi, 2009). It identifies the core essence of participants' experiences associated with the substantive area under inquiry (Bloomberg & Volpe, 2012). Within this approach, the researcher seeks to describe rather than explain, and starts from a perspective that ideally brackets researcher-imposed preconceptions and preconceived hypotheses (Bloomberg & Volpe, 2012; Lester, 1999). Conventionally, psychology as a whole has striven towards and espoused the natural sciences which has involved the use of controlled environments and quantified abstraction (Broome, 2011). Finlay (2009) indicates that all phenomenologists are in agreement on the need to study human beings and, therefore, favour a human science approach. However, Finlay (2009) also indicates:

> As a human *science*, phenomenology aims to be systematic, methodical, general, and critical. At the same time, phenomenology also pursues the intertwining of science with art, the imparting of a "poetic sensibility" to the scientific enterprise. In this sense, science blends with the stylistic realms of the *humanities* (p. 14).

Given these strands, descriptive phenomenology can be utilized from a human science psychological perspective (Giorgi, 2009) and is guided by the philosophical underpinnings of Husserl within a psychological context (Finlay, 2009). This process invites and allows deep reflection on the words and understanding of participants; hence, it translates into the collection of "deep" information and perceptions through inductive qualitative data elicitation from the

perspective of the research participants (Bloomberg & Volpe, 2012).

Within this descriptive phenomenological approach, the researcher initially focuses on the lived experiences of the participants and then writes a description of the phenomenon. These descriptions are characteristically first-person explanations, in plain language, and the researcher avoids "abstract intellectual generalizations" (Finlay, 2009, p.10). Not only does the researcher focus on description, but she also invites participants to interpret the meanings applied to that lived experience (Bloomberg & Volpe, 2012). Through this approach of individual description and interpretation, researchers aspire to reveal the vital meaning structures of a phenomenon (Finlay, 2009). Researchers also restrict themselves to "making assertions which are supported by appropriate intuitive validations" (Mohanty, 1983, cited in Giorgi, 1985, p. 9), which means staying true to the complex and abundant descriptions given by participants. Accordingly, this methodology is particularly effective in illuminating the experiences and perceptions of individuals on their own terms and from their perspectives. In so doing, presumptions and structural or normative assumptions can be challenged based on participant experience and meaning.

When situating descriptive phenomenology within a psychological context, it is important that the researcher focuses on the *lived context* of each participant, concentrating on his or her experience without influence from the researcher (Giorgi, 2009). This focus allows for findings that reflect the *voice* of the participant as much as possible, and in turn captures the common essences of the collective group (Broome, 2011; Lopez & Willis, 2004). It has been argued that as researchers we learn phenomenology by making it our own (Merleau-Ponty, 1962) and that "it is less a question of counting up quotations than of determining and expressing in concrete form this *phenomenology for ourselves*" (Finlay, 2014, p.137).

Within a psychological context, descriptive phenomenology draws upon a five-step system, modifying Husserl's initial method (Giorgi, 1985; 2009). Giorgi's five-step method seeks to attain scientific, systematic rigor while not being reductionistic (2009). Specific hypotheses will not be proposed as this method, much like the vast majority of other qualitative methods, is inductive and *discovery-oriented* (Broome, 2011). Instead, this method seeks to describe the "structure of the psychological phenomenon so that it can be understood in a deeper, holistic, and more comprehensive way than other methods can provide" (Broome, 2011, p.82). Further detail about this five-step analytic process is presented in the analysis section of this thesis.

The semi-structured interview. Within phenomenology, one of the traditional and most commonly used forms of data collection is the qualitative *in-depth* interview (Lopez & Willis, 2004). Participants' narratives, as reflected in the interviews, formed the basis for the current study. Accordingly, this interview reflected participants' subjective experiences with the diagnostic disclosure process.

Englander (2012) highlights that questions included as a part of a phenomenological interview should meet descriptive phenomenological criteria (Giorgi, 2009). Additionally, what initiates a descriptive phenomenological interview does not consist of traditional interview questions but rather is an invitation to describe a situation or experience (Englander, 2012). Thus, participants were first asked to reflect on their perspectives of telling or not telling their child about his or her ASD diagnosis introspectively. Subsequently, participants were invited to talk about their journey of deciding to disclose or not disclose their child's ASD diagnosis to the child. Inviting this description of parental experiences emerged as instructive in the discovery of phenomenological meaning units (Englander, 2012), which is discussed below.

Giorgi (2009) indicates that the initial question or inquiry approach should be open-ended as the experience of each participant will be unique to that person/family and, therefore, it is important that they are afforded the opportunity to talk about their subjective experience prior to additional questions. Once participants have reached a point where they have spontaneously offered descriptive and contextual information as desired, additional follow-up questions can be asked (Giorgi & Giorgi, 2003). It is important to note, however, that any additional follow-up questions were asked in ways that endeavored not to be leading (Broome, 2011).

Research Procedure

This section outlines research procedures, including information on recruitment, sampling, and inclusionary and exclusionary criteria. Ethical considerations and confidentiality are also discussed.

Recruitment. The current study was part of a larger project entitled *The Elephant in the Room: Talking to Children with ASD about their Diagnosis.* Within the larger project, there were three online web-based questionnaires, one for each participant group (parents, professionals, and individuals with ASD). Participants were invited to complete their respective online questionnaire (discussed in detail in the data collection section) through various recruitment methods, including: (1) poster and brochure advertisements (see Appendix A for recruitment materials) shared with community agencies and at local ASD community events; (2) conversations with health professionals and various Alberta-based ASD organizations to share information with parents; (3) recruitment campaigns on social media networks (e.g., Facebook); and (4) additional media outlets such as online radio, news segments on local television, and websites/newsletters for ASD community organizations. Participants who were interested in gaining further information were advised to contact the researcher by email. The conclusion of

the online survey included an invitation for parents to indicate consent to be contacted by the researcher for follow-up involvement in this project. The current study then recruited consenting participants, based on their responses to the online survey (i.e., whether parents had disclosed or not disclosed the diagnosis to their child). Specifically, parents who indicated a willingness to be contacted by the research team for additional involvement in this study were informed of the semi-structured interview and were asked if they continued to have interest in further participation. Data about parents who provided consent for further participation within the screening tool were identified and participants were contacted by the researcher regarding involvement in the data collection phase until a sufficient sample was achieved.

Recruitment of participants was stratified such that the sample size adequately reflected variation of parental experiences with diagnostic disclosure. Parents were thus grouped based on disclosure versus non-disclosure of ASD to their child which provided two discreet groups to be interviewed about their experience. Of note, diversity in age, cultural background, and family constellation was not explicitly sought in the sample; although, some diversity may have been represented.

Based on sampling approach guidance from the phenomenological/methodological literature (Guetterman, 2015; Mason, 2010), it was anticipated that this purposive and criterion-based sampling strategy would support saturation in terms of the experiences and perspectives of each group, thereby eliciting salient lived experiences and thus describing the phenomenon under study from the range of viewpoints of variant parents. This sampling approach and the sample size were established based on work done by Mason (2010) who completed a review on sample size and saturation in qualitative research using interviews. Mason (2010) stated that the number of participants in studies utilizing phenomenology ranged from 7 to 89 (mode [$n = 20$], mean [n

= 25]), while the majority of projects had under 50 participants (Ritchie, Lewis, & Elam, 2003). Prior to data analysis, it was decided that the sample size would be adjusted should saturation be reached prior to 20 participants in each group or conversely, if additional data was required to reach saturation.

Sampling and Screening. Purposeful sampling is frequently used within qualitative research, whereby "the researcher selects individuals and sites for study because they can purposefully inform an understanding of the research problem and central phenomenon in the study" (Creswell & Poth, 2017, p. 157). More specifically, a common method of sampling in phenomenological research is criterion sampling (Heppner, Wampold, & Kivlighan, 2008). Criterion sampling involves collecting a sample in which all participants meet study criterion, as it is vital that the participants included for the study have experience with the phenomenon under review (Creswell & Poth, 2017).

For the purposes of this study, participants were recruited through purposeful sampling, based on the following inclusionary criteria: (a) participants identified as a biological, adoptive, or foster parent of a child or children with a formal diagnosis of ASD (or Autistic Disorder, Asperger's Disorder, or Pervasive Developmental Disorder – Not Otherwise Specified [PDD-NOS], all of which comprise ASD), and (b) participants currently resided in Alberta, Canada. Moreover, recruitment reflected stratification such that the sample was deemed to sufficiently include a range of parental experiences with diagnostic disclosure. Accordingly, sampled parents had either (a) disclosed their child's ASD diagnosis to the child with ASD (using the appropriate ASD label), or (b) had not disclosed their child's ASD diagnosis to the child with ASD.

The only exclusion criterion was a lack of English fluency. Specifically, potential participants who were not deemed to be fluent enough to participate in a semi-structured

interview in English and share about their personal experiences, were excluded. However, there were no individuals who expressed their interest in completing an interview where this was a problem; therefore, no one was excluded because of a lack of English fluency.

Ethical Considerations and Informed Consent. Prior to study commencement, ethical approval was obtained from the University of Calgary's Conjoint Faculties Research Ethics Board (CFREB). As an ethical priority, it was of great importance that no harm was done to research participants. As Moustakas (1994) states, it is imperative to, "maintain… necessary ethical standards, establish clear agreements with each research participant, recognize the necessity of confidentiality, and informed consent, and provide a lay summary to ensure full disclosure of the nature, purpose, and requirements of the research" (p.109). Parents were invited to participate, and a consent form (see Appendix B) was provided to each participant for their review and signature. Prior to obtaining their signed consent, the researcher reviewed the purpose of the research, what would be asked of parents, the anticipated amount of time for participation, the potential risks and benefits of participation, the right to withdraw from the study at any time prior to data analysis, without repercussion, and the researcher's commitment to confidentiality (further explained below). The researcher also spent additional time reviewing specific details around audio recording in order for each participant to be fully aware of what would happen to their electronically-captured voice recordings and information. Before signing the consent form, the participants were encouraged to re-read this form, if desired, and were given time to ask any clarifying questions. They were informed that support was available should participants feel the need for support or further exploration relative to emotions or concerns surrounding study participation and/or exploration of the experiences with ASD. A plan was in place that if a participant demonstrated or expressed distress during the interview process, they

would be given contact information for Distress Centre Calgary or a crisis centre in their area. A few participants demonstrated an emotional reaction/expression (e.g., crying) during the interview process and were reminded of further resources; they did not seem to be required.

In eliciting a deeper understanding about parental decision-making surrounding the disclosure process, the researcher intentionally sought to display a genuine and deep respect for each participant and her/his/their viewpoint. Further, commitment to an ethical and honest stance with each participant throughout the research process was sought, with an explanation to participants about how the research would be used. Participants were informed in advance that they would receive a gift card of their choice as a token of appreciation for their participation, which was seen as "giving back to the participants for their time and efforts in our study" (Creswell, 2007, p. 44).

Confidentiality. Of ethical importance, confidentiality was maintained in the telling and reporting of participant experiences (Kaiser, 2009). The following protocols were used to ensure that confidentiality was maintained throughout data collection, analysis, and presentation of results (Kaiser, 2009; Ovienloba, 2014):

- During the informed consent process, the commitment to, and methods of ensuring, confidentiality were discussed with participants;

- Participant names were not directly linked to the participant interview data, as they only appeared on a master sheet and the consent form;

- During data cleaning and analysis, all personal identifiers were removed (e.g., names, schools, etc.), apart from information on the consent forms and master tracking sheet. If participant names were mentioned within the interviews, a participant number was transcribed in place of those names;

- All hardcopy data and signed consent forms were stored in a locked filing cabinet in the researcher's locked office;

- All electronic data was stored on the researcher's computer, which is password protected and encrypted so only the researcher could access this data.

Data Collection

Data collection was comprised of two phases. First, an initial screening tool elicited demographic information and a short online survey examined parents' positioning on ASD disclosure to their child. Second, a single interview was conducted with participants. The interview sought to illuminate the meanings that parents related to their perspective and position on ASD disclosure to their child. As the current study wanted to explore an in-depth account of the lived experience of parents, data collected from the screening tool – emerging from the larger study from which this analysis was drawn – was only used for the purposes of recruitment and collection of demographic information; hence, it will only be reported upon in minimal detail.

Screening tool. As a precursor to this study, parents of a child with ASD were recruited to complete an online survey as previously identified (see Appendix C). As a part of that larger overarching project, a focus group was held, consisting of a collaborative team of community professionals (e.g., psychologists, psychiatrists, pediatricians, and the directors of four community organizations in Alberta), to inform the generation of survey items. The online survey was developed to obtain initial demographic information about the parent and child/adolescent and to identify the position held by parents regarding disclosure of the ASD diagnosis to their child/adolescent. Specifically, participants were initially asked the question: "Have you discussed your child's diagnosis with them?" As this question did not specifically indicate to parents that they had to have shared the child's diagnostic label with her/him/them,

this was clarified by the researcher within survey responses. The survey was then designed to be adaptive in that parents' responses to respective questions would direct them to specific subsets of new questions. For example, parents who indicated that they had not disclosed the ASD diagnosis to their child were directed to salient questions (e.g., Why had they decided not to disclose the diagnosis? What factors went into this decision?). The conclusion of this survey included an invitation for parents to be contacted by a member of the research team for follow-up involvement in this project.

Data collection phase. The interview phase involved purposely sampling parents from the initial group of respondents to obtain a specific sample of 40 parents of a child or adolescent with ASD who would participate in a semi-structured interview. Parents were grouped based on disclosure versus non-disclosure of ASD to their children which provided two distinct groups to be interviewed about their experience.

After agreeing to participate in this phase of data collection, the researcher scheduled a suitable date, time, and location for each individual interview. Participants were invited to engage in a semi-structured interview either in person (if they resided in Calgary, Lethbridge, or Edmonton areas) or via Skype (if elsewhere within Alberta). Of the parents contacted, 44 parent/parent dyads replied, consented, and were available to meet with the researcher for an interview; hence, 44 interviews took place. The interviews were all conducted by the researcher to maintain consistency across interviews, and the interviews consisted of a natural and conversational format. The interview protocol can be found in Appendix D. Within interviews, parents were invited to describe their perspectives and experiences related to their decision to disclose or not to disclose ASD to their child (using the appropriate ASD label), and if disclosed, their process of disclosing. These experiences were explored with a focus on understanding

elements that were considered in parents' decision-making process to/not to disclose, including personal opinions, preferences, experiences, and processes.

To optimally capture and remain accountable to participant portrayals of their experience, the interview was audio recorded by the researcher for later transcription. The interviews were transcribed verbatim (Braun & Clarke, 2006) by a research assistant, and co-researcher on the larger project, with a strong commitment to accuracy and confidentiality. The verbatim transcript transferred everything heard on the audio file exactly, including pauses, false starts, non-verbal utterances (e.g., "umm," laughter, etc.) and changes in tone of voice. Completed transcripts were double checked, and accuracy was confirmed by the researcher. During this process, all audio recordings were compared to their subsequent transcriptions; any inaccuracies were corrected, and several non-verbal utterances were added and/or supplemented. To further seek to ensure the accuracy of transcriptions, the researcher sought clarification from another researcher when necessary. As part of this data collection process, all audio recordings and subsequent transcriptions were de-identified, in an aim of protecting the privacy of all participants. The transcribed interviews then formed the raw data for data analysis.

Upon the completion of all interviews, transcription, and initial review of the 44 interviews, it was determined that four interviews should be excluded from data analysis. In three of these interviews, the child/adolescent had attended a practitioner-led feedback meeting with their parents, where the clinician had informed the entire family about the child's ASD diagnosis. The fourth interview was also excluded as the parent had disclosed to the child that he had differences, but had not explicitly disclosed to the child his ASD diagnosis. Therefore, the final sample consisted of 40 interviews. A flow chart outlining the progression of participants through both stages can be found in Figure 1.
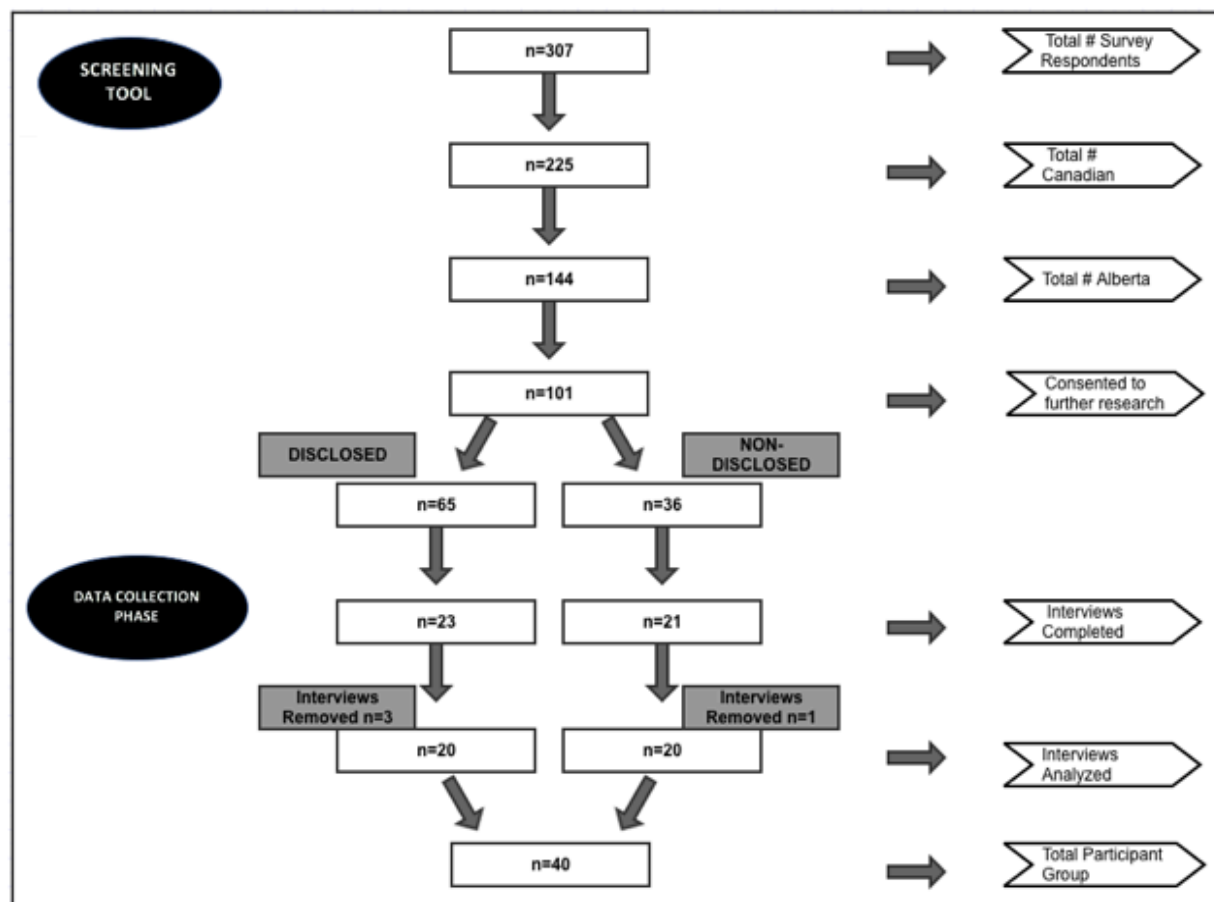
Figure 1. Progression of participants through both the screening tool, and data collection phase of this study.

Data Analysis

Descriptive Phenomenology offers a data analysis approach (Colaizzi, 1978; Giorgi, 1985; 2009; Shosha, 2012) that incorporates rigor and seeks to avoid being overly reductionistic. Data analysis commenced upon interview transcription and involved the use of Giorgi's method (2009), which was further supplemented by Colaizzi's (1978) strategy, as described below.

Giorgi refers to the first analytic step as reading the data to ascertain a sense of the whole (2009; 2012) which involves the researcher assuming a phenomenological stance, including bracketing (as much as possible) personal knowledge and perspectives in the aim of freshly examining the data. Accordingly, researchers must seek to put aside habitual or taken-for-granted understandings via self-reflection and/or a self-meditative process such that the phenomenon as

depicted by participants is allowed to emerge and speak for itself (Finlay, 2009). Within this

step, researchers must allow themselves to be fully present with the data, seeking to understand

the data within its context. Giorgi also highlights that within this first step, the reader must "get a

sense of the whole while sensitively discriminating the intentional objects of the lifeworld

description provided by the participant" (2009, p. 128-129). Based on this process, the researcher

is increasingly able to discern what was present for each participant (Broome, 2011).

The second analytic step is to read and re-read transcripts in their entirety. This step

offers a sense of the gestalt and experience of the phenomenon under study (Giorgi, 2009).

During this second step, the researcher adopts a holistic approach and starts to understand the

nature of the data (Giorgi, 2012). This step is done without critical reflection and the researcher

remains in a "phenomenological attitude" (Broome, 2011). Adopting a phenomenological

attitude implies seeking to put aside or bracket any assumed and/or taken-for-granted

understandings that the researcher may hold and rather allow the phenomenon to be conveyed as

depicted by participants (Finlay, 2009; 2014).

The third analytic step is the delineation of significant statements within the narrative so

that the data can be parsed into manageable sections for analytic coding and interpretation

(Giorgi, 2009; Shosha, 2012). In this stage, all significant statements including content that is

relevant and pertinent to the phenomenon under study are extracted and recorded in a separate

document, indicating page, line number(s), and participant number (Shosha, 2012). The

researcher then reads through each transcript and significant statement and "each time she

experiences a transition in meaning from within the aforementioned attitude, she makes a mark

on the description" (Giorgi, 2012, p.5). This process is referred to as *constituting parts* (Giorgi,

2012). Table 3 provides examples from the significant statements which were identified and extracted from participant transcripts.

Table 1. *Examples of significant statements*

Significant Statements	Transcript Number	Page Number	Line Number(s)
"I think if it comes from when they're young, and if it starts within the family environment, it's almost like an organic acceptance of Autism"	D5	33	14-15
"But I think at the end of the day I think you have to tell them. That's my philosophy, it's not a question of yes or no anymore it's a question of yes and when and how"	ND7	11-12	33/2-3
"A label is only as powerful as a negative or positive connotation we give to it"	D6	12	27
"I think every kid is at a different stage and every situation is so unique that I think it's hard to kind of come up with...like you know what I mean a suggested time line and suggested way of doing it and that kind of thing"	ND10	5	4-7

The fourth, and most laborious, analytic step is the transference of significant statements and meaning units into psychologically sensitive descriptions. In this step, the researcher examines the phenomenon at a deeper level of psychological space, thus *unearthing* the essence of meaning related to the *lived experience* (Giorgi, 2009). The psychological level is described as an individualized, personal, or worldly view, rather than a transcendental view (independent of experience; Giorgi, 2009). Moreover, this step comprises the initial change in the analytical process which elicits the "psychological value of what the subject said (and) is made explicit for the phenomenon being studied" (Giorgi, 2012, p. 5). This fourth step involves changing the meaning units into the third person, retaining meaning but transforming each into a statement. By changing meaning units into statements, the researcher should be more objective and better able to retain a phenomenological attitude (as previously defined; Giorgi, 2009).

Transformations from these third person statements into descriptive psychological expressions using Husserl's process of imaginative variation then occur (Giorgi, 2009; Husserl, 2008). This process is performed by determining which qualities of the experience are essential (determining the essence of the experience) and which are incidental or accidental; the researcher considers what is being psychologically expressed through each meaning unit (Giorgi, 2009; Husserl, 2008; Zahavi, 2003). It is important to note that through this procedure, the researcher is only "describing how it (the phenomenon under study) was experienced and understood by the participant from his or her point of view without explanation of 'why' it was experienced in the way it was" (Broome, 2011, p.89). Table 2 provides examples of how meaning statements were developed from significant statements or meaning units.

The final step is the synthesis of a general psychological structure from the context-dependent *constituents* of the experience (Giorgi, 1985; Broome, 2014). Constituents are context-dependent elements of a description and cannot be considered independent of one another (Broome, 2014). These constituents are determined by highlighting the shared meanings expressed by a group of participants pertaining to psychological meaning (Giorgi, 2009). Finlay (2014) states that any generated meaning units and shared commonalities, or themes, are then grouped together "assembling clusters of essential meanings" (p. 129) or themes (Shosha, 2012). This step is grounded in the phenomenological concept of "parts and wholes" (Sokolowski, 2000, p. 22), indicating that the value is much more significant when considering the whole picture (Broome, 2014). However, as descriptive phenomenology seeks discovery rather than a prediction of outcomes, the emergence of a general psychological structure is not a necessary element (Broome, 2011) and if included, should offer supplementary quotations and significant statements directly from the interview transcripts (Finlay, 2014).

Table 2. *Example transformation of a meaning unit*

Significant Statement	Meaning Unit(s)	Psychologically Sensitive Description(s)
"I think it's almost morally wrong to make a decision to withhold information from someone whose life is impacted, ... it's really fascinating for me just from an ethics point of view, to see how we used to withhold you know the terminal illness diagnosis and all that kind of thing and it takes away the ability for the individual if they have the cognitive ability to understand what that means" (Transcript ND3, page 14, lines 15-21).	- "I think it's almost morally wrong to make a decision to withhold information from someone whose life is impacted" -"We used to withhold…the terminal illness diagnosis...and it takes away the ability for the individual...to understand what that means" -"If they have the cognitive ability"	-She thinks it's morally wrong to withhold a diagnosis, from the individual who is impacted by that diagnosis. -If an individual has the cognitive ability to understand what a diagnosis means, it should be disclosed.

Evaluating Qualitative Research

Qualitative research, especially phenomenology, is grounded in the lived experiences of people and thus differs in the fundamental assumptions held by researchers using other qualitative approaches (Marshall & Rossman, 2006; Willig, 2012). Nonetheless, it is essential that qualitative research is methodologically rigorous (Yardley, 2000). As there is no single established and accepted way of conducting qualitative research, it is important that epistemological considerations are identified (Snape & Spencer, 2003; Willig, 2012). From a contextualist view situated within phenomenology, this study sought meaningful accounts from participants (Henwood & Pidgeon, 1994). Moreover, instead of an absolute truth, the contextualist emphasis was on explaining individual subjective meanings (Henwood & Pidgeon, 1994). From this stance, realist terms such as reliability and validity cannot be measured in the same way as a traditional psychometric approach because different people construct different meanings (Madill, Jordan, & Shirley, 2000). However, researchers must justify any generated knowledge to ensure plausibility of research outcomes.

As Giorgi (2009) states, scientific credibility is important and thus research must be conducted in a verifiable and systematic way (Finlay, 2014). Along with steps for data collection and analysis, the presentation of findings offers corroborative text quotes and examples directly from the interview data that in turn demonstrates *trustworthiness* and seeks to bring readers closer to the lived experience of the participants (Finlay, 2014).

In researching and exploring conversations, it is important that researchers remain true to the lived experiences of participants and to that end, Tracy (2010) offers eight quality criteria that were utilized: worthy topic, rich rigor, sincerity, credibility, resonance, significant contribution, ethics, and meaningful coherence (Tracy, 2010). *Worthy topic* ensures the identification of an area of inquiry and approach whereby "good qualitative research is relevant, timely, significant, interesting, or evocative" (Tracy, 2010, p.840). This suggests that research ideas are generated from a theoretically or conceptually compelling standpoint, and may arise as a discipline priority or stem from a societal event (Tracy, 2010). Tracy advises that research must provide a significant contribution in addressing a research/literature-based gap of knowledge. To ensure that this study explored a worthy topic, the researcher completed a comprehensive literature review to highlight paucity in the literature and, as a part of the larger study, a focus group highlighted the need for this study within broader community and field of ASD.

Tracy also indicates that qualitative researchers must acknowledge biases or preconceived notions (*sincerity*) and must stay true to the participants' experiences (*credibility*) while at the same time impacting the reader through an evocative voice (*resonance*). Moreover, Tracy specifies that meaningfully coherent studies accomplish and achieve their stated purpose, use methods that partner well with theoretical paradigms, and weave prior literature with the current focus, method, and findings (2010). Lastly, *rich rigor* refers to sufficient attention paid to

the collected data and researcher allegiance to prudent research process (Tracy, 2010).

Specific to this study, the researcher utilized a second coder to review the data (the initial coding of interviews at the start of the data analysis process and the theme clusters generated within the data) to help demonstrate the authenticity of the researcher and credibility within the data analysis process. As an example of this rigor, both the researcher and second coder identified their potential biases several times throughout this analysis process and shared these biases with one another to seek optimal sincerity and accountability. This type of rigorous analysis yields a transparent and detailed explanation of the data collection and analysis process.

Transparency (e.g., outlining the steps taken to answer research questions, so that others can follow the decisions made in the study) and reflexivity (e.g., constant reflection) have been highlighted as important means by which to evaluate qualitative research rigor (Butler-Kisber, 2010). *Consistency* was initially obtained by listening to recorded interviews while reading transcriptions, thus ensuring the accuracy of the transcribed data. To ensure constant reflexivity, the researcher engaged in several activities such as maintaining a reflective journal and seeking support to promote study integrity and credibility (Caelli, Ray, & Mill, 2003). Furthermore, the researcher kept an audit trail (Patton, 2002) in which she maintained clear and detailed records that describe the research process in detail. Lastly, the *credibility* of the study reflects the potential relevance of emergent descriptions for the population and phenomenon under study. A focus on the nuanced description of study procedures and processes are offered, as are a discussion about the limitations of the study including the sampling approach and considerations related to those for whom the final product may be relevant. Judgments can then be made regarding the fit of the research and for whom the research may or may not be relevant (Butler-Kisber, 2010).

Chapter Summary

This chapter outlined the qualitative research design, epistemological, ontological, and theoretical considerations, phenomenological approach to qualitative inquiry, information on data collection and recruitment, ethical considerations, analysis procedures, and means of demonstrating research rigor. Further, this chapter justified the descriptive phenomenological approach that was implemented in this study, grounded both within psychology and family systems approaches. Through this approach, the researcher endeavored to illuminate theoretical and methodological tenets upon which the study has been built. The next chapter presents participant characteristics and expounds upon results from the study. Accordingly, findings amplify both the lived experiences of disclosure/non-disclosure for parents and their internal decision-making process surrounding whether or not to disclose an ASD diagnosis to their child.

Chapter 4: Results

This chapter presents the findings from this study. It begins with a description of the research participants including demographic information and then presents the theme clusters and themes that emerged from the data. The results include detailed descriptions and verbatim quotes to illustrate and corroborate the theme clusters and themes.

Participant Characteristics

The final sample used in this analysis consisted of 40 parents or parent dyads who met inclusionary criteria and completed a semi-structured interview with the researcher. Of these participants (as noted above), half ($n = 20$) were parents/parent dyads who had disclosed (D) the diagnosis of ASD to their child and half ($n = 20$) were parents/parent dyads who had not (ND). One mother also reported on experiences related to her two children diagnosed with ASD. There were three families where both parents participated in an interview together as a parent dyad. Amongst all participants ($n = 40$), interview duration ranged from just under 11 minutes to approximately an hour and fifteen minutes (10:48 to 1:14:40), lasting approximately 34 minutes on average. On average, the interviews conducted with parents who had not disclosed were shorter ($\approx$28 minutes) than interviews conducted with parents who had disclosed ($\approx$39 minutes).

Within the screening tool and data collection phase, demographic information was reported about participants (parent/parent dyads) and their child(ren)/adolescent(s) with ASD. The following participant information was obtained for the purposes of this study: parent(s) involved in the interview (e.g., biological, adoptive, step, foster, etc.), family home geographical location, parent reported gender of the child with ASD, formal ASD diagnosis, additional diagnoses, child's age at ASD diagnosis, child's current age (at time of the interview), and if applicable, child's age at the time of initial disclosure. Further breakdown of demographic

information can be found in Table 3 for Disclosed participants and in Table 4 for Non-Disclosed participants.

Of the interviewed parents, 33 were biological mothers, three were biological fathers, one was an adoptive mother, and three families participated as biological mother/father dyads. Overall, the families were located across nine locations in Alberta, including: Calgary ($n = 25$), Edmonton ($n = 5$), Sherwood Park ($n = 2$), Airdrie ($n = 2$), Fort Macleod ($n = 1$), Lacombe ($n = 1$), St. Albert ($n = 1$), Langdon ($n = 1$), and Lethbridge ($n = 1$). Of these interviews, 36 were conducted in person, either in the family's home ($n = 13$) or a public place of their choosing (e.g., coffee shop, library; $n = 23$), and four interviews were conducted via Skype due to the family's location or preference.

Regarding child demographic characteristics, parents reported on their child's gender, sharing that of the 41 children represented, 32 identified as male, 8 identified as female, and 1 identified as transgender. Parents also reported on their child's formal diagnosis, all falling under the ASD umbrella. Overall, children/adolescents had been given a formal diagnosis of ASD ($n = 20$), Autistic Disorder ($n = 8$), Asperger's Disorder ($n = 7$), and PDD-NOS ($n = 6$). Children ranged in age at the time of diagnosis from two to 22 years, on average receiving their diagnosis at approximately six-years-old, with over half of the children receiving their diagnosis between the ages of two and four years ($n = 24$).

Among families who had disclosed the diagnosis of ASD to the child, the children ranged in age at the time of diagnosis from 2 to 22 years, on average receiving their diagnosis at approximately eight-years-old.

Table 3. *Demographic Characteristics of Disclosed Participants*

Interview #	Parent(s) Involved in Interview	Child's Diagnosis(es)	Child's Gender	Age at Diagnosis	Age at time of Interview	Age at Disclosure
D1	Adoptive Mother	Two children with ASD	*Child 1a -* Male	*Child 1a - 6 years*	*Child 1a - 20 years*	*Child 1a - 10 years*
			Child 1b - Male	*Child 1b - 2 years*	*Child 1b - 16 years*	*Child 1b - 6 years*
D2	Mother	Asperger's, SLD, ADHD, OCD	Male	22 years	34 years	22 years
D3	Mother	PDD-NOS, ADHD	Male	14 years	19 years	14 years
D4	Mother	ASD, Epilepsy	Female	9 years	12 years	9 years
D5	Mother & Father	Autism	Male	2 years	4 years	4 years
D6	Mother	ASD	Male	3 years	4 years	3 years
D7	Mother	PDD-NOS, OCD, Seizure Disorder	Female	4 years	28 years	26 years
D8	Mother	Asperger's, SLD	Female	4 years	17 years	4 years
D9	Mother	ASD, ODD, ADHD	Transgender	15 years	18 years	15 years
D10	Mother	Asperger's, Dyslexia, Gifted	Male	10 years	12 years	10 years
D11	Mother	ASD, ADHD, Neurological Disorder	Male	8 years	8 years	8 years
D12	Mother	ASD, ADHD	Male	9 years	22 years	15 years
D13	Mother & Father	ASD	Male	4 years	12 years	9 years
D14	Mother	Autism	Male	2 years	8 years	6 years
D15	Mother	ASD, ADHD, SLD	Male	10 years	12 years	10 years
D16	Mother	Asperger's, ADHD	Male	10 years	20 years	10 years
D17	Mother	PDD-NOS, ADHD	Male	5 years	13 years	11 years
D18	Mother	ASD	Male	4 years	6 years	4 years
D19	Mother	PDD-NOS	Male	8 years	15 years	11 years
D20	Father	PDD-NOS, ADHD, GAD	Female	8 years	17 years	15 years

Table 4. *Demographic Characteristics of Non-Disclosed Participants*

Interview #	Parent(s) Involved in Interview	Child's Diagnosis(es)	Child's Gender	Age at Diagnosis	Age at time of Interview
ND1	Mother	Autism	Female	4 years	7 years
ND2	Mother	Autism	Male	3 years	7 years
ND3	Mother	Autism, ID, Mood Disorder - NOS	Male	2 years	20 years
ND4	Mother	ASD	Male	2 years	2 years
ND5	Mother	Asperger's, Gifted, SLD	Male	5 years	8 years
ND6	Mother	ASD	Male	2 years	15 years
ND7	Father	Autism	Male	4 years	9 years
ND8	Father	ASD	Male	3 years	13 years
ND9	Mother	Autism	Female	2 years	6 years
ND10	Mother	ASD	Female	2 years	8 years
ND11	Mother	Asperger's	Male	2 years	12 years
ND12	Mother	ASD	Female	7 years	8 years
ND13	Mother	ASD, ADHD	Male	4 years	6 years
ND14	Mother	ASD	Male	2 years	4 years
ND15	Mother	ASD, ADHD, Gifted	Male	4 years	7 years
ND16	Mother	ASD	Male	3 years	5 years
ND17	Mother & Father	PDD-NOS, Expressive Language Disorder	Male	4 years	7 years
ND18	Mother	Autism	Male	3 years	7 years
ND19	Mother	ASD, ADHD	Male	12 years	12 years
ND20	Mother	Asperger's, Gifted, SLD	Male	13 years	22 years

Of families who had not disclosed the ASD diagnosis to their child, the children ranged in age at the time of diagnosis from 2 to 13 years, on average receiving their diagnosis at approximately four-years-old.

Some parents also reported additional diagnoses that had been given to their child(ren). Specifically, 20 parents reported that their child had been given additional diagnoses, having received these diagnoses at various times over the course of their childhood and adolescence. Of these 20 children, eight had been given one additional diagnosis and 12 had been given two or more additional diagnoses. Moreover, of the 20 parents who reported that their child had additional diagnoses, 65% ($n = 13$) were families who had disclosed the diagnosis of ASD to the child and the remaining 35% ($n = 7$) were families who had not disclosed the diagnosis of ASD to that child. It was not specifically reported if families were consistent in disclosing/not disclosing ASD relative to patterns of similarly disclosing/not disclosing the additional diagnoses. Additional diagnoses included: ADHD ($n = 12$), Specific Learning Disorder (SLD, including dyslexia; $n = 6$), Giftedness ($n = 4$), Obsessive Compulsive Disorder (OCD; $n = 2$), a seizure disorder ($n = 2$), Generalized Anxiety Disorder (GAD; $n = 1$), Oppositional Defiant Disorder (ODD; $n = 1$), an (unspecified) neurological disorder ($n = 1$), Expressive Language Disorder ($n = 1$), Mood Disorder – Not Otherwise Specified ($n = 1$), and Intellectual Disability (ID; $n = 1$).

Children's age at the time of the interview ranged from 2 to 34 years, with an average age of approximately 12-years-old. Looking at families who had not disclosed the ASD diagnosis to their child, the children ranged in age from 2 to 22 years; on average these children were nine-years-old, with half of the children currently between six and eight years of age ($n = 10$). Looking at families who had disclosed the diagnosis of ASD to their child, their ages ranged

from 4 to 34 years; on average these children were 15-years-old. Lastly, when asked about their

child's age at the time of ASD diagnosis disclosure, parents who had disclosed (parents = 20,

children = 21) reported that children ranged in age from three to 26 years, on average (mean =

10.57 years), and most frequently (mode = 10 years) disclosing the diagnosis at approximately

10-years-old.

Descriptive Phenomenological Results

Overall, 663 significant statements were extracted from the 40 transcripts, split into two

participant groups: those who had disclosed the diagnosis of ASD to their child ($n = 20$), and

those who had not disclosed the diagnosis of ASD to their child ($n = 20$). This chapter will first

describe results that were common to both participant groups. Subsequently, the experiences of

all non-disclosed parents (ND) will be outlined, followed by the experiences of all disclosed (D)

participants through the use of overarching theme clusters and corresponding themes. Complete

versions of these conceptual frameworks can be found in Appendix E (ND participants) and

Appendix F (D participants).

Both Participant Groups

Different theme clusters of essential meanings emerged from the non-disclosed

participants in comparison to disclosed participants. However, as both participant groups

expressed common information while sharing their stories pertaining to their journey of

receiving their child's ASD diagnosis this initial theme cluster will be discussed relative to both

participant groups.

Common theme cluster 1: Journey of receiving the ASD diagnosis. In this first theme

cluster, many parents ($n = 35$) from both groups began their stories by describing what led them

to seek out an assessment and/or diagnosis, their experience of the diagnostic process, and their

subsequent experience of finding out that their child had ASD. Within this initial theme cluster, the following themes emerged: (1) What's going on?; (2) Parent experience of the diagnostic process; and (3) Experience of finding out that their child has ASD.

Theme 1.1: What's going on? Many parents described their early journey noticing that their child was "different" and initiating their process into the healthcare system to find out what was going on. These parents saw it fitting to share pertinent background information about what differences or deviations from neurotypical child development they noticed in their child along the journey towards an ASD diagnosis. For some, they shared about the absence of differences leading them to believe that at first their child was progressing typically through development and couldn't have ASD. These parents also described their child's development and communication relative to a sibling or peer, and identified the times when they realized that there was "something bigger going on" (ND2). Other parents shared that their child seemed different, but indicated that they weren't sure that there was something wrong.

> Yeah so [child x] was in grade 3, and I think it was because although [wife] and I didn't really have the knowledge base to say that, you know, it looks like she's on the spectrum, we'll go and see a child psychologist and get an assessment. It was more, [child x] is exhibiting certain behaviours, that seem a little different, and so we need to see whether there is an issue or not. (D20)

Further, parents described the moment in time when their child's differences were identified by someone external to the home environment. One mother described an interaction between her child and a relative surrounding the possibility of an Autism diagnosis: "So, he hid behind the van and then he hid in the closet and she [aunt] said, 'boy, it's like he's autistic'"

(ND20). Alternatively, one parent shared about how her child's school indicated the possibility of their child having ASD and suggested going through an assessment process.

Other parents noted specific differences that led to "red flags" and having to acknowledge that something seemed wrong or that their child was having difficulties. One parent outlined that her child wasn't meeting certain developmental milestones: "I was like, okay each child will develop in their own time, but there [were] milestones that [child x] did like right away, and there [were] some that were like, okay, he should be able to do this" (ND14). Other parents acknowledged that they had always known their child was different and that there was no way they could disguise that difference: "That's all I've been focusing on...I knew from the day…he was born that there was something a little bit different…(ND16). Lastly, for some parents, they shared the experience of having to justify that there was a "problem" and not being able to explain their child's differences to other family members: "But I kept thinking, ok there's a problem but everybody's telling me, there isn't" (ND20).

Overall, parents often shared that at an early stage in their child's life they initiated their process into the healthcare system to find out what was going on for their child. These parents indicated that their child underwent a variety of tests: "So the kid basically had been tested, you know, stem to stern" (D2). Some parents also shared about an absence of ASD-like qualities, leading them to believe that something else might be happening in their child's development. Many of these parents also identified a variety of alternate diagnoses that their child received along the way: "Because historically, we haven't really been dealing with Autism throughout her life, we've been dealing with all these other issues. Autism has been the least of our concerns" (D7). The above examples highlighted the beginning of a journey towards an ASD diagnosis for

parents, identifying differences, alternate diagnoses, and the experiences of trying to identify what was going on for their child.

    Theme 1.2: Parent experience of the diagnostic process. Many parents continued their story by sharing about their journey waiting to start the diagnostic process. Parents shared about their progression through a lengthy and complicated process towards an ASD diagnosis. "As far as the diagnosis for Autism goes, it's probably not typical…In that it took a very, very, very long time for my son to actually be diagnosed" (D12). Moreover, this theme encapsulated parent experiences and thoughts about the overall diagnostic process (assessment and feedback meetings), and thoughts about the public versus private systems for seeking an ASD assessment.

    Firstly, some parents indicated that they had to see many professionals and had to rule out many other "avenues" prior to their referral for an ASD assessment: "[it] was a big process of going through to narrow down all of the other things to say you know it's not medical, it's not, it can't be you know Chiropractor, Cranial sacral, all those sorts of things" (ND12). Parents noted concern about how long they had to wait before even beginning an assessment and indicated that there was a lengthy wait once a referral had been made. Some parents revealed that they not only had to see a multitude of professionals but received many other diagnoses along the way:

> I started looking for help for him when he was twenty-eight months old, and although there were many diagnoses along the way, some of which were incorrect, he wasn't actually diagnosed as having Autism until he was nineteen years old. Which of course comes with whole host of challenges because of the lack of an accurate diagnosis. (D12)

Similarly, other parents shared that diagnostic clarity took a great deal of time as professionals (such as psychiatrists) only saw their child briefly and often over protracted periods of time.

Other parents shared their feelings of frustration with the diagnostic process and indicated that an assessment should be started quickly. Several of these parents described feeling "sick of the wait" within the public system and stated that families who have the means should seek an assessment privately. One parent's frustration is exemplified in this passage:

Cause like we had a waitlist to go through the Children's [Hospital] to get a free assessment, like through Alberta Health, and was going to be at least a year. And I'm like no way…His age is time-sensitive. I don't care what it costs, we're doing it now…But like I said, we were very pushy and we really, like when they wanted paperwork we had it the next day. Just cause we did not want, we were like we want to get on this as soon as possible. This is our little guy here so… (ND4)

Parents also spoke about their experience in the diagnostic feedback meeting and the confusion around where their child fit within the Autism spectrum. For some parents, they spoke to the differences between the diagnostic categories in the *DSM-IV-TR*, lack of clarity about the diagnosis they were receiving/had received, and the shortage of support given to parents when the diagnosis was initially given:

Um, I mean, he chewed a lot. It was like 'what the heck?' Um, so we went to the doctor, and we got the diagnosis of Asperger's, and he said 'here's some online things you can read. Have a nice day.' That was it. I had no idea what we were doing. (D16)

Several other parents also expressed their frustration with the brevity of the meeting at the conclusion of their child's diagnostic assessment and the limited time professionals spent with the child to make a diagnosis. Parents indicated that "the waiting list they have is so long" (ND1), and yet they didn't feel satisfied with the process because the diagnosing professional

only saw the child briefly, and the final feedback meeting was very short. The following quote illustrates another parent's frustration:

> Then they uh call you, put you in a room, chuck the paperwork at you that says this is your son's diagnosis. Depending on which physician is there that day, you get the run down from the developmental pediatrician that's there, um some better than others. And that was basically it. Here's your diagnosis and your folder of this is what I recommend, go and that's it. Like they washed their hands of you at that point. (ND18)

Many parents explained that although their child understood that they were going through an assessment process, the diagnosing professional often asked the individual with ASD to leave the room during the final feedback meeting where a diagnosis was given to the parents:

> And then, when they gave the diagnosis, I asked if [child x] could be in the room. And this proved to be much more controversial than I expected. Um, and they said, you know 'we really discourage kids from being in the room' and I said 'why, right? It's their body'…And then the, the answer was 'well, it's not a developmentally appropriate concept', and I said 'so, make it developmentally appropriate'… Children aren't real people in society to begin with. Disabled people are often not real people in society to begin with. Disabled children are not acknowledged, and in this case, he was not acknowledged. (D6)

The above parent statements offered commanding examples of challenging elements experienced during the diagnostic process. Moreover, such experiences constituted major parts of the journey towards receiving an ASD diagnosis and grappling with the diagnosis.

Theme 1.3: Experience of finding out my child has ASD. The experience of finding out about their child's ASD diagnosis was another common theme expressed by parents at the end of

their *Journey of receiving an ASD diagnosis*. Many parents continued their story by sharing a myriad of feelings or emotional reactions when they were finally given the diagnosis by a professional. More specifically, parents shared various and mixed feelings which included some of shock and disbelief, grief, stress, anxiety, sadness, and some of confirmation and relief. Additionally, this theme also included initial parent thoughts on being able to access supports, and extended family considerations.

Many parents expressed their initial shock and disbelief upon being given their child's diagnosis of ASD. In some cases, parents stated that they felt the diagnosis given was too "general," and wasn't the diagnosis under the Autism spectrum that they were expecting (i.e., Asperger's instead of PDD-NOS). Other parents reflected that they weren't "expecting" the diagnosis at all and shared that initially they felt as though the diagnostic label couldn't possibly describe or fit their child. This is described by one of the parents as follows: "Yeah it wasn't easy because at first you have that ignoring thing, no not me, not my kid" (ND1). Another parent recounted a similar experience as they tried to understand what the diagnosis meant for their child:

> So that was, I wasn't expecting that so that was… Because the picture that I had in my mind of ASD was something that…you know somewhere in school where it was sort of a child in a corner of a room rocking silently. Not connected to their, you know their environment at all. (ND15)

Some parents shared their initial feelings of grief and loss when they received their child's diagnosis. Parents expressed having to balance feelings of grief for the loss of a neurotypical child and stress upon receiving the diagnosis:

And it's not just the child that gets diagnosed too, it's the families, it's the parents, right? And…we've looked at all kinds of stuff too, and like divorce rates on you know, I think a lot of the stress comes from not, also not there being support for the parents after the diagnosis. What happens now?...But no one says 'this is the stuff for you...Take some time, think about it'. (D5)

Parents said that it took them time to process and accept the diagnosis themselves, as they felt overwhelmed and experienced feelings of grief. Another parent's feeling of grief and shock is exemplified in the passage below:

You know the traditional bubble pop… oh my god my dreams of a typical child is gone because he's not going to go to school, he's not going to have a job, he's never going to get married you know just explodes a whole lifetime in front of you. That shock passes and then you start to realize oh my god he's actually doing really well. (ND7)

In contrast, other parents indicated that they had a very different emotional reaction than their spouse, which served as an emotional balance:

You know for me the, the beginning was really tough, and I think I was stuck in that, ah, 'this is a nightmare,' 'this is a tragedy'... And [husband] was more like 'you know what, it's gonna be fine. You know, we'll do what we need to do, and he is who he is, and he's still my son'...but [husband] brought that emotional balance too to this thing, and...I think it's made our situation as a family easier to, to manage, feeling like we're on board together, and it's not just my load as the mom. (D5)

Several parents indicated that learning about their child's diagnosis impacted their lives significantly as parents, and for some, negatively impacted their mental and physical health. These parents reflected upon their experience further, indicating that they were grateful that they

hadn't disclosed the diagnosis to their child initially when they found out as it would not have

been a positive experience:

> Because if I had I disclosed to him when I found out, or even a couple of years later, my
>
> delivery would have probably been pretty brutal. Pretty rain man'ish… you're going to
>
> be institutionalized, not that severe, but you've got some problems right?...You have a
>
> disease, okay we gotta fix you, right? And it would have been very old school
>
> thinking…(ND7)

Another parent recounted a similar experience surrounding her initial reaction towards her

child's diagnosis, and her thoughts and fears looking towards the child's future:

> Okay, so what's this going to mean like [crying], what does this mean for him. Like he
>
> has older parents? Am I going to be able to look after him and keep him safe? Is he going
>
> to be able keep himself safe? Is he going to try his hardest because he wants to have
>
> friends because he's social and believe everything everybody tells him? I think that was
>
> my first thing, I don't care what it means for us as a family, I just don't want him to get
>
> hurt. (ND13)

Additionally, some parents shared that their experience had been different upon learning

of their child's diagnosis and expressed that they felt relieved as the diagnosis served as

confirmation. Further, some articulated that they were expecting the diagnosis before it was

formally given.

> There was never really a grieving. Again, when, when your child is born distinctly
>
> different, I think that people have an experience of their child regressing, or following a
>
> very strict path, and then having a strong diversion away…Um, we didn't have much to
>
> grieve, we always kind of knew. So, when we got to the diagnostic table, and they sit

down, 'well, we're here for a query of Autism.' And we said: no, no, we're here for a

confirmation of Autism. (D6)

Another parent explained that the diagnosis instilled a feeling of relief as she felt that her child's

behaviours were due to bad parenting:

So, I was actually relieved when they said: yeah this is what it was. I thought it was

honestly, it was bad parenting...so that's when he finally got the diagnosis, which was

kind of a relief because then I knew…this answers some of my questions why he does the

things he does. So, it meant it was just not bad parenting. (ND17)

For other parents, learning about their child's diagnosis instilled a sense of urgency for

access to supportive services to help them understand and deal with the diagnosis, and several

felt that not enough support was available. Moreover, some parents shared that learning about the

diagnosis started a conversation about whether or not to disclose the diagnosis to extended

family and questions about whether family would be supportive.

Non-Disclosed Participants

Aside from the common theme cluster, six remaining theme clusters of essential

meanings emerged from non-disclosed participants: (Theme 2ND) Reasons for non-disclosure;

(Theme 3ND) Reasons for disclosure considered; (Theme 4ND) Potential outcomes of

disclosure; (Theme 5ND) Where are we now?; (Theme 6ND) Decision about disclosure; and

(Theme 7ND) What might our process be? These theme clusters were then further broken down

into 25 themes, that will be described in more detail below as exemplified by participant

statements. The results in this section include the experiences collected within 343 significant

statements, presented as verbatim quotes to corroborate and illustrate the theme clusters and

themes. Underpinning these theme clusters is the recount of experiences over the passage of time as outlined pictorially in Figure 2.
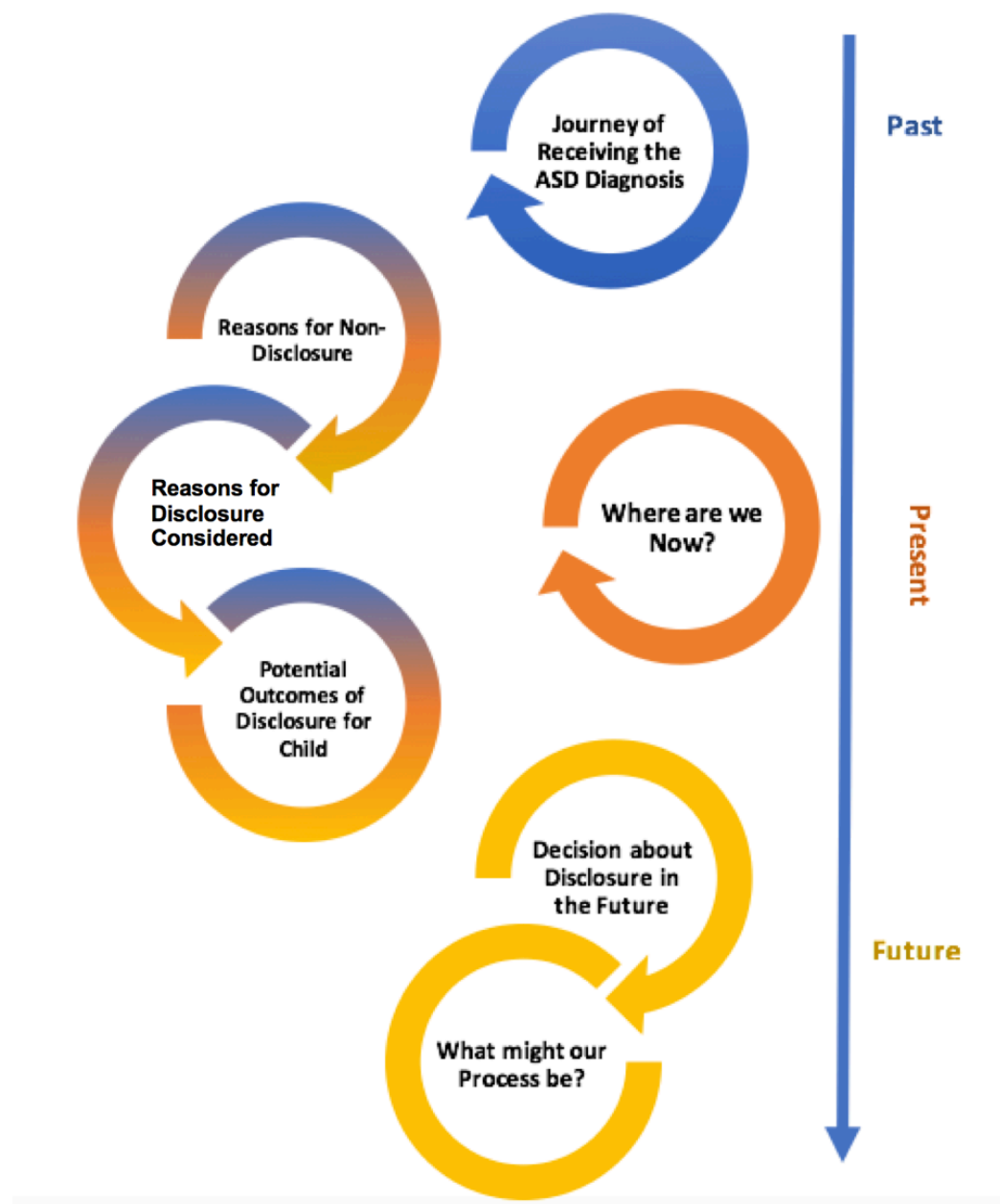
Figure 2. Theme clusters of essential meanings for non-disclosed participants, as unscored by the passage of time.

Theme cluster 2ND: Reasons for non-disclosure. In the second theme cluster, *Reasons for non-disclosure,* all parents (*n* = 20) continued their story by providing a rationale or their

consideration of reasons for not disclosing the ASD diagnosis to their child. Within this theme

cluster, the following overarching reasons or themes emerged: (1) Will there be a need?; (2)

Labelling; (3) Don't want to give child an excuse; and (4) Unwanted attention from others.

Theme 2.1ND: Will there be a need? Parents described considering if there was a need

for disclosure to the child. They offered a variety of considerations leading to or justifying non-

disclosure which included: doubting/questioning whether the diagnosis would be noticeable to

others, children hadn't noticed any of their own differences, and children wouldn't understand.

Some parents expressed that they didn't feel that their child's diagnosis was noticeable to

others and wouldn't be noticeable to others in the future. Moreover, they shared that they felt

they should wait to "see if there [was] going to be any point" (ND2). Some revealed that the

children had made many gains over their life thus far, that any characteristics they still possessed

seemed very "mild," and, therefore, they didn't think that disclosing the diagnosis would be

"necessary" or "of any benefit" (ND10). Parents also spoke to the notion that they didn't believe

the children currently noticed or questioned their differences or supports; thus, parents doubted

that there would be a need to disclose the diagnosis to the child? One parent shared, "He had an

aide up until grade three. And he never questioned why there was somebody with him. So again,

we waited and didn't [disclose]" (ND11). One parent also articulated that she didn't know if their

child would continue to meet criteria for the diagnosis in the future and so they wondered if there

would be any relevance or benefit if disclosing a previous diagnosis.

Other parents shared that they haven't disclosed the diagnosis to their child as they don't

believe that their child would understand the disclosure. Specifically, parents spoke to their

child's language level, developmental level, cognitive ability, and challenging behaviours. One

parent shared that she didn't feel her child would be able to understand as her behaviours might

interfere: "her behaviours can certainly make things challenging because if she's not calm, or she's hyper, or she's not interested in listening" (ND9), and thus this might pose challenges during a disclosure conversation. Some indicated that they did not feel their child would ever understand, whereas others stated that the child didn't understand at this point. One parent shared her realization that her child may never understand the disclosure: "It's probably not right…to withhold that information...that was the hardest thing to sort of deal for myself, was recognizing that I would have a child who didn't, that I would never be able to have that conversation with" (ND3). However, most parents indicated that they see the relevance in disclosing to other children who could understand.

Theme 2.2ND: Labelling. This theme described the concept of labelling, whereby parents expressed their concerns, fears, and considerations about disclosing the diagnostic label to their child. Within this theme, parents spoke about the diagnosis as a part of who the child was, how there wasn't a want or need to label the diagnosis, and fears about the child thinking negatively of themselves because of a label.

Some parents shared that an ASD diagnosis was just a part of who their child was. They stated that they did not know if the label needed to be discussed as they wouldn't overtly sit children down to discuss other dimensions of their character or physical self. One parent shared that he never felt a need to treat his child with ASD any differently than his siblings:

> We…never felt um the burning desire to treat him any differently…And we felt that was a more important message for him given his development than you're special, you need to be handled differently you know all that sort of stuff…So that's been our; if we made a decision it was more that way than we need to take you aside and treat you differently. (ND8)

Parents reflected on the idea of labelling, and indicated that regardless of a label, their children could do anything they wanted in life. Further to this, they shared that "there's no need to put a name, it really doesn't change much. I think it's more about understanding what you can do to deal with frustrations. Like how we can make sure that he knows how to help himself" (ND13).

Other parents expressed that although their children recognized some of their differences, they had never chosen to label those differences. One parent stated: "it's just something that's not in our consciousness even, he's just [child x]. He's not [child x] the autistic child" (ND8). Parents offered the opinion that instead of telling the child she/he/they have ASD, maybe it would be better to describe what makes that child unique. Moreover, some parents expressed fear that upon disclosing the diagnosis their children would start to think negatively of themselves. Parent's shared that they feared that their child might experience low self-confidence, low self-esteem, denial, or frustration if they disclosed. One parent highlighted this: "you're telling him something, that you know that you have a disability. You know that denial of it and that frustration, saying like you know you're telling me I'm different and I'm not different" (ND6). Parents further shared worries around labelling the diagnosis, as they were afraid that disclosure would exacerbate negative feelings that children already had of themselves, and stated that their children were already afraid of looking different:

> Because I guess that would be my biggest fear around this is you know not saying it the right way because him, he already seems to have low self-esteem and at times seems somewhat depressed so I guess my fear is that he'll you know...take it as a bad thing, right? (ND19)

Theme 2.3ND: Don't want to give an excuse. Often parents expressed hesitance over disclosing the diagnosis to their child as they feared that their child would use the diagnosis as an

excuse or *crutch*. One parent shared her fear by saying: "I'm afraid by telling him the truth that will change him fundamentally to say nope I can't be that anymore because I've got this, something's wrong with me" (ND7). These parents shared that their child was already having difficulties, and they didn't want to "give them an excuse" for getting out of anything. One parent's perspective is articulated by the following passage:

> Last year… she was quite emotional about…not being able to connect with any of the girls at school…but again our other concern is that she might use the diagnosis as a crutch. Just that she would, maybe not try certain things or anytime she would have a problem, like the way her personality is… we were just fearful that she might then say: 'Oh, I can't. I have Autism'…almost like using it as an excuse. (ND10)

On the other hand, parents shared their concern that their child might give up their drive and belief that they could do anything they want to. One parent voiced,

> I can't do this because…I want my kids to be limitless with their decisions and with what they want to do with their lives…Not I can't do this because of something…I want them believing in themselves. That no matter what conditions anybody has or whatever. (ND17)

Lastly, some parents reflected on hearing the experiences of others. They shared that a professional or another parent had shared an example of when a child had used their diagnosis as an excuse:

> She [behaviour consultant] doesn't want to tell me what to do…and I appreciate that; however,…she always kind of ends with a story of, you know, working with this kid and you know, they say, 'Well I can't do it because I have Autism'…And oh I certainly don't want that to be the case, right? (ND2)

Underpinning this theme was an overall fear expressed by parents that children would be limited, and that they would give up on themselves.

  Theme 2.4ND: Unwanted attention from others. From the parent's perspective, there was fear that a child who had been disclosed to would share their diagnosis with others and receive unwanted attention. They further explained that they didn't want their child to disclose the diagnosis to others until she/he/they understood what she/he/they were telling people. One parent illustrated this concept by sharing that they worried their child would disclose to anyone: "He doesn't have much of a filter… I would be concerned that he might go, 'Hey guys, I have Autism!' …And they'd be like you know, these seven year olds out on the playground. What does that mean?" (ND2). Another two parents shared that reasons for non-disclosure could be due in part to cultural factors and the potential for unwanted attention from others after disclosure occurred. One parent explained by saying:

  Yes, okay so in short… [child x] is diagnosed with Autism and my wife is from China, and we have the in-laws living with us... plus um we have a sort of a cultural implication in the sense that my wife is not particularly enthused about disclosing any of his conditions to either [child x], his brother, or neighbours, friends, relatives you name it. She wants it to be kept to herself. I understand the nature of the sensitivity…living in China for a number of years, I understand how intense the interdependence can be, and that includes neighbours and total strangers. And once they find out, they will come to the house on a daily basis, and say 'how he's doing?' (ND7)

Another parent recounted a similar reason:

  We were very focused on the Latino population…I remember having families [who I worked with] …who said we don't want anybody in our family…don't list us as

members in anything public because we don't want our family to know. Because it's a great source of shame in some cultures…In other cultures it's like, oh we can't let grandma know or other families. (ND3)

Moreover, parents described that disclosure could lead to being *singled out* as different or lesser: "We didn't want other kids to single her out for being different or as having something wrong with her…Or other kids would, you know kind of use it…almost against her" (ND10). Thoughts about children being singled out led to parents expressing further apprehension about their child sharing their diagnosis with others, as it could be used against them, or lead to bullying. Parents expressed that they did not want their child to receive unwanted attention, in the form of bullying, as exemplified by a parent who stated, "I guess justifications for not telling have been...to be used against him as you know insulting or abusive to be bullied, use that [diagnosis] for being bullied or unwanted attention" (ND7).

Theme cluster 3ND: Reasons for disclosure considered. In the third theme cluster, *Reasons for Disclosure Considered*, all parents (*n* = 20) continued by providing some of their considerations or reasons for potentially disclosing the ASD diagnosis to their child, even though they had decided not to disclose at this point. Within this theme cluster, the following overarching reasons or themes emerged: (1) Child asking questions; (2) Understanding; (3) Fear that they will find out another way; and (4) Medical reasons.

Theme 3.1ND: Child asking questions. Many parents discussed the notion that they would disclose, or consider disclosing, if their child started asking questions. They reflected that if children were able to notice some of their own differences, it would be an indication they were ready for disclosure. One parent shared,

I've just gotten used to having [his sister point out differences] and he hasn't yet come… reached a level of self-awareness where he's said to me, 'Mom, you know… I can't do this or I feel uncomfortable with that.' He doesn't have those conversations yet…I'm kind of waiting for him. (ND2)

These parents often stated that they thought that children asking questions about their differences would indicate that they were ready to know more information. However, there were a few parents that expressed fear that their child may never be able to, or know how to, ask the questions that they were waiting for. Parents shared that this could lead their child to have unanswered questions, and this concern developed into a rationale or consideration for disclosure:

The one concern that I sort of have with our approach, is that um our son does have difficulty communicating and sometimes expressing himself. So, I think if it really was bothering him he'd get it out somehow, but there is sort of that lingering doubt in my mind. Does he know? Is he curious but doesn't know how to ask? (ND8)

Some parents also voiced concerns about a rationale for disclosure, as they indicated their child was already asking questions and noticing differences. One parent shared that his child seemed to be seeking answers:

Well it comes in the form of a statement but you can tell there's a question behind it. His statements are generally: 'I'm really good at this, I'm not good at this. I like this, I don't like that.' These are usually statements he couldn't say four years ago, but now that he's come to be verbal, he's able to share challenges… I could be misinterpreting it, like is it a cry for help, like what's going on with me? (ND7)

Another parent recalled a similar thought: "But I think it would answer some questions that he's, he doesn't know why, you know he's trying to figure out… Like there's wires cut in his brain, right like he's trying to make sense of it" (ND17). Generally, parents expressed that if children asked questions it might be an indication that they needed more information about themselves.

Theme 3.2ND: Understanding. Parents often spoke of their child's understanding as a reason for why disclosure should occur. Specifically, parents shared that they wanted their children to be able to better understand themselves and their struggles/difficulties and that they deserved to know. Parents communicated that if their child could understand, they wanted to disclose the diagnosis to them.

Several parents shared that they wanted their child to have an appreciation for how they function differently in the world and "understand what they have" (ND14). These parents shared that they didn't want their child to feel any shame about her/his/their diagnosis but indicated that she/he/they needed to know and understand the diagnosis so they could be better informed. Other parents also shared that they wondered if disclosing would help their child understand why at times things are more difficult. Parents suggested that there might be a greater reason to disclose the diagnosis if the child was struggling: "It's one of those things where if it becomes necessary for some reason that he needs to know more…Or if he's struggling where we think that telling him in more detail about this specifically would help him" (ND5). Some parents also indicated that they thought their child already felt they were different and couldn't understand what was going on. One parent provided an example:

> I thought you know maybe it would help her to understand who she is, because she feels
> different than the rest of the family. She feels that she doesn't fit in. She often feels
> unloved. She feels that she would be better off in an orphanage even though she doesn't

fully understand what that means. She runs away from home, she uh, you know, pretends, you know down the street. The other day she threatened to kill herself to punish me because I, you know, it can be something simple like I didn't let her have dessert or I didn't let her [do something]…So, I think of sharing with her this diagnosis so she understands this is why she feels so strongly, and I don't quite know how to make that all connect. (ND12)

Other parents spoke about children having a right to know about their diagnosis and indicated that it might "do more harm than good" (ND19) to continue with non-disclosure in the future. These parents expressed that they wanted to continue being as honest and authentic with their child as possible. Moreover, parents shared that their children had a "right to know" (ND9) everything about themselves, or at least what others already know. Several stated that by not disclosing, child/youth rights are denied, further potentially decreasing her/his/their independence as a person. One parent expressed that she felt it was morally wrong to withhold a diagnosis from the individual who is affected by that diagnosis. This parent also indicated that if an individual has the cognitive ability to understand what a diagnosis means, it should be disclosed:

> I think it's almost morally wrong to make a decision to withhold information from someone whose life is… affected by a diagnosis or you know, because… it takes away the ability for the individual if they have the cognitive ability to understand, what that means… I think especially kids are a lot more savvy than we give them credit for, and its, you may think that they don't know that they're different but even typical people think that when you're a kid, that they're different and you're the only ones. So, I think it's probably not right…to withhold that information. Because it gives the child, or the

individual permission to look for help, permission to try and seek out others and find their

community to, you know not feel like there's something wrong with them so you know. I

don't see any positive. (ND3)

Other parents spoke to the children and their level of understanding and indicated that regardless

of their age, "maturity level" (ND9), or ability to understand language, if they could comprehend

their differences that they should know about their diagnosis. Therefore, many of these parents

expressed that they would disclose to their child at some point in the future, when their

comprehension and understanding was greater.

Theme 3.3ND: Fear that they will find out another way. Fear, particularly around the

child learning of their diagnosis another way, was a rationale expressed by some parents for

disclosure. Parents expressed that children could have their diagnosis disclosed to them by

another person, or find documentation stating their diagnosis. One parent reflected on the

possible outcome of someone, other than a parent, disclosing the diagnosis:

I think if somebody told him before we did. I think that would be awful because I don't

think he would have the context and you know, it's a lot easier… proactive is better than

reactive you know. So, I think it would be a lot easier to manage how he feels coming

from us. If he heard from someone else I think that would be a horrible step back. Yeah

that would be really difficult. (ND15)

Another parent spoke about her worry and difficulty if her child found documentation about his

assessment and it hadn't already been previously explained: "If it is during a tumultuous

moment, or if he found any documentation in our house…yeah it'd be difficult if he found

something and said, 'Mom, what is this?'" (ND11)

Alternatively, parents remarked that other people already notice their child's differences, and they could foresee someone saying something that would indicate the diagnosis to the child. Parents spoke about both their child's peers and siblings commenting on the child's differences and shared that they would like to disclose to the child so that they could better explain their differences within their peer group. One parent also indicated that if the child's school noticed differences and wanted to openly discuss the diagnosis with the child that the parent(s) would want to consider disclosure beforehand.

Theme 3.4ND: Medical reasons. Lastly, a handful of parents spoke about medical reasons as rationale for diagnosis disclosure. Some shared that although they were hesitant about disclosure, they would choose to disclose if their child needed to know about their own genetic information, or upon reaching adulthood:

> Maybe if she ended up having her own children, Um, that kind of thing. Then I think it's almost more important, like medical information. You know? Yeah so, the whole genetic link and stuff, then I think it would almost be more beneficial at the stage of life you know? (ND10)

Another parent elaborated by saying that, although knowing about genetic information may not change anything, they felt that their child needed to know all of her genetic information. Another parent shared alternate medical reasons and assumed that they would eventually disclose as their child had a medication protocol to follow:

> And we know that we're going to have to share with him eventually because I mean he does have the med protocol that he has to take. And you know right now, like we call them his vitamins, to keep his brain healthy, but you know he's pretty bright. And I think he knows there's something going on. (ND15)

Theme cluster 4ND: Potential outcomes of disclosure. In the fourth theme cluster,

Potential Outcomes of Disclosure, parents (*n* = 15) further explained some of their

considerations around disclosure. Specifically, parents highlighted some potential outcomes that

disclosure could have for their child and discussed trying to decide what would have the best

outcome for their child. Within this theme cluster, the following themes emerged: (1) Parent

perceived outcomes and (2) Uncertainty of the response, understanding, or impact.

Theme 4.1ND: Parent perceived outcomes. Parents articulated some of the possible

outcomes for their child, should they choose to disclose. More specifically, some parents

indicated that they had heard of success stories in disclosing and others had shared positive

outcomes. For example, one parent shared some of the positive feelings that her son could

experience as a result of disclosure:

> But knowing [child x] the way I do, I think he'll take it in stride…So I think I'll get a
>
> pretty good read pretty quickly, and my guess is he'll take it as relief, a clarity, a
>
> satisfaction, a sort of filling in the blanks, a lot of that light comes on sort of a hot
>
> moment. (ND7)

Other parents shared that they felt their child would have more empathy for others who are

different, "greater understanding and self-awareness" (ND15), and even excitement:

> I'd like to think that if I disclosed to him right now that he'd be like all laughing about it.
>
> All excited and I'd throw in there you know what you can be whatever you want to do
>
> and stuff like that...it's just a harder challenge, right and he'd probably be all excited or
>
> that's how I see it playing out in my head right…so I gotta work just a little bit harder to
>
> be at this pace, not a problem, you know? (ND6)

Other parents predicted different feelings and anticipated outcomes for their children. Several shared the potential for anxiety, feeling "lesser" (ND20), and resistance towards hearing about the diagnosis:

We both just know how resistant he is to hearing things like this, because he didn't accept the ADHD diagnosis very well. And was very resistant to anything that might happen because of it um, so yeah, we figured this will probably be the same way. (ND19)

Within this theme, some parents also expressed that they felt children would need time to process what the diagnosis meant for them and others would ask many questions on their journey to understanding. One parent gave the example that he felt his son would have to accept and internalize the diagnosis and would take time to emotionally and psychologically make meaning. All in all, many parents expressed that they greatly considered what the outcome of disclosure might be for their child when trying to decide if disclosure would be a good fit for their family.

Theme 4.2ND: Uncertain of the response, understanding, or impact. Several parents expressed trying to weigh potential outcomes; however, they were either uncertain about their child's response and level of understanding, or didn't think that disclosure would make a difference for their child. Some parents shared that they felt uncertain about how disclosure would go for their child and others considered multiple outcomes. Other parents were uncertain about how much their child would understand, as expressed by the following statement, "I don't think that [if] I really tried to tell her now, she'd just be like yeah…she wouldn't get it" (ND9). Other parents expressed similar notions around understanding while considering that disclosure might not make a difference: "I think [child x] in some ways already knows that he's different a little bit. I don't know if it would change anything. I really don't know" (ND13). Another parent

expressed that she felt that the diagnosis wouldn't "impact how we function as a family either" (ND18).

Theme cluster 5ND: Where are we now? In the fifth theme cluster, *Where are we now?*, the majority of parents (*n* = 18) continued their stories into the present and articulated where they currently were at as a family in terms of their decision-making process about disclosure. Within this theme cluster, the following themes emerged: (1) Conversations with child; (2) Parent feelings about the decision process; and (3) Parental disagreement about disclosure.

Theme 5.1ND: Conversations with child. Parents often spoke about the conversations that had already occurred with their child, as well as the conversations that they felt they would eventually have. Many parents started by sharing that although they had not disclosed the ASD diagnosis to their child, they had started having conversations in which they explained how all people are different and some had shared an alternate diagnosis with their child (e.g., learning disorder, giftedness, or ADHD). One parent offered, "I think we just kind of explained without labeling, that everybody's different and this is the stuff that you have problems with and this is the stuff you're good at" (ND5). Other parents had gone into more detail with their child to describe the specific challenges or differences and why supports were in place: "I decided that we were going to tell him like, you have problems with, interpreting people. And we sent him…to friends' classes and they went to a lot of psychologists" (ND20). Some parents spoke about their child's differences relative to another diagnosis or premature birth and explained that their brain worked differently. Several parents described a specific incident when they had spoken with their child about a peer's diagnosis or differences. For these parents, they wanted to judge their child's level of understanding and to see if their child had any questions.

Now there was one incident, one time when we were talking about another child with

Autism and he said: 'are you guys talking about me?' And I don't know if we were using

the specific term of Autism or if it was just certain characteristics…that this child

exhibited that he thought was him or whatever… But that's really the closest we've ever

come to kind of describing it to him. (ND8)

Regardless of conversations that had already taken place with their child, parents

frequently stated that they would continue to have conversations over time as things came up.

For some, they described these conversations as "piecemeal" (ND2), and for others "a series of

revelations" (ND11). Another parent shared that, "there'll be more. Every conversation will be

different. But for now, I just tell [child x], you're different" (ND14).

Other parents shared that they planned to have additional conversations with their child in

the future. For some this was a continuation of the *you're different* conversation, without

emphasis being placed on the label:

I think maybe just the whole like, instead of saying 'you have Autism,' maybe it's, this is

what makes you unique. But then my younger daughter is unique too. You know so… I

don't know if I want that. I don't know that we ever want the label. (ND12)

One father reported wanting to tell his child about his own experiences as a child and their

similarities, and then follow-up by sharing that he had never been diagnosed. Moreover, this

parent wanted to share that, "you're [his son is] just like me [the father], and you're going to be

fine…so that he doesn't feel isolated or different" (ND17).

Theme 5.2ND: Parent feelings about the decision process. Other parents described

where they were now, in terms of their own feelings surrounding their decision-making process.

Some parents described feeling overwhelmed and expressed that the decision had been weighing heavily on them:

> I was also a bit…overwhelmed and didn't have all my ducks in a row and all my resources. So I would have felt like I was scrambling, I didn't have all the answers and I think like with certain things you need to have most of the answers and then be able to say, 'I'm not sure about this' and 'but we can look into it.' (ND11)

Another parent shared that if she'd had any hesitancy about disclosure that she would withhold the diagnosis at that time. This parent communicated that although she felt at some point you had to share the diagnosis with the child, one must first have a sense of clarity as a parent. Two more parents also revealed their feelings about continued non-disclosure, indicating that there wasn't anything to be gained from withholding a diagnosis:

> I just think hiding it and denying it puts us back sixty years ago where you swept everything under the rug, right? And I have seen it because I've got um, aunts and uncles from my, you know, dad's generation, where my grandparents pretended this didn't happen, it'll go away. And it doesn't go away. Like it just gets worse and worse and worse and worse, and if you don't talk about it and you don't deal with it, it just turns into, well it's a lifelong nightmare. (ND4)

Theme 5.3ND: Parental disagreement about disclosure. Seven families reported disagreement within the parenting couple about whether disclosure should occur. More specifically, one father shared that although he thought disclosure would be significant and very important for their son, his wife did not want to disclose the diagnosis due to cultural implications:

Respecting my wife's sensitivity to the cultural implications, I have also some challenges of my own. I would like [child x] to know, and I would like his brother to know, and I would like his friends and his teachers and so on, and everybody should know…I won't do it without my wife's consent. I need her to be on board. I need her to be supportive, understanding… you know it's an important note that I think that the family needs to be on board for that, it isn't a single person's choice. I think it needs to be a family unit decision. (ND7)

Three other parents shared that their spouse didn't believe the diagnosis and subsequently didn't agree about the need for disclosure to occur. One parent shared,

I have a very different opinion about it...I think she wants to tell him, and I don't feel there's anything wrong with him… From the point of view, saying hey…look you're different than everyone else. I don't like that because I don't know… I just, I've heard the word people say that he's, with a disability and stuff like that, and it just makes me mad because he's not disabled. And he's just, to me he's just different. He just thinks differently, he just does things differently. (ND17)

Similarly, other parents expressed that their spouse felt that once children had the tools to cope with their diagnosis, there wouldn't be a need for disclosure:

Well I want to let [child x] know, my husband doesn't. Because my husband I think is in a little bit of denial still. And he feels that once [child x] has the tools he needs to cope and just carry on with life, what's the point?... But it takes me a lot to get to that same page so that's my next mission, to get him [spouse] on the same page. (ND16)

Generally, parents who disagreed about disclosure often shared that they didn't want to disclose until both parents were on the same page about disclosure.

Theme cluster 6ND: Decision about disclosure in the future. In this sixth theme cluster, all parents (*n* = 20) shared that they were looking towards the future for a decision surrounding whether or not to disclose the ASD diagnosis to their child. Within this theme cluster, the following themes emerged: (1) Not yet, but eventually; (2) We would disclose if they could understand; (3) Uncertainty; and (4) Non-disclosure or the absence of a decision.

Theme 6.1ND: Not yet, but eventually. Nine parents shared that although they hadn't disclosed the diagnosis to their child for various reasons, they believed that they would disclose in the future. Some parents articulated that their child was still too young, and they didn't feel children would be ready for full disclosure until they were older: "So, I think just saying 'you're different' is relevant now, and when the time comes, Autism will be introduced" (ND14). These parents shared that age was their greatest consideration and that they would disclose the diagnosis when their child was at "the right age and has the understanding" (ND4). For others, age was also expressed as a significant consideration, but they articulated that they didn't want to wait too long before disclosing to their child.

Another parent expressed that he didn't believe disclosure was a question of yes or no, but instead a decision around *when* and *how*. This father shared an example of when he spoke to another family member with ASD and asked questions about when his nephew found out about his diagnosis:

My sister's son who's 14 [was] just recently diagnosed with Asperger's… For 12 years of his life had no idea, and nor did his parents, until the diagnosis came last year. When the diagnosis came out, now they are struggling with what I'm struggling with: do we tell him or not? And they waited a full year and put him through numerous programs, and at the end of the day decided okay we're going to tell him… I had a conversation with [my

nephew] when I was in Victoria recently and asked him, what do you think? Should I tell

my son that he's autistic? And [nephew]'s response was 'absolutely, he needs to know.'

And coming from somebody on the spectrum telling us that it gave me huge confidence

that yeah absolutely he needs to know; now the question is how and when. (ND7)

Similarly, another parent articulated that disclosure would be necessary for her son and

expressed that her son's happiness was her greatest consideration.

    Theme 6.2ND: We would disclose if they could understand. Three parents stated that

they would disclose the diagnosis of ASD to their child if they felt their child was able to

understand the diagnosis. One parent shared:

If [child x] had the cognitive ability to understand what it meant applicable to him then

we would tell him. His receptive language is poor, and he just doesn't have the ability to

comprehend that he's different or that he has a "quote unquote" label. (ND18)

Another parent described her child's processing delay and indicated that she could mention the

diagnosis but that he wouldn't understand. Several parents noted their child's lower cognitive

ability and developmental level, and shared that they didn't feel that their child would be able to

process a disclosure conversation.

    Theme 6.3ND: Uncertainty. Six parents conveyed uncertainty about whether to disclose

to their child in the future, and spoke about the pros and cons around disclosure. One parent

spoke to the notion that she was not ready to decide as she was fearful that her decision would

impact her child in a negative way:

I've never really thought about it, you know what… and literally I sat down with my

husband and was like would you tell him and I don't even know. He's like I don't know.

Then we start running through the pros and cons of it and it's like okay, I'm not quite at

that decision yet to tell him or not because again I don't want it to backfire. I'd rather him never know and keep driving through life, keep that ambition…Right then have him backfire in my face and say oh there's funding there, I don't have to work another day in my life. (ND6)

Other parents shared that they see a difference in their child and not a problem or label, so they wouldn't explicitly say something unless disclosure came up organically. Overall, within this theme, parents expressed uncertainty about what the correct decision would be regarding disclosure:

Honestly, I don't know what the right thing is and…I'm just like, I don't mean to read all that much about it anymore, I think I'm just going to go with my gut…I guess I'm kinda at a point where there's a lot of talking, a lot of talking with my husband. And just thinking there's no need to make any decisions about anything. (ND13)

Theme 6.4ND: Non-disclosure or the absence of a decision. Two parents shared that non-disclosure or the absence of a decision resulting in non-disclosure was best for their family. One parent discussed the success with intervention that her child had experienced and articulated that she didn't feel that disclosure would benefit her child:

Like my daughter's eight now, and she was diagnosed when she was two and a half. I think because we accessed so many different forms of early intervention, she's at the point now where it's not that noticeable. Like nobody in her class would know if she was diagnosed, has a diagnosis, or um, while so she has quirks or issues like, it's just so mild to the outside world that we thought that wouldn't be of any benefit to necessarily tell her. (ND10)

This parent shared that she wouldn't have a problem disclosing ASD if it would be of benefit for the child to have the information; however, she wouldn't initiate the disclosure process. Another parent described his non-disclosure as the *absence of a decision*:

> It's almost our absence of a decision that's made our decision… we never really knew the label or the diagnosis as something that needs discussion. Just, so, no, I don't foresee sitting him down and saying here's what the deal is, or anything like that. Just like I wouldn't sit down and explain it to my daughter why her eyes are blue, like they're just, they just is what it is. So, we kind of view it as a dimension of his character or his physical being or his mental being. (ND8)

For this family, the parent explained that he didn't feel strongly either way about disclosure versus non-disclosure, but didn't think that there would be a need for this discussion.

Theme cluster 7ND: What might our process be? In the final theme cluster for non-disclosed participants, *What Might our Process Be?,* many parents (*n* = 19) expressed their potential process for disclosure, if it should arise in the future. Within this theme cluster, the following themes emerged: (1) When to disclose; (2) How to disclose; and (3) Supports.

Theme 7.1ND: How to disclose. Several parents started their explanation by expressing that as parents, they needed to initially prepare and do research. They shared that they wanted to be *ahead of the game*, not causing further problems for their children. One parent shared,

> Stuff like this, this conversation isn't just something you just sit down and just blurt it out, right? Like you want to, you want to prepare yourself to explain it, right? Cause you don't want to come across as you're a failure or you're, you're dumb or anything like that right? Like it's a sensitive conversation and has to come out the right way, right? (ND4)

Parents communicated that although there was some uncertainty about how to disclose, they felt

that they needed to "go with your gut, really. And what's right for you" (ND5). Moreover, they

shared that parents best know their child and "at the end of the day you need to do what's best

for your child and…take yourself out of the equation" (ND2).

Parents also shared ideas around how information should be presented in an

individualistic and understandable way and as a gradual conversation over time. These parents

articulated that they wanted to begin sharing about the diagnosis slowly and in small pieces, with

the hope that their child would understand and not be overwhelmed. One parent said, "I think it's

going to be stuck in my brain for the rest of my life. Mean what you say, say what you mean"

(ND1). Several parents shared that they would have to gauge their child's understanding and

capacity to digest the information being shared with them:

> Every case is unique. You'd have to assess on the child, their age, the environment
>
> they're in, their siblings, their whole family dynamic, all that stuff would have to be taken
>
> into consideration. You know and the extent he's willing to hear it, obviously if he shuts
>
> us down then we'll say ok, bite size pieces, we'll break it down…absolutely and he may
>
> not completely understand it but at least the conversation will have started, he can ask me
>
> questions. (ND7)

Other parents discussed their thoughts around a possible narrative for disclosure. Some

articulated that their narrative would be ongoing as a progression from talking about everyone's

differences. One parent shared that she would disclose all their child's diagnoses at the same

time: "We haven't told him he's gifted yet either and we haven't told him he has ADHD either

so, it's probably going to be a packaged deal you know as in not everybody's brain works the

same" (ND15). Parents also shared that they would talk with their child using examples from the past and examples specific to their child as a means to disclose the diagnosis:

> Then I could start bringing up some stuff that when he was younger, so why did we? How did we know that word? Well, because there was also a time when you were three that you would not eat off of anything except if it was yellow. Yellow bowl, yellow plate, yellow cup, yeah and it had to be a specific kind of spoon. It couldn't be… it had to be our wedding color. It couldn't be anything else. And then we would talk about that. (ND11)

Parents often expressed that they wanted to focus on their child's strengths and the positive aspects of ASD and reassure their child that he is still the same person:

> But you know, if I did it now it would be delivered in such a way that this doesn't change anything. You're the same person you are now as you were yesterday. All that you know now is that you know, the combination of all the different things that you do throughout the day and the way that you play and the way you do your work at school and the way you play with your sister…All those little things together kind of add up to you know, what's called this thing. It's called Autism. But you're the same person you are and you don't have to worry about it…You know I guess it's all about…how that information is delivered. (ND2)

As illustrated above, parents verbalized that they wanted to tell their child in a way that was positive, reinforcing, and encouraging. They shared that they would have to disclose in a positive way to benefit their child, but hadn't done so yet as they were still unsure about how to accomplish that goal.

Theme 7.2ND: When to disclose. Although some parents expressed that one barrier to disclosure was not knowing when to disclose, some parents communicated a specific idea around when would be an appropriate time for their child. A couple of parents stated that they wanted to wait until there was a calm and comfortable time to disclose, as they didn't want their child to be overwhelmed. However, a few parents shared that there would have to be a context for disclosure, and thus it would have to occur organically and wouldn't be a designated moment in time:

> The fact that I want to play on the positive, is just a moment in time that I need to be able to grab… and run with it. Because I can't say I'm going to say it October 25th. I'm going to have to… situational. (ND11)

> Some parents expressed that their child's age is a consideration for when disclosure should occur. Some parents stated that disclosure should occur when the child recognizes her/his/their differences and is old enough to understand; they felt that their child would be able to understand and comprehend the disclosure at an older age:

> If they're old enough too then you can kind of provide them with that type of information then like, the younger they are the more you kind of have control of how you present it...but I think as they get older one of the benefits, again depending on the child would be that they can kind of do their own research as well...they might find like support groups or like, I mean there's lots of like even social groups or interests like special interest groups. (ND10)

Conversely, other parents shared that it was only a matter of time before disclosure would occur and that they preferred to disclose while the child was at a younger age:

I don't want to tell him too late, when it gets to the point of why didn't you tell me this, you know? I've been wondering, struggling…and it would have been nice to know…I don't want to it to be that late, like not when he's in his teens and you know going through hormones and everything else. (ND15)

One parent shared an experience from her childhood as explanation for why she should possibly would tell her son about his ASD at a younger age:

I think if he could understand then I don't think it would be a big deal. You know…I was told about my dad being actually my stepdad…I think I was 12 when I found out. I was very upset…I was just mad at everyone, but I always felt that I should have been told when I was younger. It wasn't, like I don't think it would have been a big deal. So, I don't know…Cause now I look back on it too, maybe they were just waiting for the right time or I don't know. (ND16)

Theme 7.3ND: Supports. Parents often shared their hope for child-specific supports around disclosure and thought professional help may be helpful during the disclosure process. One parent recommended, "maybe somebody helping to explain it to her, like a psychologist or you know, somebody that's experienced in the field. Cause maybe she'd understand a little bit different, you know better" (ND9). Another parent thought that her child would benefit from attending a seminar about ASD where a professional would provide context for the diagnosis on a larger scale. Some parents shared specific supports that they thought would be beneficial for their child, including: a supportive school environment, books, social stories, and internet websites geared towards helping individuals understand ASD.

Alternatively, other parents expressed that they would like to know what other people say about the disclosure process and wanted others within their family's core social sphere to be on the same page about the diagnosis prior to the disclosure process. One parent shared,

I think everybody needs to know. So, if we got to that point then we would maybe say to family and friends first okay we're going to tell him you know...yes just be aware that he might have questions and this is what we're going to tell him. So, there's almost like a scripted answer for everybody to give so that he can comprehend a little better. (ND18)

Moreover, a handful of parents identified their hope around learning about other families' experiences, suggesting that this would be a significant resource for their family in moving towards disclosure.

Summary of non-disclosed experiences. Non-disclosed parents described their journey over the course of their decision-making process around disclosure versus non-disclosure. They reported working through a variety of processes not only on their journey of seeking and receiving an ASD diagnosis but also reflecting on their parental experience after receiving the diagnosis. These parents shared where they were currently at, with respect to non-disclosure, including their rationale and considerations for why disclosure had not occurred or did not feel right for them/their family. Moreover, parents often expressed fear of the unknown and possible negative outcomes should disclosure occur. Parents also regularly shared what their considerations or reasons would be for potentially disclosing the ASD diagnosis to their child at some point in the future; for all, there seemed to be a complex array of factors for parents to consider.

Alongside their potential rationale for disclosure, many parents identified worries, but in this instance, their worries surrounded fears related to what could happen if they didn't disclose

the diagnosis, thus driving considerations for disclosure forwards. This group of parents, although encompassing many unique situations, often temporally continued their stories into the present, and thus reflected on current conversations that they had (or were having) with their children thus far. These parents highlighted the likelihood of the continuation of these conversations over time and underscored parental feelings around the decision to disclose. Non-disclosure was influenced by reasons for and against, identified barriers, and perceived potential outcomes. However, almost every parent ($n = 18$) indicated that they had reached a decision about disclosure as they moved forward and some spoke about their potential process for disclosure progressing into the future.

Disclosed Participants

Overall, aside from the common theme cluster, four remaining theme clusters of meanings emerged from disclosed participants which included: (Theme 2D) Leading up to disclosure; (Theme 3D) Reasons for disclosure; (Theme 4D) Process of disclosure; and (Theme 5D) Advice to others considering disclosure. These theme clusters were then further broken down into 18 themes, and will be described in more detail below. The results in this section include the experiences collected from 320 significant statements, presented as verbatim quotes to corroborate and illustrate the theme clusters and themes. Underpinning these theme clusters is the passage of time as outlined pictorially in Figure 3.
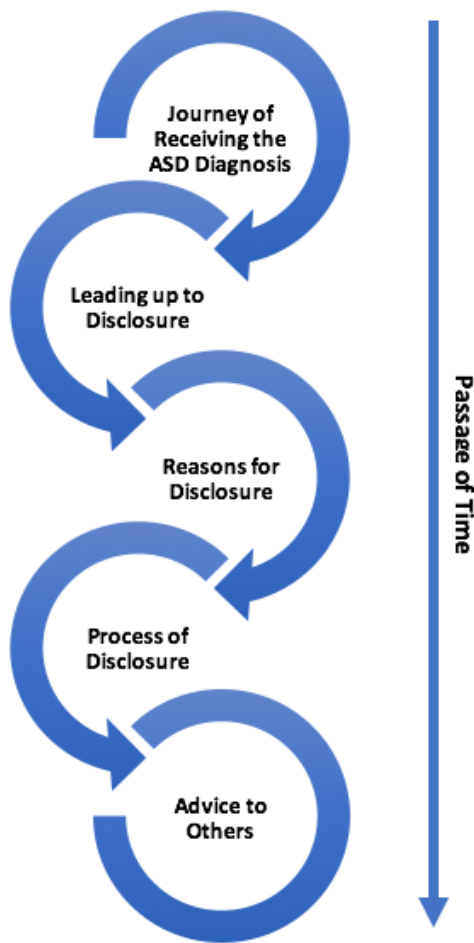
Figure 3. Theme clusters of essential meanings for disclosed participants.

Theme cluster 2D: Leading up to disclosure. In the second theme cluster, *Leading up to Disclosure*, some parents (*n* = 11) continued their story by providing more information about how they prepared themselves and their children prior to disclosure occurring. Within this theme cluster, the following overarching themes emerged: (1) Planning and researching; (2) Conversations without attaching a label; and (3) Parents need to be on the same page accepting the diagnosis.

Theme 2.1D: Planning and researching. Many parents shared that they engaged in researching, talking with other parents about their experiences, and planning and preparing for disclosure itself leading up to disclosure with their child. Parents indicated that they read books

about ASD, sought out materials online, and tried to comb through the limited available

resources about the disclosure process itself. One parent shared her experience about researching

ASD and what she wished was available for other parents:

> I was lucky because I have done my own research and I know a bit. By no means am I an
>
> expert. But you get to kind of become an expert when you grow up with an autistic kid.
>
> You don't know anything and then all of a sudden you have to get all of this information.
>
> But no I didn't go through any kind of a website, or publication, or I didn't ask anybody
>
> for help. Mostly because I didn't feel like I needed it. But…maybe that would have been
>
> handy to get like a pamphlet. Because I know that, not everybody is as comfortable
>
> talking to their kids about disabilities, and some people might not be quite as able to get
>
> the information. So, it, may be that is something that would be handy to have as a
>
> pamphlet as something that they hand out, in wherever, in pediatrician's office, when you
>
> get the diagnosis, or even before when you suspect it. (D18)

Some parents shared that their best resource along the way was speaking with other

parents and reading about their experiences online (e.g., in a blog or informal means). One parent

shared that she had asked questions about timing and rationale for disclosure but decided that she

had to do what was best for her child and family.

Other parents spoke about their planning and preparation process before disclosure

occurred. They shared their considerations around timing, the busyness of their home

environment, and potential impacts of disclosure versus non-disclosure. Parents also shared that

they wanted time to think about and prepare what to say to their child prior to disclosure so they

could potentially also prepare for the questions their child might ask. One parent shared,

There were things that I thought about that were more about timing. Like, how long to

wait, and how does that impact [pause] how you see it? So, I think that most of our prep,

like our discussions and our planning was around it becoming a normalcy. Having a

disability being just normal. (D1)

Another parent spoke about a plan that she had created with the diagnosing psychologist

to bring her child in for a disclosure appointment with the professional. However, she shared that

regardless of their prepared plan, parental disclosure occurred ahead of schedule:

Well, I had planned, because when the diagnosing psychologist had said um, 'what we'll

do is we'll have this appointment, and then, you know, I can tell him at that appointment,

and I'll spend some time with him, and just talk it over.' And he asked before that, you

know. So, we'd had the plan that he would be told at this appointment, but when he asked

[her son asked in advance of the doctors appointment], I thought well I don't, and why

not, and it was a good time. (D3)

Theme 2.2D: Conversations without attaching a label. Many parents also shared that

they had engaged in conversations with their child about her/his/their differences and special

needs in general terms prior to disclosure of the ASD diagnosis. Firstly, these parents shared that

they spoke about the supports that the child accessed relative to the notion that every person is

different until disclosure occurred: "Up until then we just kind of talked about things, well

people are different. People learn differently" (D1). One parent also shared that their support

team helped the child access resources about disabilities, and they engaged their child in an

informal puppet show about children who have special needs:

So, we don't know the impact right. So, could be good or maybe something hurting him.

But my OT she said that we can do something, not really directly telling him. But show

him some news, some book, or even [pause] like a puppet show…They have the puppet

show…So she read, bringing some newspaper, some script or some video talking about

special needs people, disability people. So, we give him the tools to say that some people

are differences, they have unique, they are unique, and [have] different needs. But it

doesn't mean you are garbage or useless...so that's the strategy. (D17)

Theme 2.3D: On the same page and accepting the diagnosis. Leading up to disclosure,

parents also shared that it was very important that both parents were on the same page and that

both parents involved accepted the diagnosis themselves first. Parents shared that by being on the

same page, they acted as a support for one another upon receiving the diagnosis and as a unified

front acting on behalf of their child:

You gotta have parents that are all in. Like you can't have one, you know maybe not

engaged in it, and one fully, or over- overly engaged…because then it won't work...And

in agreement, right? When you say a unified front on treating them…Cause there's lots of

decisions, and there's lots of stresses, and things to overcome, as a family unit. (D5)

Parents also verbalized that they felt they needed to first accept their child's diagnosis

themselves, as this acceptance led to an increased comfortability in dealing with the diagnosis.

One parent shared that: "I think that you know, if parents accept the diagnosis, they have to not

view it as negative, and not view it as something that, 'Oh gosh, we can't talk about this" (D12).

Parents also shared some of their feelings around non-disclosure and indicated some fears about

potential outcomes for a child if a parent didn't accept their diagnosis:

I worry about the experience the parent is going through when they're deciding to not tell

their child, because I think that that's not only harmful to the child. I think it's harmful to

the parent, because you're, you're just not owning it…whatever that process is for you.

And, you're going to have to navigate it. (D6)

Some parents shared their worry that children would find out about their diagnosis, see

that one or both of their parents didn't accept the diagnosis or want to share, and wonder what

was wrong with themselves.

Theme cluster 3D: Reasons for disclosure. In the third theme cluster, *Reasons for Disclosure*, all parents (*n* = 20) continued their journey by providing some of their considerations

or reasons for disclosing the ASD diagnosis to their child. Further, the subthemes within this

theme cluster included both reasons for disclosure and possible ramifications for non-disclosure

as rationale for disclosure. Within this theme cluster, the following overarching reasons or

themes emerged: (1) Never thought not to disclose; (2) Just another part of who they are; (3)

Children were asking questions, and aware of their differences; and (4) Fear they would find out

another way.

Theme 3.1D: Never thought not to disclose. Many parents expressed, in some capacity,

that non-disclosure wasn't even a consideration as they have an open and honest communication

style within their family: "There was never a doubt…because I always was open, and

communicated with him" (D9). Many of these parents shared that they "didn't ever not tell [child

x] he had Asperger's" (D10) and that they regularly used ASD terminology in their lives.

Another parent stated that "it never even occurred to me to…talk out of earshot" (D12). For

these parents, they indicated that they had to be open and honest with their child to empower

her/him/them.

Many parents also revealed their dislike for *keeping secrets* and stated that a decision

towards non-disclosure would have been deceptive. These parents often paired keeping secrets

with feelings of shame, embarrassment and confusion and feared these negative feelings for their child. One parent articulated these feelings:

> Yeah, and if they don't get it, holding it back doesn't do the kid any favours. It doesn't do anybody any good, because then it just becomes this shameful...it's hide the secret, 'because we don't want anyone to know, and we don't want you to know you're different.' Well, they already know they're different. They're not dumb. Oh – it's not something to be ashamed of. It's not something to be hidden. It's not something to go, 'oh, I really didn't want to tell you,' but…It is what it is. (D16)

Not wanting to keep secrets from their child was one of the most frequently articulated considerations towards disclosure and an aim to avoid potentially negative outcomes for their child:

> I've read some articles from adults who did not find out until they were adults, and then they find out that their parents knew. And what they've talked about is that being an enormous breach of trust. 'How could you know something so fundamental about me, and not share it with me?' You know, and that's...it's horrible disrespectful... (D13)

Theme 3.2D: It's just another part of who they are. Other parents expressed that an ASD diagnosis was just a part of the child's identity and, therefore, an essential consideration moving towards disclosure. Parents conveyed that there isn't often a consideration around the disclosure of a medical diagnosis (e.g. diabetes) but that ASD can at times come with stigma attached to it. These parents shared that regardless of a label, how each person's brain works is important to who that person is and shared that one's differences are one's own. Parents expressed that as humans, we all want to know who we are as a person:

Every person is a unique individual. We don't come with a map, or a guide book;

although, I would like one. Um, and all of us have the same question 'who am I?' Right?

We all wanna know 'who am I?' Well, this is part of who you are, like, deal with it. (D7)

Parents also articulated that having ASD should just be another part of the conversation:

So, to me I think it's really important for anything…to just be a part of the conversation.

So, they grow up accepting it, just like you grow up accepting that you have ten fingers

and ten toes...You know, and blue eyes. Yeah so what's the big deal, I don't remember a

time that we didn't know about it. (D12)

Parents contributing to this theme expressed that ASD is factually part of who their child is and

that there was no question that the child deserved to know. One parent also shared her realization

that the diagnosis wasn't part of her identity as a parent but was instead part of her child's

identity:

The other thing that I would say is 'this is not your identity, it's theirs.' And that's a hard

lesson for parents to learn. The irony of person-first language is we refuse to allow

disabled people to define themselves. And yet, almost every parent of [an] autistic child I

know defines them self as an Autism parent. So, you're allowed to use Autism to define

yourself, but you won't let your child define themselves by it, who actually is autistic…

This is not your story. It is their story. You are a supporting character. You are the

narrator in a lot of senses. Right, I am my son's translator and his tour guide. I am many

things, but I am not living an autistic experience. (D6)

Theme 3.3D: Child was asking questions, and aware of their differences. Parents

shared that one of their primary reasons for disclosure surrounded their child identifying their

differences and asking questions about those differences. Several parents felt that the time had

come for children to learn about their diagnosis as they had been identifying how different they felt and parents articulated that they didn't want their children to go through life not understanding why they were different:

> My biggest thing is 'just tell him.' Cause they already know. I don't care if they're five years old, or if they're ten years old, or if they're twenty years old, they already know it. And it makes them feel ashamed, cause they are different, and they don't know why…And I thought, why would you make your kid go through life…not understanding why they're different, not understanding why they do things differently...I thought, you know what, he is so confused. That if, if I don't tell him what's going on, he'll always wonder why he's different, why he's strange. (D16)

In some instances, parents shared that they believed children recognized that they were different from their peers, even though they hadn't yet articulated it. One parent said, "we just got to the point where there is an awareness that was coming to his perception" (D1). Another parent articulated:

> And I think he understands that there's that difference between his world, and how he interprets things in, in our world, right? And sometimes you see that, that look of 'you know, I'm struggling, why can't you let me be?' Or, 'why don't you understand me?' kind of look, you know…And I think as he gets older, he's only starting to realize that more and more, you know. (D5)

Some parents also shared that the children were asking questions about their differences, and in some instances, asked directly if they had ASD. These parents shared that it was better to disclose information to their child as questions and situations arose:

I think it was, if I recall, it was either later in elementary school, or early in junior high where she asked why she was different, or why she couldn't do some of the stuff that the other kids could. And, so that's when we sat her down, and talked to her about it. (D8)

One parent shared that her child already recognized his own differences and by asking questions, was seeking confirmation of those differences.

Theme 3.4D: Fear they would find out another way. Parents indicated that their child's peers already recognized her/his/their differences and that many supportive individuals already knew about their child's diagnosis, and subsequently, they feared their child would learn of their diagnosis from someone else. Some parents shared that their child experienced bullying and teasing, as other children were pointing out that they were different. Others indicated that they didn't consider disclosure as relevant until their siblings and other family members noticed and identified the child's differences. Parents highlighted that by others noticing their child's differences, they felt that it was important to disclose the diagnosis to some supportive individuals (e.g., therapy team, school staff, etc.). As information was shared or they disclosed to others, they worried that their child would hear someone talking about their diagnosis and not understand why their parents hadn't told them. Others shared that either the school was not careful with confidential information (e.g., assessment reports, etc.) or the school wanted to disclose to other students about their child's diagnosis:

You know like, at [child x]'s school, they're, they're not careful with his reports and stuff. Like, you know, they're supposed to be locked up in a filing cabinet, but you can walk by people's offices or the teacher's desk, and they're just sitting out…so, I mean, it's far better having it come from the parent, than you know, a kid walking by, and glancing, and not sharing that information ourselves. (D11)

Theme cluster 4D: Process of disclosure. In the fourth theme cluster, *Process of Disclosure,* all parents (*n* = 20) described elements of their progression and journey through the actual disclosure process. Within this theme cluster, the following themes emerged: (1) When disclosure occurred; (2) How they disclosed and the narrative of disclosure; (3) Factors influencing the child's understanding; (4) Resources to support disclosure; and (5) Parent feelings about disclosure.

Theme 4.1D: When disclosure occurred. Many parents shared their thoughts on when disclosure should occur with a child and gave examples about when disclosure happened for their family. Some parents indicated that they didn't see disclosure happening as a mere moment in time, but as an ongoing discussion part of their everyday lives. They explained that either disclosure occurred in their day-to-day interactions with their child over time or had occurred immediately after their child's assessment had been completed. One parent shared, "Tell them as soon as you know. Number one, that way it's not hidden. They don't feel like it's something they should be ashamed of" (D16). Another parent stated that she continually spoke about ASD after she and her husband disclosed to their older child (about his own diagnosis), and her perceived experience for their younger child:

> I mean, that just happened on a day to day basis, just in interactions… but he did see the chart and he saw us making the chart [chart previously made for an older sibling about strengths and differences], and he was listening in on it. But, he was too…too little to have really...And, I mean, it was on the wall, and we did everybody, and so, we talked. I mean, he saw it. We've talked about it. He heard us talking about it. He was on the chart, he just was not the focus of the conversation. (D1)

Other parents indicated that disclosure wasn't a planned process, but instead happened situationally. For these parents, disclosure was described to have occurred on a typical day, without having planned or prepared in advance for what they would say to their child. Parents shared that disclosure consisted of a regular conversation, and they just allowed the discussion to happen:

> And then, just allowing that discussion to happen, and you know, we, we found with him in general, things would come out. And, you know, you're again like a lot of neurotypical kids, you're driving down the road, and you know, stuff just comes out...Cause that's when your, your kid decides to talk about, say sex, for example, is-When you're driving down the road. (D13)

Moreover, these parents articulated that they began sharing more information when their child started asking questions or demonstrated some inquisitiveness about their differences. One parent shared that she felt it was better to have disclosure arise naturally than to plan a special meeting time. Another parent explained that she needed to be ready to disclose in the moment but found this challenging as she didn't know what developmental level her child would be at:

> Just that if the issue came up, I didn't want to sweep it under the rug. Um, and I didn't want, I knew that it had to be discussed in the moment. I couldn't just ignore it, I wanted to use the opportunity…It's hard to prepare for because you're not sure what developmental stage they're going to be at. And it's hard to find material that talks about Autism at a child's level, but also that talks about…kids who are verbal on the spectrum, at a child's level. So…I hadn't bought anything or kept anything really formal around. (D14)

In contrast, some parents shared that they felt it was best to plan and prepare for the optimal time to disclose to their child. Specifically, several parents discussed how they tried to plan disclosure during a calm moment such as over a school holiday:

> I guess a piece of advice for other people is to, to wait until you're on vacation, or like, things are just relaxed around your house, … There is time in case there are a lot of questions, because yeah, otherwise, …if they have a lot of questions, or you need to look up resources or whatever...Yeah, and when they're not in school, they have some time to sit and think about it also, right. (D11)

This parent explained that a relaxed home environment allowed for more time to find answers to questions that their child had. They elaborated by stating that this was an ideal time as the child then had time to process the conversation without having to go back to school right away. Other parents shared that disclosure should occur when supports were present and readily available.

Lastly, many parents spoke about age as a determinant for when disclosure should occur. Often parents shared the belief that disclosure should start when the child is young, "within the family environment. It's almost like an organic acceptance of Autism" (D5). Another parent similarly favored disclosure to their child at a younger age:

> Um, I think I told him when he was young enough that it wasn't that big of a [deal] – Um, that's like telling a kid that they're adopted when they're three, and so that they know it all the way through… [or] telling them when they're sixteen, and it's a big slap in the face...and it's, sooner or later, they're gonna figure it out. (D16)

Many of these parents expressed that they started sharing information with their child when they were younger but that it was a process that occurred over time. They suggested that

certain information was more relevant earlier for their child as something to embrace as a part of the child's life, with the introduction of new information as it becomes important or necessary:

> So, we have those conversations all the time. In our day to day...You have to try…those are all part of talking to him about what Autism is because for him at this age, Autism is about getting those skills. I think for him as he gets older, it's also about processing what those difficulties mean to him, and how he's gonna relate to the rest of the world. Um, um, so we do have those chats with him. (D5)

These parents indicated that disclosure was often a series of many conversations occurring over days, weeks, months, and years. Parents shared that they wanted children to dictate their comfort level for when new information should be shared. Many parents also revealed that they wished they had disclosed to their child at a younger age. Several reminisced that disclosure could have been more casual (i.e., "less of a big thing"; D13) and that their child then would have more time to process the information:

> I think for some kids, Um, [pause] younger is more ready to hear it or they're more aware. They're more aware of what's harder, maybe for them because of it, or, or not, right? So, if they're more aware, I think especially if comes down to impacting self-esteem kind of things, then I think that could be perhaps posed a little, brought up earlier, in a way to make it so it isn't a blame...to let yourself be easier on yourself, right, Um, so that you're not hard on yourself for the things that you do have to work at cause everybody has parts that they can't do as easily [laughs]. (D1)

Regardless of parents expressing that they could have disclosed earlier, some shared that there would always be uncertainty about ideal circumstances and methods of disclosure of ASD

to the child. Upon reflection of this process and timing, they noted that they couldn't know if sharing the diagnosis earlier would have had a different outcome for their child.

    Theme 4.2D: How and the narrative of disclosure. Another primary theme that parents often discussed while sharing their process for disclosure involved details around *how* they disclosed and the narrative that they presented to their child. Specifically, parents shared that they used specific examples around their child's difficulties, told the child enough information that they could do their own research, and emphasized that they didn't want to solely focus on negatives or challenges. Parents also shared some key elements within their disclosure narratives: exposure to ASD and that all people have differences, that their child's brain is unique, the diagnosis relative to received supports or other diagnoses, and insight related to the fact that the label of Autism wasn't going to stop them from doing anything they wanted to do in their lives (i.e., achieving their potential).

    Often, parents started their process of disclosure by sharing about the narrative that they had verbalized to their children. Some parents wanted to expose their child to ASD and the notion that all people are unique and different: One parent shared,

> So at first, I just kind of started exposing him to talking about Autism, not personally, and I happened to work at a place that was a treatment centre for Autism, so we started doing volunteer work. Started just talking about what Autism was and why we were helping volunteer and do stuff like that, and still talking a lot about how people were different...And, so I didn't really tell him so much, but I had a whole conversation. (D1)

These parents reported that they introduced their child to others who had ASD to help introduce the topic and as a way to have ASD become a part of their lives. Parents also wanted to express to their child that ASD was just another part of who they were:

It was like, you know 'you have asthma, you have allergies, you have Autism, you have glasses, you have whatever, right?' Um, so it was just sort of that's just the way that you're made and...They're all just things about us. (D1)

These parents reportedly told their child, "it's just another label. Now people'll understand" (D9). Parents also shared with their child that all people are unique, and that her/his/their brain worked differently. In identifying these unique differences and abilities, parents presented notions that individual characteristics make us unique as people.

Many parents also expressed that they had to be very direct with their child and had to provide specific examples about their difficulties as a way to explain ASD:

We were quite direct with [child x]…And, because they see everything in black and white, you have to be very specific. Yeah, and you have to say…these are some of the problems that you may have because you have this. (D2)

Parents also reflected upon their experience of disclosing and shared that they wanted to include examples of their child's difficulties and access to supports as many of them had been struggling. They often described specific situations in the child's life, described what ASD was, and then explained that ASD was the reason for some of those difficulties. They also described ASD relative to that child's supportive services, schools that they attended, and parents reportedly disclosed other diagnoses at the same time. One parent gave the following example:

I took him out for a walk, and started talking to him about, you know, do you know, you know you're a little different in school, and you get help and support, and whatever. You have something called Autism…And then we talked about, he's also got ADHD. So, we talked about, you know, why he takes the meds, and how it makes his brain feel, and um, you know, he's just, he's such a good natured little person, right, so we're walking along,

and I said: 'do you have any questions?' 'Can we go to the park?' That was his first

question. (D11)

Within this theme, some parents stated that they wanted their child to lead the

conversation and sought to tell them just enough information so they could ask their own

questions and do their own research: "And, I think what's been successful for us is allowing him

to lead the discussion…and patience, you know…it's gonna take time to absorb" (D13). These

parents described wanting to give their child the tools to find their own information and correct

any misinformation along the way. Parents tended to indicate to their children that they as

parents were they to help them find the answers:

> And you know like, 'and if I don't know the question, if I don't know the answer, then
>
> maybe we could ask so and so, or maybe we could go online and see if they have an
>
> answer', you know, that kind of thing. (D2)

Parents identified sharing limited information with their children and then waiting for

them to think through/process that information before further disclosure occurred. Many shared

that for their children, disclosure would be a continual process whereby they wanted to set an

environment for openly talking about ASD:

> For him, I think, opening the door and then just giving him the time to walk through it
>
> when he felt that he was ready...And so, you know, when it started to come from him,
>
> then we gave him some more info. When opportunity presents itself, you know, um, then
>
> you, you take advantage of it. (D13)

Lastly, parents shared that within their disclosure narrative they wanted to emphasize to

their children that ASD wasn't going to stop them from doing anything that they wanted to do in

life and wanted to discuss the positives associated with ASD:

We just said like, it's not gonna stop you from doing anything. You are going to be able

to [do] anything that you want. And, things may have to be explained to you in a slightly

different way, but it's not gonna stop you from doing anything. (D4)

To illustrate positive expectations and hope, parents often offered their child examples of famous

people who potentially had ASD. They described explaining to their child some of the wonderful

things that these individuals had done and shared that ASD shouldn't and wouldn't be used as an

excuse. Parents also normalized ASD by sharing ideas such as the notion that they weren't

telling their child about a terminal illness, so it shouldn't be viewed or treated as such. They

shared that they wanted to ensure that they focused on positive factors surrounding ASD:

I appreciate that…a good thing to focus on I think [is] all of those positive factors, and all

of those positive abilities and characteristics. Everyone has their own challenges. Right,

so, we really focused it on everybody having their own challenges and their own

strengths, and we just kind of left it at that. (D1)

Further, parents articulated that they felt their child was more receptive to dialogue when they

weren't using "bad lingo" and instead focused on ASD as a gift by describing it positively:

It can be a celebration. It doesn't have to be a grieving. Parents set that tone. Um, more

and more important than anything else, I think we set that tone. And how others will treat

our children is how we speak of [and to] them. So, language matters, and the implication

of hiding it to me is something that I worry about a lot…So, a label is only as powerful as

a negative or positive connotation we give to it. (D6)

Subsequently, many parents also communicated that by focusing on strengths and positives, they

wanted to ensure that ASD wasn't discussed in negative terms. These parents shared that ASD

shouldn't be considered as something that is abnormal, or as one parent described, "[not] having

a horn growing out of the middle of your forehead" (D12). The following passage exemplifies the balance of truth telling with normalizing that many parents expressed during disclosure process:

> So, I told him. And I said, do you know what…this is what it is. This is what you're dealing with. It's just part of who you are. It's nothing horrendous. I mean, you learn differently. You do things differently. It makes you unique, and this is what it does. And, about three days later, and, and once we started to realize...looking at his learning style compared to just sitting at a desk, which he did at school, he went 'Mom, I'm not stupid.' And it was this, this brilliant light bulb above his head, and this grin on his face, and a 'we got him!' (D16)

Theme 4.3D: Factors influencing child's understanding. Further to the *how* and *when* of disclosure, many parents spoke in more detail about specific factors such as language, cognitive level, and age as considerations impacting a child's level of understanding during disclosure. Parents felt that they should disclose and speak openly about the diagnosis with their child regardless of external factors, but shared it was important to tailor the conversation to that child's specific needs:

> And to me…even if the child doesn't understand, I think it's, I think it's really important [pause] to include discussion about it within earshot because how many times do you hear stories, that somebody was adopted and they didn't find out until there was some kind of medical emergency. You know when they were in their thirties and it was like, 'We meant to tell you but we could just never find the right time.' (D12)

Specifically, some parents spoke to their child's level of language and indicated that it was still important to talk about the diagnosis and what that entailed for their child although the

child was non-verbal. They shared that if the child couldn't provide verbal feedback, they watched for non-verbal/body responses and waited until their child had more functional language to share more detailed information. One family shared that one of their challenges during disclosure was that their child was very literal with his language and wanted to know exactly what Autism meant for him. Another parent shared that she often explained the same concept to her child several times, and in different ways, to ensure that he understood the core ideas associated with disclosure.

Other parents spoke to their child's cognitive level or ability as another consideration during their disclosure process. These parents indicated that they didn't initially know how to disclose to their child, as they didn't know what their child would understand or comprehend. However, one parent shared that she had to find a different way to tell her younger son about his diagnosis, than her older son, as the younger son's level of understanding was lower than that of the older son:

> I didn't do the whole chart with my younger son...his cognitive understanding is significantly lower... I truly don't think he would have really grasped the whole chart thing. He is a question guy, but he doesn't really process the answers... It would have had been much more concrete…But I think for him, it made some sense to him as to why he thought the way he thought. Um, and he was at a cognitive level to be able to process that kind of stuff as he got older. (D1)

Alternately, some parents spoke to age as a consideration for how to best disclose to their child. For these parents, they shared that disclosure is very age dependent, and should be considered relative to the child's current stage of life. Moreover, parents shared that they needed

to use more child friendly language for younger children, keeping information developmentally appropriate, brief, and simple:

> And then with [child x], it was talked, um, it was explained in kid language, in terms that she could understand. And she was able to ask questions. Um, I mean it was just kept really simple for her...and not longer than five minutes. (D4)

Many parents similarly shared that if their child had been younger at the time of diagnosis, they would have had a very different conversation with their child. These parents indicated that when the child is at a younger age, one cannot speak in complex terms (i.e., giving the child a scientific explanation of what ASD is) and expect her/him/them to understand. One parent shared his thoughts about the importance of disclosure being age appropriate and suggesting that parents use parental discretion to ascertain what would be suitable for the child:

> My feeling is…obviously your discussion needs to be age appropriate...And I guess it helped, but also I think what helped is that [other parent] and I were always fairly open with the girls, and again our feeling was if they're old enough to ask, they're old enough to deserve an answer. And it might not be the full answer, the full Monty kind of thing, you have to be sort of age appropriate. You don't want to introduce concepts that literally they do not have a chance of acknowledging…So [laughs] so I would strongly recommend an age appropriate conversation around the diagnosis...The chances of a positive outcome, or much higher outcome are much higher than a negative outcome. And in this case, I think the chances of a negative outcome, because you should, you're a parent, you should know your child better than anybody else. So, you know what an appropriate approach, and an appropriate method for a discussion. So, considering that as a given, in my mind the downside is very very slim. You know appropriating it, again if

it's done sensitively and not just kind of, my child is 6 years old and here's the verbatim umm summary of the report, and that poor kid is going to switch off after the first sentence. (D20)

Theme 4.4D: Resources to support disclosure. Throughout their recounting of the disclosure process, parents shared some of the resources and tools that aided them during disclosure with their child, resources that they gave their child after initial disclosure and supports that they had themselves accessed. Some parents started out by describing the tools that they developed to better introduce and/or explain the diagnosis to their child. One parent shared:

And we even made a little chart that we hung up on the wall as to here's the things that you can do really well, and here's the things I can do well, and here's the things that are hard for you, and hard, we did everybody in the family, even the dog. And we left it hanging on the wall for quite some time, and we circled the things that maybe were hard because of Autism or easy because of Autism. And, we even circled them on us, and just said well, these are the things that are easy for me, and it's probably not Autism that makes it easy for me, but it is something that you can also do easy cause of your Autism, right, umm you know, things like that. (D1)

Another parent shared that he would engage his son in imaginative play to introduce new or difficult topics to him and would draw cartoons with thought bubbles to help him think outside himself. One parent made her own book to describe Autism and how her son's brain worked differently, including some of the ways that he could calm down. Alternatively, one parent described that she threw a party for her child to celebrate his neurodiversity after disclosure had occurred:

We had a party actually, the next day, we had a huge party. We had thirty people here,

and it was a neurodiversity celebration, and everybody coming to confirm what we

already knew, but to accept and welcome [child x] in this new journey in his life, right?

He's starting a new path of identity…Right, like, what a great moment to celebrate. It's a

benchmark of individuality. Right and at the time, I was kind of thinking a benchmark of

becoming an adult, and clearly a four-year-old isn't becoming an adult. But of distinction

of self. Right, I am my own person. I have my own journey. It was great. Um, his friends

came. Everybody got a social story explaining what Autism is. And he was proud. (D6)

Some parents also spoke about books, movies, and websites that they introduced to their

child after disclosure. Parents emphasized that they wanted their child to access a resource to

which they could relate and to help give hope about the life ahead of her/him/them. One parent

described sharing resources with her child as a catalyst for having further discussions:

What was really huge for him was reading, um, the Temple Grandin book…he identified

as that being really where he started to think about what Autism is. And you know, like,

that impacted him quite a bit, so. And then, just recently we watched the movie, the

Temple Grandin movie with him. And that was, we just, we had it, we got it back from a

friend of ours. He saw it there and he was like 'oh, can we watch this?' And so, he's

been, that's been sort of, really, um, a catalyst for having lots of discussions. (D13)

Another parent described utilizing a professional as a follow up after having disclosed the

diagnosis to her child:

And then what we did was we met with the psychologist, and he took him in and talked

to him and explained the strengths of you know, his diagnosis, and what some of the

appropriate accommodations would be for him…and so it was really a positive experience. (D3)

Other parents shared that throughout the disclosure process they accessed parent support groups on social media sites, such as Facebook. These resources served as a means to share experiences and strategies for coping.

Theme 4.5D: Parent feelings about disclosure. Some parents also recalled their feelings throughout the disclosure process. For some there were feelings of stress, nervousness, and fear, with some reflecting that they did not feel ready to disclose. One parent shared,

At the time, I definitely didn't feel like he was ready for it. I didn't feel like I was ready for it. But, I think that in retrospect what I wasn't ready for was for it to be a big talk. (D13)

Parents recollected that although they tried to appear calm in disclosing to their child, they experienced both stress and nervousness as they wanted to be able to better explain ASD or, in hindsight, they were still processing the diagnosis for themselves. Another parent described the moment when her son started asking her questions and shared that initially she experienced shock and fear and tried to avoid his questions. Yet one parent stated that disclosure felt easy for her.

Yeah, so it was pretty easy. And it's come up several times like with the (Autism resource centre) conversation, where he gets to tell his little brother, you don't get to go. You don't have Autism. So, umm, it's not something that he is ashamed of. He talks about it, I have Autism, and it's just the way it is. So, I think it worked out really well! (D18)

Overall, parents experienced a variety of thoughts and emotional responses throughout the disclosure process, but upon reflection, appeared satisfied and generally pleased about their decision to disclose the diagnosis to their child with ASD.

Theme cluster 5D: Advice to others considering disclosure. In the final theme cluster associated with disclosed participants, many parents (*n* = 18) offered thoughts and advice to other families who might be considering disclosure to their child. Many parents emphasized that there is no correct way to decide about disclosure. Within this theme cluster, the following themes emerged: (1) How parents present information; (2) Normalize the process; and (3) Process, prepare, and access resources.

Theme 5.1D: How parents present information. Many parents emphasized that it is important to recognize that parents know their child best, and, therefore, parents need to make decisions that are best for their child, who they described as unique and individual. One parent offered:

> And the other piece of information I do is if the scientist and the experts tell you to do something, do it if it feels right, don't do it if it doesn't feel right...I have not followed every piece of information I have been given by every person. I've looked at our situation, our education level, and my child and gone, 'Is this gonna work?' And this is exactly what the books have said. If it doesn't feel right, don't do it. (D10)

Parents also shared that every person and situation are different and thus will require different approaches. These parents communicated that although they feel that disclosure is best for most children, parents need to make disclosure appropriate for their own child (e.g., age, personality, etc.). They also offered that parents are the best people to know when it's the right time, and parents need to trust their instincts.

Parents also offered the advice that families need to present information in a way that the child can understand. They shared that if a child has the intellectual capabilities to understand, then disclosure should occur in a developmentally appropriate way. For some children, they may benefit from having information chunked or broken down in tangible pieces, whereas for others, they may need information presented in a straight forward way. Regardless, parents verbalized that the person disclosing ASD should keep the conversation natural and relaxed and leave room for the child to ask questions. The following two passages are examples of the advice given by parents relative to this theme: "Yeah, I would just say: support your child. Love your child. Be there for your child. And do it gently. Or do it at the ability or the level that they can accept" (D9). Another parent stated:

> From my perspective, I think it's in the child's best interest…I honestly believe in my heart of hearts that it does empower the child. I think with the right support for the, for the kid and for the family [pause], it's, it's the best thing for them. Um, I think when you can find the right terminology for them, it takes away the scariness, it takes away the unknown, and it helps them understand why they see things – why they see the world the way that they do... (D4)

Although many parents expressed only wanting to give general advice, as to not influence other parents currently thinking about disclosure, these parents often came back to offering the re-occurring notion that disclosure should be strength-based. One parent shared an example from popular media as the basis for her explanation that disclosure shouldn't only focus on the child's difficulties:

> I watched an episode of Parenthood where they told their son his diagnosis, and you would have thought they were telling him he had cancer. And...you know, after having

gone through it myself, I just thought well, why in the world are they doing it this

way?...And so for us then, it wasn't like, oh this is the end of the world because we've

seen success. And…it's just like: okay, yeah, but that's why they have trouble with this

and that, and that's why you know, they need more downtime, and that kind of thing,

so...Strengths seem to be almost extreme strengths. (D3)

Parents also shared that disclosure should be factual, compassionate, and should highlight

the child's strengths:

Definitely emphasize the positives...you know your child, and you know what the

positives are, and then emphasize that there's definitely accommodations for the areas

that they struggle. And I wouldn't call it weaknesses, areas that they might struggle more,

you know. And, I guess yeah, just as natural as that. (D3)

Theme 5.2D: Normalize the process. Several parents also offered advice around the act

of normalizing parenting and shared that decisions around disclosure can be just like the

decisions that you would make when you parent a neurotypical child:

I think that so much of… what I've gone through, and what I'm going through really has

nothing to do with Autism, it's truly parenting any child, period. You know, I don't, I

think there are some unique, maybe weirdly different experiences, umm and

conversations that you never thought you would have. But you have those as a parent

anyways, right?...But you know, I think that is, in a way, it's a very normalizing

parenting thing, and I think that's why it's important to connect to other families, because

it does normalize it. Because in the end, it's all just parenting. Right so, if you're not

connecting to other parents and you're very isolated, you feel like all of this is just

happening to only you, when really it is just parenting. (D1)

These parents shared that parents need to choose love, as one cannot find love and peace in trying to change another human being. Parents shared the importance of accepting mistakes and moving forward despite the challenges with parenting and determining how and when best to disclose ASD to one's child:

Remove yourself from their experience, and understand…they're not doing it to you, right? This is not actually about you...This is parenting. This is what parenting looks like. It's unexpected. It's tough. It's very, very jarring, and you just don't know that your neurotypical kid isn't going to get into a car crash…you just don't know. This isn't actually a pre-written story. You aren't calling the shots; you are not choosing your own adventure. It's not happening to you. (D6)

Finally, these parents suggested that parents give themselves some latitude in potentially making mistakes, yet further recommended accessing information and education to better make informed decisions and reduce parenting stress.

Theme 5.3D: Process, prepare, and access resources. Many parents shared their belief about the benefit of parents processing and understanding the diagnosis prior to preparing for disclosure and the importance of accessing resources to support to disclosure process. They recommended conducting research before disclosure and seeking to understand the diagnosis as a parent before trying to explain it to the child:

I would say research and process everything yourself before you even think about trying to explain it to someone else, and make someone else understand. Cause if you don't understand it, you can't deal with it…I think that your view on Autism as a parent will dictate how you manage that…Right, so, yeah. I'd say, first thing, research and see where you see yourself in the situation. If you're still in that incredibly angry phase, it may not

be the time to have this discussion with your child, because I-I think the child's gonna

have enough to deal with, without feeling like their parents also see him as broken, or

inadequate, because…that's, that to him is just the way he is. (D5)

These parents further described the benefits of speaking to other parents about their

experiences, and preparing to talk about a child's strengths and difficulties during the disclosure

process. They suggested accessing books, articles, videos, and any other developmentally

appropriate resources to best support the child:

A great way to find information, is other people's experiences. Well this is how we did it,

and this is how our son or daughter responded. So, I think that is the best way to put this

kind of information out there. But it's nice to find out the information in… a way that

kind of comes from a, like it has been already applied. It's not some clinical tidbit...I hate

those. (D18)

Parents described the importance of having a pool of other parents with whom to connect at any

time, as other families can help to provide constructive perspective. However, they also

emphasized that at the end of the day, parents know their child best and must make the decision

that is right for their family:

I would say, if you're a little bit nervous about it, go to the two sources. One is whoever

did the assessment on your child or who is providing some professional support, talk to

them. And also talk to other parents who've been through that decision and get their

feedback. And if they disagree with you, ignore them [laughs]. (D20)

Summary of disclosed experiences. Disclosed parents described their journey over time

as they moved towards and experienced disclosure. Many parents initiated their stories by

reflecting on their experience of seeking out an assessment/diagnosis, moving through the

diagnostic process, and subsequently receiving their child's diagnosis of ASD. They shared many of their considerations and reflections as a parent, both after having received their child's diagnosis and prior to disclosing that diagnosis to their child. Not only did all parents explain some of their reasons for disclosure, but they also often included potential ramifications for alternatively not disclosing the diagnosis as a rationale for their decision to disclose.

For some parents, disclosure reflected less of a decision-making process, with several suggesting that non-disclosure was never considered as an option. Many parents also shared that ASD was just a part of their children's uniqueness; they felt that if children were aware of their differences and asking questions accordingly, they deserved to know about their diagnosis. Further, a driving factor for some families was concern that their child would learn about their diagnosis in another way and under a negative connotation.

Much of the narrative expressed by this group of parents centered around their process of disclosure, as an entity largely occurring as a process over time. For many parents, they shared when and how they had disclosed their child's diagnosis of ASD to the child. For some, they communicated that they had always spoken with their child about ASD from the moment the diagnosis was received, while others began this process later such as initially having conversations with their child about her/his/their differences without use of a label. Parents within this group expressed that they had both planned, in some instances, and not planned, in others, when and how disclosure would occur. Parents also discussed age, language ability and use, and cognitive level as factors that had impacted their decision about how and when disclosure occurred. Throughout their recounting of the disclosure process, parents shared some of their emotional reactions and resources that they had developed and utilized. They offered advice that they would give to others considering disclosure. Although all disclosed parents

emphasized the importance and benefits of disclosure for their children, they continually circled back to the notion that parents know their children best and that every situation and child are unique. Lastly, parents emphasized the importance of normalizing ASD and focusing on the strengths of the child.

Chapter 5: Discussion

The overall purpose of this study was to explore the lived experience of parents relative to their decision-making around the disclosure/non-disclosure of their child's ASD diagnosis to the affected child. The need for this study arose as there has been a limited focus within the literature on if, how, when, and by whom a child is informed about their ASD diagnosis. Overall, forty parents or parent dyads participated in semi-structured interviews. Data was analyzed and organized, first by participant characteristics, and then by the theme clusters and themes represented within each participant group. As there was a continued need to hear and reflect on the voices of these families on the issue of disclosure, it was anticipated that a representation of these experiences may serve as a potential resource for families considering if disclosure is right for their family.

The previous chapter articulated the key findings of the current study, seeking to describe parents' experiences without interpretation and to produce a narrative of these experiences. The purpose of this chapter is to summarize the main findings of this study, both as a means to contrast and compare both participant groups, while making connections to the four primary research questions. This chapter will also consider the findings relevant to those within the existing literature and is followed by an overview of findings and an evaluation of the limitations and research and clinical implications, including a discussion of potential future directions.

Main findings

The findings generated from this study consider the decision-making process that parents go through when deciding whether or not to share an ASD diagnosis with their child. Although this study consisted of two participant groups, disclosed versus non-disclosed, it seems more

relevant to discuss the findings relative to the entire participant group as there was much overlap, and a similar progression in process that appeared between the groups.

  A comparison of the two groups. Although differences emerged, underscoring the results from both participant groups appeared to be the progression of time, starting with the journey that families navigated when receiving an ASD diagnosis for their child. The common theme cluster, *Journey of receiving the ASD diagnosis,* presented information expressed within parents' narratives describing when they noticed a difference for their child from neurotypical child development, often describing this recognition as the point of initiation into the healthcare system. Many parents then continued their narrative by sharing experiences around their progression through a lengthy and complicated diagnostic process followed by the myriad of emotional reactions upon receiving their child's ASD diagnosis. While not directly asked about, the early journey of receiving a diagnosis for their child, parents often initiated their narrative around decision-making at the point in time when a difference in development was highlighted as a potential concern. Rarely did a participant in this study start by sharing about their decision around disclosure without first explaining how they came to a place where the consideration to disclose could even occur.

  The overall progression of time seemed to occur similarly for both participant groups; however, the choice around what information was shared during interviews and how it was presented differed slightly between the groups. For non-disclosed parents, information was presented on a past-present-future continuum (see Figure 2), as opposed to the general progression over time by disclosed parents (see Figure 3) as disclosure had already occurred for this group. More specifically, aside from the common theme cluster, non-disclosed parents discussed much of their narrative relative to present day, weighed in on the reasons for and

against disclosure, tried to identify what the potential outcomes of disclosure could entail, and shared where they were at currently with respect to their decision-making and feelings about disclosure. This group of parents then looked to the future, trying to ascertain when they might decide, what that decision would be, and what their process would entail if disclosure was chosen. In contrast disclosed parents largely described their journey over time as they moved towards and experienced disclosure, instead looking back to reflect on their decision, and they tended to provide advice to others considering whether to disclose.

Another difference between the two participant groups was that less information was shared by disclosed parents around reasons for non-disclosure and potential outcomes, as a decision to disclose had already been made and that disclosure had already occurred. More specifically, there were seven theme clusters of essential meanings that emerged from non-disclosed participants and only five theme clusters of essential meanings that emerged from disclosed participants. In fact, for some disclosed parents, disclosure reflected less of a decision-making process, with several families suggesting that non-disclosure was never considered as an option. Moreover, some disclosed parents shared information around the potential ramifications of non-disclosure as further rationale in their decision to disclose.

Overall, it appeared that non-disclosed parents had more information to share around their consideration of possible risks and benefits, underscored by many by their fears of the potential outcome once disclosure had occurred. Regardless of the fears and worries expressed by many non-disclosed parents, almost every parent in this group indicated that they had reached a decision about disclosure as they moved forward. Although many parents expressed hesitancy and fear around the decision-making process, several non-disclosed parents shared that they planned on disclosing but were not yet ready ($n = 9$) or would disclose if they thought their child

could receptively and cognitively understand ($n = 3$). The remaining parents conveyed uncertainty about whether or not to disclose ($n = 6$) and/or that they had chosen continued non-disclosure ($n = 2$) unless in the future they would feel that it would benefit their child.

Connection to the Research Questions

Research question one. The first research question sought to identify which factors and/or considerations go into a parent's decision-making process when choosing whether or not disclose the child's ASD diagnosis to that child. The non-disclosed parent group described a state of ambivalence in the consideration of reasons for and against disclosure, followed by further deliberation of potential outcomes, and sometimes a subsequent decision. Although the disclosed parent group also provided their rationale for disclosure, they often also described the possible ramifications for non-disclosure as further justification for disclosure to occur. An underlying expression of fear was communicated by both parent groups but seemed to be more predominant within the non-disclosed parent group coupled with both apprehension and uncertainty around making a decision about disclosure. A more detailed exploration into the specific factors was involved for these families when considering disclosure can be found below.

Considerations and factors expressed around non-disclosure. As was previously mentioned, considerations around the notion of non-disclosure were reported by the non-disclosed parent group and fundamentally was encapsulated in an expression of fear. This parent group provided explicit reasons for non-disclosure and expressed potential negative outcomes should disclosure occur – subsequently leading them to a decision of non-disclosure or fear and uncertainty around making a decision. When exploring reasons for non-disclosure (Theme cluster 2ND), four overarching themes emerged: will there be a need? (Theme 2.1ND); labelling

(Theme 2.2ND); don't want to give the child an excuse (Theme 2.3ND); and, unwanted attention from others (Theme 2.4ND).

Within this theme cluster, non-disclosed parents seemed to doubt or question if their child's diagnosis would be noticeable to others, now and in the future. Moreover, these parents expressed that their child hadn't appeared to have noticed any of their own differences, and they wondered if there would be a point in highlighting those difficulties or differences for their child. Within the theme of necessity, parents also provided specific factors that could inhibit their child from understanding disclosure: level of language, development, cognition, and presence of challenging behaviours. More than the need to share information, parents also often expressed their concerns, fears, and considerations around disclosing the diagnostic label to their child. Specifically, these parents spoke about the diagnosis as a part of who their child is and likened it to the notion that they wouldn't sit down to discuss idiosyncratic traits such as, hypothetically, why a child had blue or green eyes. Other parents expressed that although their child had recognized some of their own differences, they had never felt the need to label the diagnosis and explained that they felt it might be better to instead describe what makes the child unique. Underlying the theme of labelling seemed to be the shared fear that their child might experience low self-confidence, low self-esteem, denial, frustration, or an exacerbation of negative feelings that the child already held if disclosure occurred.

Non-disclosed parents also expressed hesitance over disclosing the diagnosis to their child as they feared that the child would use their diagnosis as an excuse or *crutch* and might also receive unwanted negative attention or stigma from others. Underpinning these themes was an overall fear expressed by parents that their children would be limited in their potential, singled out as being different or lesser, or that their children would disclose their diagnosis to others

without understanding what they were telling people. Cultural implications were also expressed by two families whereby they indicated that by disclosing the diagnosis to their child other people from their communities might find out, and this would lead to the potential for unwanted attention or isolation for their family.

Several non-disclosed parents often spoke about possible outcomes should disclosure occur and expressed that they were trying to make the decision that would have the best outcome for their child. However, some families shared the potential that their child might experience anxiety, feeling lesser, and resistance toward hearing about the diagnosis. Some parents also expressed that they felt the children would need time to process what the diagnosis meant for them and envisioned that the child would take time to make emotional and psychological meaning for themselves. Other parents indicated that in trying to weigh the potential outcomes for their child, they were either uncertain about their child's response and level of understanding or didn't think that disclosure would make a difference for their child. All in all, these factors and considerations led some non-disclosed parents toward a decision of uncertainty or non-disclosure. These parents shared in some cases that they weren't ready make a decision as they were fearful that their decision would impact their child in a negative way. Further, for some families there was also a component of disagreement, and the notion that a decision wouldn't be made until consensus was reached. Other parents shared that they felt non-disclosure was the best option for their family and articulated that they would only disclose the diagnosis if there were explicit benefits that arose for their child.

Considerations and factors expressed around disclosure. Considerations and factors around the notion of disclosure were communicated by both non-disclosed and disclosed parents. When exploring reasons for disclosure considered as communicated by non-disclosed parents

(Theme cluster 3ND), four overarching themes emerged: child asking questions (Theme 3.1ND); understanding (Theme 3.2ND); fear that they will find out another way (Theme 3.3ND); and, medical reasons (Theme 3.4ND). When exploring reasons for disclosure as communicated by disclosed parents (Theme cluster 3D), a similar yet distinct set of four overarching themes emerged: never thought not to disclose: it's not a secret (Theme 3.1D); just another part of who they are (Theme 3.2D); child was asking questions, and aware of their differences (Theme 3.3D); and, fear that they would find out another way (Theme 3.4D).

Within this theme cluster, both parent groups seemed to consider their child's level of understanding and their ability to notice differences or ask questions as an indication that disclosure might be appropriate. Specifically, disclosed parents reflected on their rationale and in some cases shared that their child was already asking questions and therefore had a right to know about their diagnosis. These parents suggested they wanted their child to be better able to understand themselves and possess an appreciation for how they function differently in the world. Disclosed parents also shared that in some instances their child had directly asked them about ASD, and these parents indicated that it was better to disclose information to their child as questions and situations arose. Parents in general shared that they didn't want their child to feel any shame about their diagnosis and instead posited that it might *do more harm than good* to continue along a path of non-disclosure. One parent went as far as to say that she felt it was morally wrong to withhold a diagnosis from the individual that has the diagnosis and stated that by not disclosing the child is denied their rights and a certain level of independence as a person. Disclosed parents expressed that an ASD diagnosis was just a part of their child's identity and, therefore, essential that the child knew this information. Parents elaborated to say that how each person's brain works is important to who that person is regardless of the label. One disclosed

parent also shared their realization that the diagnosis wasn't a part of her identity as a parent, but was instead a part of her child's identity. Thus, these parents indicated that they wanted children to grow up accepting their diagnosis as a part of who they are, just like any other part of themselves.

Other parents shared their child asking questions about the diagnosis would be an indication she/he/they were ready for more information or disclosure to occur. Both groups of parents spoke to the children's level of understanding and indicated that if they could comprehend their differences that they should know about their diagnosis regardless of their age, developmental level, maturity level, ability to understand language and process information. However, some non-disclosed parents elaborated on this rationale by expressing their fear that a child might not ever be able to, or know how to, ask the questions that would lead to disclosure. Parents shared that these children might have unanswered questions and this concern developed into a rationale or different level of consideration about disclosure. Thus, some non-disclosed parents made the decision to move towards disclosure in the future if their child could understand.

Both parent groups also shared that either previously or currently, they felt concern around the idea that children could learn about their diagnosis in another way, regardless of parental disclosure. They expressed that either their children's peers already recognized their differences and supportive adults already knew about the diagnosis, or would find out, and subsequently they worried that their children would learn of their diagnosis from someone else. Some parents also shared that as information is disclosed to others, they worried that their children would hear someone talking about their diagnosis and not understand why their parents hadn't told them. Other parents expressed that they had received documentation when their

child's diagnosis had initially been received, and they were concerned that their child would stumble upon this documentation and not understand why it hadn't been communicated. All in all, this theme, as represented by both groups, was presented more as a possible ramification of non-disclosure and consequently led them on a journey towards disclosure.

Alternatively, some in the disclosed parent group also expressed, in some capacity, that non-disclosure wasn't ever a consideration as they wanted to reflect an open and honest communication style with all members of their family. For these parents, they described that they had always used ASD terminology in their home and revealed their dislike for *keeping secrets* and *deception.* Not wanting to keep secrets from their child was one of the most frequently articulated considerations towards disclosure presented by this group, with an aim of avoiding potentially negative outcomes (e.g., feelings of shame, embarrassment, and confusion).

Lastly, the non-disclosed parent group articulated one final reason for disclosure centering around medical factors. This group of parents shared that although they felt hesitant about disclosure, they would choose to disclose if children needed to know more about their own genetic information, if children were having a child of their own, and/or if they had a medication protocol to follow. All things considered, many non-disclosed parents expressed that they greatly considered the possible positive outcomes of disclosure when trying to decide if disclosure would be a good fit for their family. This group indicated in some respects that they had heard of success stories following disclosure and indicated that they hoped their child would take the information in stride, develop a greater sense of empathy towards others, improve their own self-awareness, and even feel a sense of excitement. Thus, it was no surprise that almost half of the non-disclosed parents indicated that disclosure was right for their family, but shared that it hadn't yet occurred. These families expressed that they either felt their child was too young and thus not

ready, or that they were trying to decide when and how they would disclose to their child. Overall, these parents shared that disclosure would be necessary for their child moving forwards and expressed that their child's happiness was their greatest consideration.

Research question two. The second research question investigated how parents navigate the disclosure process with their child. Within this question, non-disclosed parents discussed the conversations that they had already had with their child and information about what their potential process might entail should they choose disclosure. For disclosed parents, this question encompassed planning, researching, and initial conversations with their child leading up to disclosure, including details how and when disclosure occurred, paying specific attention to factors that would influence their child's understanding.

Leading up to disclosure and initial child conversations. Regardless of non-disclosed parents not (or not yet) having disclosed, both parent groups discussed the conversations that they had started with their child without attaching a label. Non-disclosed parents often spoke about the conversations that had already occurred with their child and elaborated on providing information about conversations that might happen over time. Largely as a precursor to these conversations, parents discussed how all people are different and spoke about how their child's brain worked a bit differently, with some also sharing an additional diagnosis with their child (e.g., learning disorder, giftedness, or ADHD). Other parents described how they had gone into more detail with their child about specific challenges or differences as a means to explain why supports were in place. Regardless of conversations that already occurred, these parents often shared that they would continue to have conversations over time as a continuation of the *you're different* conversation without attaching a label, whereas disclosed parents spoke about the early conversations they had engaged in with children about their differences prior to disclosure of the

ASD diagnosis. Much like the non-disclosed parents, disclosed parents spoke about how all people are different, child specific differences, and differences relative to supports.

Disclosed parents shared information about planning and researching as a part of their early process leading up to disclosure. These families indicated that they read books about ASD, sought out materials online, and tried to comb through the limited available resources about the disclosure process itself. Some of these parents also shared that their best resource in preparation for disclosure was speaking with other parents and reading about parent experiences online (e.g., blogs). When preparing, parents also indicated that they considered timing, the busyness of their home environment, and potential impacts of disclosure versus non-disclosure. This group of parents shared that they wanted time to think about and prepare what to say to their child prior to disclosure so they could potentially also prepare for the questions their child might ask.

Potential process for non-disclosed parents. Non-disclosed parents expressed their potential process for disclosure should it arise in the future. These parents spoke to how this process might look by speaking to factors involving timing, how they might disclose, and ideas around their possible narrative for disclosure. Much like disclosed parents, these families started their explanation by expressing that they would need to initially prepare themselves and do research. As many of these parents were still experiencing a level of uncertainty about disclosure, they communicated that they felt they would need to *go with their gut* to do what was best for their child and family.

Although some non-disclosed parents communicated that one barrier to disclosure was not knowing when to disclose, some parents shared they would need to consider their children's age, if children recognized their differences, and if they would be able to understand. Some parents shared that they would wait for a calm and comfortable time to disclose, like a school

vacation, and indicated that they preferred if disclosure would arise organically. Non-disclosed parents also shared how they thought the information should be presented in an understandable way and as a gradual conversation over time. These parents indicated that they didn't want to overwhelm their child and instead wanted to begin by sharing about the diagnosis in small pieces while gauging their child's understanding. Although these parents didn't know if and how this disclosure might occur, many shared that they thought disclosure would occur as a progression from earlier conversations with their child about their differences and verbalized that they wanted to tell their child in a way that was positive, reinforcing, and encouraging.

The disclosure process as expressed by disclosed parents. Lastly, disclosed parents shared their thoughts on when and how disclosure occurred for their child, and spoke about specific factors as considerations impacting a child's level of understanding during disclosure. Disclosed parents felt that they should disclose and speak openly about the diagnosis with their child, regardless of external factors but shared that it was important to tailor the conversation to their child's specific needs.

Many disclosed parents shared their thoughts on when disclosure should occur and specified when disclosure occurred for their own child. For some of these families, it wasn't a matter of *when* (i.e., disclosure as happening at a moment in time) but rather shared that they had always spoken about ASD. For other parents, they gave examples where they planned and prepared for disclosure to occur at the optimal time for their child (e.g., specific age, calm environment, calm moment) and spoke about instances when disclosure happened in an unplanned and situational manner. In both cases, parents articulated that it was important that this process allowed the conversation(s) to happen and ensured that time was available for any questions that their child might have. Parents also expressed, in some instances, that they began

sharing information when children demonstrated some inquisitiveness about their differences and felt that it was better for their family to have disclosure arise naturally. These parents indicated that disclosure was often a series of many conversations, as a process over time, occurring over days, weeks, months, and years, introducing new information to the child as it became important or necessary. Regardless of some disclosed parents expressing that they could have disclosed earlier, they shared that there would have always been uncertainty about ideal circumstances and methods of disclosure of ASD to the child. Upon reflection of this process and timing, they noted that they couldn't know if sharing the diagnosis earlier would have had a different outcome for their child.

Regardless of when disclosure occurred, disclosed parents also discussed how disclosure occurred for their family, some of the factors they considered, and important aspects of their disclosure narrative. Particularly, parents often shared that they used specific examples from their child's life to explain his/her/their difficulties, told children enough information that they could understand and ask questions, and emphasized that they didn't want to solely focus on negatives or challenges. Parents also shared some key elements within their disclosure narratives: exposure to ASD and that all people have differences, the child's brain is unique, the diagnosis relative to received supports or other diagnoses, and insight related to the fact that the label of ASD wouldn't stop children from doing anything they wanted to do in their lives (i.e., achieving their potential). Moreover, parents often shared information about famous people who have ASD to normalize the diagnosis and ensure the child understood the positive factors surrounding an ASD diagnosis. These families explained that their child was more receptive to disclosure when they used positive language and described that ASD shouldn't be considered as a negative.

Disclosed parents also discussed specific factors such as language, developmental level, cognitive level, and age as considerations impacting a child's level of understanding during disclosure. Some parents spoke about their child's level of language and shared that it was important to speak about the diagnosis, even if they were non-verbal, while watching for signs of understanding (e.g., non-verbal body responses). Parents also discussed the need to speak about ASD in a very concrete and direct manner as their child understood the conversation in a very literal manner. Other parents spoke to their child's cognitive level, sharing that they didn't initially know how disclosure would occur for the child. They indicated that they had to find other ways of communicating about the diagnosis and often explained the same concept several times and in different ways to ensure they understood the core ideas of the conversation. Lastly, some parents spoke to age as a consideration for how disclosure should occur, indicating that disclosure should be considered relative to a child's stage of life and sharing that information should be developmentally appropriate, brief, and simple.

Research question three. The third research question explored how disclosure is experienced by parents who have a child with ASD. Overall, there were two salient ideas that were discussed by parents when they communicated their own experience: parent feelings prior to disclosure and parent feelings during disclosure. Non-disclosed parents shared their experiences prior to making a decision about disclosure both in terms of their feelings around making a decision and around parental disagreement about whether or not disclosure should occur. More specifically, some parents shared that they were overwhelmed and hesitant, expressing that the decision was weighing heavily on them. Others indicated that they felt having clarity around the diagnosis as a parent was important prior to communicating the diagnosis to the child. Specifically, seven families shared that they had experienced disagreement within the

parenting couple about whether disclosure should occur. When providing clarity, these families postulated two explanations around the disagreement: cultural implications and the situation where one parent in the family hadn't accepted the diagnosis. In the case where one parent disagreed about disclosure, some parents explained that they felt their child didn't experience any confusion about her/his/their differences and thus felt that disclosure wouldn't be necessary. Regardless of parental feelings around the decision-making process, many non-disclosed parents shared that they didn't feel there was anything to be gained from withholding a diagnosis from the child. However, for families where disagreement had occurred, parents often expressed that they didn't want to disclose until both parents were on the same page about disclosure.

Similarly, leading up to disclosure, disclosed parents also shared that it was very important that both parents were on the same page and that all parents involved accepted the diagnosis themselves first. They expressed that they felt by being on the same page, parents acted as a support for one another and as a unified front acting on behalf of their child. Disclosed parents also verbalized that accepting their child's diagnosis led to an increase in comfortability dealing with the diagnosis and subsequently better outcomes for their child once disclosure had occurred.

Disclosed parents also spoke about their experience throughout the disclosure process and recalled a variety of emotional responses. These parents recollected that although they tried to appear calm during disclosure with their child, many felt nervous and fearful wondering if they were ready to disclose. Another parent expressed that she experienced feelings of shock and fear when her child initially began asking questions that caught her off guard. Overall, parents described a variety of experiences and emotional responses throughout the disclosure process,

but upon reflection, appeared satisfied and generally pleased about their decision to disclose the diagnosis to their child with ASD.

Research question four. The final research question examined the resources that are perceived as necessary for supporting families during the disclosure process. Although this was a question of inquiry, limited information was provided by parents around resources that were accessible for families and disclosed parents often shared information about the creation of their own tools to support the disclosure process.

In general, non-disclosed parents often shared their hope that child-specific supports around disclosure would be created and indicated that it would be beneficial to learn what other families had experienced. Moreover, some non-disclosed parents indicated that they felt that involving a professional in the disclosure process could be beneficial for their child, providing context for their diagnosis on a larger scale. Other parents shared specific supports that they thought would be beneficial for their child, including: a supportive school environment as well as books, social stories, and internet websites geared towards helping individuals understand ASD. Generally, non-disclosed parents expressed that they wanted others within their family's core social sphere to be on the same page prior to disclosure and indicated that a significant resource or help in moving towards disclosure would be to hear from other families who have disclosed.

Some disclosed parents spoke about books, movies, and websites that they introduced to their child after disclosure, often involving information about famous individuals on the Autism spectrum; however, many shared that they could not find a lot of information about disclosure. Parents emphasized that they wanted their child to access a resource to which they could relate and to help give hope about the life ahead of them and used these tools as a catalyst for further

discussion. Other parents indicated that they accessed parent support groups on social media sites and utilized professionals as a follow up with their child after having disclosed the diagnosis.

Other disclosed parents described the tools that they had created and the strategies that they had used as a family to better introduce and/or explain the diagnosis to their child. One parent shared that he engaged his child in imaginative play to introduce new topics and would use his child's interest in drawing to facilitate conversations. Another parent shared that she created her own book about Autism to explain how her child's brain worked differently. Further to this, one family created a chart of things that they could each do well and the things that were difficult for each of them as a means of illustrating that everyone has strengths and difficulties. Alternatively, one parent described throwing her child a party once they had disclosed to celebrate his neurodiversity. All things considered, many disclosed families indicated that they had wished there were more resources available to them when they had disclosed and wanted to offer advice to other families who might disclose in the future.

Advice from parents who have already disclosed. Although many disclosed parents offered thoughts and advice to families, they wanted to keep this information general as to not influence other parents currently thinking about disclosure while emphasizing that there is no single correct way to disclose. In offering advice, three overarching themes emerged: how parents present information (Theme 5.1D); normalize the process (Theme 5.2D); and, process, prepare, and access resources (Theme 5.2D).

First and foremost, many parents stressed that it is important to recognize that parents know their child best and therefore need to make decisions that are best for their child and family. This group of parents also shared that every person and situation are different, requiring different approaches; however, they often came back to the notion that disclosure should be

factual, compassionate, and strength-based. Disclosed parents shared that although they felt disclosure was best for most children, it would be important for parents to present information in a developmentally appropriate manner so that it is appropriate and understandable for that child, with room for the child to ask questions. More specifically, they articulated that some children may benefit from having information chunked or broken down into tangible pieces, whereas others may need information presented in a straight forward way.

Disclosed parents also offered the advice to normalize parenting, accepting that challenges will occur, and mistakes will be made along the way. Many also shared their belief that parents need to process, understand, and accept their child's diagnosis before planning for disclosure. These parents suggested that families should access information about ASD, speak to other parents about their experiences, and prepare to discuss their child's strengths and difficulties during the disclosure process. Disclosed parents shared that by accessing information they were better able to make informed decisions which helped to reduce overall parenting stress. However, this group of parents articulated that as a parent knows their child best; regardless of the information they find, they must do what is viewed as right for their family.

Connecting the Findings with the Existing Literature

ASD diagnostic process and disclosure for parents. Parents often began their narrative about the diagnostic process by indicating that they had noticed differences and had *red flags* that their child was deviating from typical development. Findings from the wider literature base would suggest that the acknowledgement of differences is often how the diagnostic process begins for many families (Dawson et al., 1998; Howlin & Moore, 1997; Stephanos & Baron, 2011) as these concerns often lead families to seek professional opinions on the nature of the differences (Mansell & Morris, 2004). Many of the parents in this study also reported that the

diagnostic process of seeking an ASD diagnosis for their child was prolonged, complicated, and stressful, and parents shared that they were generally unsatisfied with the diagnostic process. Moreover, parents indicated that they experienced a lengthy referral process while receiving many misdiagnoses along the way and often had to see many different professionals, many of whom only saw the child briefly. All of these findings seem to fit within wider research that suggests the process of receiving an ASD diagnosis can be lengthy and arduous despite parents expressing early concerns about their child's development and seeking professional guidance (Oswald et al., 2017). Additionally, the literature generally suggests that although best practice for professionals providing an ASD diagnosis has been outlined, parents often still indicate dissatisfaction with the diagnostic process, including timeframe delays, lack of information provided by professionals, and insufficient support from professionals (Chamak et al., 2001; Siklos & Kern, 2007). Overall, how parents cope with receiving their child's ASD diagnosis can be based on a number of factors, including their level of satisfaction with the diagnostic process (Reed & Osborne, 2012). Moreover, how parents learn about their child's diagnosis and experience the diagnostic process may influence their overall thoughts and attitudes around ASD (Abbott et al., 2013) and subsequently how they communicate information with their child.

As the current study focused on the process of disclosure, it was important to also consider how diagnostic disclosure was experienced by parents. In line with much of the research exploring diagnostic disclosure to parents, participants in this study often shared that they experienced many emotions during the diagnostic process, including frustration with the process, confusion about their child's diagnosis or where they fell on the spectrum, and feeling rushed during the final feedback meeting with the professional. These experiences and feelings fit within the wider literature base and further corroborate literature suggesting that parents tend

to prefer a firm diagnostic label for their child, clear explanations from start to finish of the diagnostic process, and strong collaboration between parents and professionals (Brogan & Knussen, 2003; Crane et al., 2015; Moh & Magiati, 2012). Parents in this study also expressed a myriad of emotional responses upon receiving their child's diagnosis, including shock and disbelief, grief, sadness, stress, anxiety, confirmation, and relief. Research findings similarly suggest that parents may experience a variety of initial thoughts and reactions, as well as both negative and positive emotional responses, ranging from anger to relief (Avdi et al., 2000; Finnegan et al., 2014; Nissenbaum et al., 2002). As many parents in this study also spoke about their need for parental acceptance around the diagnosis and personal clarity while understanding the diagnosis prior to disclosure occurring, it is important to link the comparability of these findings to the literature at large.

Diagnostic disclosure to children. Some of the factors and considerations, as well as the process of disclosing ASD, bear similarities to the literature on childhood diagnosis disclosure of other developmental, genetic, or chronic medical diagnoses to children. Diagnosis disclosure has been seen as a complex process, with many individual factors that need to be considered prior to disclosure (Allmon, 2014; Sisk et al., 2016). More specifically, in both this study and the areas of literature previously mentioned, some factors considered prior to disclosure include specific child characteristics (e.g., age, developmental level, maturity, culture, ability to comprehend disclosure), correct timing and delivery of disclosure, whether the child has previously asked questions; family situation or environment, personal beliefs about disclosure, what perceived outcomes of disclosure might be and an examination of the child's desire and right to know (Allmon, 2014; Cantrell et al., 2013; Chesler et al., 1986; Claflin & Bararin, 1991; Domek, 2010; Gallo et al., 2005; Vreeman et al., 2010; Waugh, 2003). Additionally, parents often felt that they

needed time to personally process and accept their child's diagnosis prior to disclosing the diagnosis to their child (Chesler et al., 1986; Clarke et al., 2005; Sutton et al., 2006).

Parents in both this study and the broader body of literature similarly considered and weighed factors for and against disclosure. Similarities when considering factors for non-disclosure included protection of the child from potential stigma or adverse effects of disclosure; the thought that their child was too young or not developmentally ready for disclosure; not feeling ready or prepared as a parent to disclose or answer their child's questions; and wanting to speak with the child, but not wanting to label the child's diagnosis (Jithoo, 2010; Sutton et al., 2006; Vreeman et al., 2010; Waugh, 2003). When considering factors in favour of disclosure, similarities included not wanting to keep secrets or mislead their child, fear that the child would learn about their diagnosis from an outside source, and perception of an essential need for children to build their own self-identity and have control over their own information and their life (Jithoo, 2010; Last & van Veldhuizen, 1996; Sutton et al., 2006; Todd & Shearn, 1997). In summary, the literature in this area suggests that parents consider factors relative to disclosure; however, the current study appeared to further reflect a more conscious deliberation period and detailed decision-making process among parents around whether or not to disclose an ASD diagnosis to their child.

Although the literature in this area largely focused on the factors and considerations that occurred for parents prior to disclosure, there were some similarities identified regarding how parents navigated the disclosure process with their child. Specifically, parents in both groups shared that diagnostic disclosure to their child was a worrisome and stressful undertaking, with uncertainty experienced on how and when disclosure should occur (Perry et al., 2005). However, some parents detailed how they first researched about their child's diagnosis, attempted to

control their child's environment, tailored conversations to their child's developmental level (e.g., using child friendly language), indicated that they were more likely to start disclosing when their child began asking questions, and, accordingly, that disclosure was a continuing process that unfolded over time (Cantrell et al., 2013; Chesler et al., 1986; Gallo et al., 2005; Perry et al., 2005; Young et al., 2002). Thus, although many similar factors and considerations prior to disclosure were identified, and some factors were expressed relative to how parents navigate the disclosure process, this study provided new insight into how parents navigate the disclosure process with their child over time.

Disclosure of an ASD diagnosis. Many aspects of the results gleaned from this study seem to fit with the findings found in the limited literature base regarding the experiences of parents disclosing their child's ASD diagnosis to the child. Similar to Finnegan's and colleagues' work (2014), this study found that parents often grappled with the notion of disclosure to their child and felt apprehensive about potential outcomes from that disclosure. As a study exploring disclosure versus non-disclosure in ASD, they also found that parents often wanted to protect their child while also ensuring the child learned about her/his/their diagnosis. Although Finnegan's and colleagues' work echoed the fear and anxiety that parents often feel prior to diagnosis disclosure, they focused on disclosure as a consideration only when a child had *high functioning* Autism or Asperger's syndrome and did not explore in great detail other factors that indicate a child might be ready to learn about their diagnosis. However, comparably was the notion of when disclosure should occur: waiting for the right age and place for disclosure and finding a time where the diagnosis would serve as useful information for the child such as when the child was asking questions or recognizing their differences.

When comparing the current study to the work done by Rossello (2015) on parents who had had chosen a path of disclosure, findings suggest that parents in both instances wanted to have engaged in preparation and research prior to starting the disclosure process with their child. Moreover, both groups of disclosed parents shared that they wished they had received the diagnosis earlier and, therefore, had the option to disclose sooner. However, two strong differences were found as Rossello (2015) focused on only individuals with Asperger's syndrome and did not specifically speak to methods and process for disclosure or factors that were considered prior to disclosure occurring.

The most comparable work to the current study was Duprey's (2011) dissertation exploring the parent disclosure process when sharing an ASD diagnosis. Duprey's study only included parents who had disclosed a diagnosis yet that sample reflected similar characteristics: diversity in terms of developmental level and severity of ASD traits, recruitment from both rural and urban areas, and only some factors of family diversity. Parents in both studies reflected on similar experiences when seeking a diagnosis and their struggle to receive support once they had received a diagnosis. Moreover, both studies shared factors that they considered during their deliberation process (potential benefits and costs of disclosure) and expressed an overall sense of ambivalence (especially when compared to non-disclosed parents from this study) around the potential outcomes of disclosure. Differentially, the current study gleaned more information on the actual decision-making process that parents engage in prior to disclosure as parents expressed more information on their rationale for or against disclosure, not always directly related to potential outcomes.

Overall, both the current study and the work done by Duprey (2011) found that disclosure often occurs as a gradual process changing and developing over time, as the child becomes more

aware and understands more information. Although, the current study set out in a somewhat comparative stance looking to distinguish differences in the decision-making process for disclosure versus non-disclosure, much of the process reflected by both groups was similar and only differed based on where they were situated on the timeline of disclosure. Both disclosed and non-disclosed parents indicated that they initially had conversations with their child, not labelling the ASD diagnosis, and provided only some information as to not overwhelm the child. When situating the current findings in the results found by Duprey (2011) on navigation of the disclosure process, the majority of the current findings fit within this three-stage theoretical model (consideration and preparation, disclosure, and consequences), with only some parents' experiences not directly following this outlined process. More specifically, Duprey outlines that the process of disclosure is cyclical, such that parents often revisit their initial thinking around disclosure prior to sharing more information. This only differed in the current study for some parents who either: a) did not wish, or see a need, for disclosure to occur at all, or b) had already disclosed the diagnosis to their child immediately following the assessment process. For both sets of these parents, there did not appear to be engagement in a cyclical process and a decision had been made whether or not to disclose and consideration was completed.

Limitations

Several limitations are evident in the current study. Firstly, the sample may be more homogeneous than initially hoped for and anticipated. The recruitment of participants was stratified such that the sample was reflective of parental experiences with diagnostic disclosure (either disclosed or non-disclosed); however, others areas of diversity within this stratification was not sought. Particularly within the non-disclosed participant group, parents were in fact predominantly in favour of disclosure but indicated that it had not yet occurred or were still

uncertain about their decision to disclose. Therefore, the non-disclosed participant group may have yielded different results had further stratification occurred to specify that parents should participate if they had decided never to disclose. Moreover, an inherent sampling bias may be anticipated in that it might reasonable to anticipate less willingness among parents who are fundamentally opposed to diagnostic disclosure, to participate in a disclosure-based study.

Other factors contributing to possible sample homogeneity included limited diversity in age, cultural background, and family constellation, as such factors of diversity were not directly pursued and thus may have been only minimally represented. The representativeness of this sample to the general population of families who have a child with ASD may also have been limited by a variety of elements. Specifically, participation in this research initially required the use of a computer to complete the online screening tool prior to contact being made to participate in an in-person interview. Further, recruitment was based on an initial willingness to respond to the screening tool and thus the motivation to share their experience. Therefore, participants may have been limited to those who were not only interested, but had the means and were able to articulate and express themselves in the English language.

The location of participants also could have limited the study and impacted the ability draw definitive conclusions to the aforementioned research questions. All participants were in Alberta, which may have inherently produced different results than other locations. As many participants indicated, Alberta as a province provides a greater level of ASD funding for families and offers extensive resources and access to increased services for the ASD population. Therefore, the parents who participated in this study may hold differing perspectives based on their access to resources and geographic location.

For the purposes of this study, participants were also only included if they identified as a parent (biological, adoptive, or foster) of a child or children with a formal diagnosis of ASD (or Autistic Disorder, Asperger's Disorder, or Pervasive Developmental Disorder – Not Otherwise Specified [PDD-NOS], all of which comprise ASD), as given by an appropriate health care professional (e.g., psychologist, psychiatrist, pediatrician). However, parental report of a formal diagnosis was not verified; such verification could have improved the rigour of the study design. However, it is believed that a confirmation of the child's diagnosis would not have altered the narratives and experiences shared by parents, and thus, it is unlikely that this limitation negatively impacted on the findings.

Although, data saturation was achieved, choosing to conduct this study in a descriptive phenomenological manner limited the number of participants who could participate and share their narrative around the concept of diagnosis disclosure. A quantitative methodology could have produced a much larger sample size, thus potentially expanding the ability to generalize these results across a larger population. While the significance of phenomenological research has been previously articulated, traditional terms such as reliability and validity cannot be measured in the same way, as people construct different meanings around their own experiences (Madill, Jordan, & Shirley, 2000). Although it is arduous to generalize conclusions based on the methodology utilized, the results that were garnered from this study have both future research and clinical implications for informing the decision-making process. The intent of this work is in the depth of understanding rather than quantitative notions of generalizability relative to population breadth. Accordingly, the results are context bound due to nature of this qualitative study and the use of purposeful, criterion-based sampling. It is important that these results are

taken with this context in mind, as they are intended to provide a greater understanding of the experience for these families.

Implications

This study has some noteworthy findings within an area of literature that is otherwise limited in its level of empirical investigation. The current study met its primary research aim, which was to explore the lived experience of parents relative to their decision-making process around whether or not to disclose their child's ASD diagnosis to the child. Findings suggest that the disclosure of an ASD diagnosis to a child is a complex process that often occurs over time and is impacted by the consideration of factors for and against disclosure, factors influencing a child's ability to understand disclosure, and a parent's experience of receiving and navigating the disclosure process.

Research implications and future directions. The findings of this study provide additional information to an otherwise limited empirical base around childhood diagnosis disclosure. This study offers detailed information around the lived experiences of parents who have both disclosed and not disclosed as a means to explore more deeply the decision-making process that parents engage in around disclosure to a child over time. One primary theme highlighted predominantly by disclosed parents is that the decision of whether or not to disclose a diagnosis to a child is very child and family specific. Parents often provided a caveat when offering advice to other families, indicating that parents know their child best, disclosure is not a *one size fits all* model, and children with ASD and their families will require unique approaches because every person and situation are different.

Further, there is a need for age- and developmentally-appropriate information and resources for parents as there is significant neurodevelopmental variance in phenotypic

presentation and cognitive level across individuals with ASD. This focus would place an even greater emphasis on the need for disclosure to occur with children with ASD as these children transition from childhood into adolescence and adulthood where vastly different expectations and supports will likely be needed and available, and parent support and mediation may potentially lessen as parents age and their support, over time, may be replaced by other caregivers. Therefore, knowledge of individuals' diagnosis presented in a developmentally appropriate way could potentially assist in their understanding of the diagnosis and who they are, and the development of a positive self-concept and identity within their environment (Huws & Jones, 2008), and ability for self-advocacy. Notwithstanding these considerations, every child, family, and situation is unique; therefore, the disclosure process is complex and many factors need to be considered.

Although there is more substantial information investigating parenting stress for those who have a child with ASD, and parental experiences with the diagnostic process, there is still a great need to investigate the experiences, fears, and stresses of families as they navigate the disclosure process to their child. Comparable to the wider literature base, parents often emphasized the importance of processing, understanding, and accepting their child's diagnosis before disclosure occurred. As fear was identified as a salient theme underlying much of the decision-making process, especially for non-disclosed parents, this could be considered as a future area of exploration. More specifically, as it has already been highlighted within the pre-existing literature that parents who have a child with ASD experience a higher level of stress than parents of children with other developmental disorders (Sanders & Morgan, 1997), particularly around decisions associated with caregiving (Huws et al., 2001), future research should explore potential means to reduce stress associated with disclosure. Particularly, as it was

identified by most parents that disclosure is often a series of conversations over time, a longitudinal study on the influence of long-term decision-making processes over time may be very influential.

There is also a great need to hear the voices of individuals themselves with ASD regarding how they learned about their ASD diagnosis and its impact on the self. This study did not seek to hear the narratives of the children/individuals represented, relative to diagnosis disclosure. Given that parents often expressed hesitancy and uncertainty, with underlying concern around how, when, and if disclosure should occur, it would be of great significance to hear the reflections from individuals to which disclosure happened and calibrate these experiences to parents' posture, preparedness and approach in disclosure. A similar descriptive phenomenological qualitative design could be employed with this group to explore the parallel process that individuals experience when learning about their ASD diagnosis. Specifically, individuals could be asked to share their own lived experience but then asked concrete questions around how and when disclosure occurred, what impact disclosure had on them as an individual, what they liked and disliked about the disclosure process, and recommendations for other families deciding whether or not to disclose an ASD diagnosis. However, it is important to consider that some challenges may arise when conducting future research of this topic. Particularly, this type of study may pose difficulties in participation for individual's dependant on their age, cognitive and developmental level, mode of communication, and overall understanding about their diagnosis.

Clinical implications. Although the findings from this study are very context specific and situational for the parents who participated, these results provide important points for professionals to consider when working with parents who have a child with ASD. The results

from this study continue to highlight the need for improvements in the diagnostic process, as parent's echoed previous research around an unsatisfactory diagnostic experience. Moreover, parents often indicated that they wished there was a greater basis for support upon initially receiving their child's diagnosis, and during their initial journey processing and researching ASD and disclosure. As it has been emphasized by parents that the disclosure process is complex and unique for each family and child; the findings would suggest that responding to requests for advice might be challenging. As the findings from this study and previous work by Duprey (2011) would suggest, parents experience disclosure at a unique pace, time, and process comfortable for themselves and their child. Accordingly, it will be important that professionals stay neutral when sharing opinions around whether or not to disclose. The findings from this study indicate that professionals could provide support to families by offering to share the experiences of others, helping parents to outline and process their reasons for and against disclosure, providing what resources are available around disclosure as a means to reduce parenting stress and if needed, and developing additional resources that do not currently exist around how, when, and what information should/should not be disclosed.

Conclusion

This study provided findings that help to fill a gap within the literature base on the topic of the decision-making process that parents engage in when trying to decide whether or not to disclose an ASD diagnosis to their child and, if so, the process of that disclosure. Ultimately, it would seem that the disclosure process can be unique to each family, with the underlying premise expressed by the majority of parents that there are many significant reasons for disclosure. Yet, many parents also experience fear and wonder if they are making the right decision. Specifically, many parents shared that if their child was aware of their differences and

asking questions, they deserved to learn about their diagnosis in a developmentally appropriate and child-friendly manner. Much of the narratives expressed by both participant groups was centered around their process or potential process for disclosure. Throughout their recounting of the disclosure process, many indicated that disclosure often started through conversations with their child, not using a label, and then continued as a series of conversations over time as their child asked questions and understood more about themselves and the world. All in all, many parents emphasized the importance and benefits of disclosure, completed in a compassionate and straight forward manner. However, parents continued to circle back to the notion that parents are the experts on their child(ren) and therefore have to make the decision, and complete disclosure (if they choose) in a manner that is best for their child and family.

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Appendix A – Recruitment Materials

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

Are you an individual with Autism Spectrum Disorder (ASD), a parent of a person with ASD, or a professional working in the field of ASD? If so, the Autism Spectrum Research, Education and Training team at the University of Calgary would really like to hear from you!

'The Elephant in the Room' project aims to examine if, how and when, parents disclose their child's ASD diagnosis to them, in addition to what went well/poorly, what resources they had or wish they had, and what advice they would give other parents.

Information will be collected through an online questionnaire. Three separate questionnaires have been developed in order to attain insight from:
1. Individuals with ASD
2. Parents of a child with ASD
3. Professionals working in the field of ASD

We thank you in advance for your willingness to help us with this important research! For links to the questionnaires please tear off a tab or use the scan code with your smart phone

This study has been approved by the Conjoint Research Ethics Board.

If you have any questions, we would be happy to hear from you at asert@ucalgary.ca

Yours sincerely,

Dr. Adam McCrimmon, Ph.D, R.Psych, Amanda Smith, MSc, and Sarah Cadogan, BA.
ASERT
Educational Studies in School Psychology
Werklund School of Education
University of Calgary
ucalgary.ca/asert/Discussion

The Elephant in the Room Project ucalgary.ca/asert/Discussion

Who is Eligible to Participate?

- We are looking for parents of children, adolescents, or adults with ASD to complete an online survey that will provide us with information regarding if, when, how, and why parents choose to or not to formally talk to their child about the ASD diagnosis.

- In addition, we are looking for professionals who work with children, adolescents, or adults with ASD to obtain information on their perspectives regarding talking to individuals with ASD about their diagnosis.

- Finally, we are interested in hearing from individuals with ASD about their experiences with being informed of their diagnosis. If you are an individual with ASD who is over the age of 18 and you would like to tell us about your experience please email us at smiad@ucalgary.ca and we will provide you with the link to the survey. If you are under the age of 18, please have a parent email us and we will provide the link to the survey to them for you to complete.

Research Team

Principal Investigator:
Dr. Adam McCrimmon
Assistant Professor
School and Applied Child Psychology
Faculty of Education
University of Calgary

Graduate Students:
Amanda Smith, M.Sc.
Sarah Cadogan, B.A.

For more information on participation in this study, please contact us at:

Phone:
Email:
Web: www.ucalgary.ca/asert/ **Discussion**

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

Appendix B – Consent Form

UNIVERSITY OF
CALGARY

Name of Researchers & Email:
Amanda Smith, M.Sc.
Sarah Cadogan, B.A.

Supervisor:
Dr. Adam McCrimmon, R.Psych, Educational Studies in School Psychology, University of Calgary
Dr. David Nicholas, RSW, Faculty of Social Work, University of Calgary

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

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, Dr. Adam McCrimmon 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, Dr. Adam McCrimmon. 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:

Dr. Adam McCrimmon, R. Psych.
Educational Studies in Psychology, Werklund School of Education
Tel:
E-mail:

If you have any concerns about the way you've been treated as a participant, please contact an Ethics Resource Officer at (403) 210-9863 or cfreb@ucalgary.ca.

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.

Appendix C – Online Survey

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 Dr. Adam McCrimmon, 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 Dr. McCrimmon at 403.220.7573 or awmccrim@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 Distress Centre, 403.266.HELP (4357) 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 403.210.9863 or cfreb@ucalgary.ca. 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,
Adam McCrimmon, Ph.D., R.Psych.

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:

Appendix D – 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:

PREAMBLE: Can you reflect on your perspectives of telling or not telling your child about their 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, if any, went 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 indicate 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?

    d. How do you think it would be different if you had not disclosed?

8. **If parent has not disclosed:**

    a. How do you think it would be different if you had disclosed?

    b. What do you think is the outcome of not yet disclosing?

9. What support(s), if any, might be helpful to parents in this process?

    a. Do you have any advice that you would give to other parents?

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

Appendix D – Non-Disclosed Participant Conceptual Framework

Common Theme Cluster 1 – Journey of Receiving the ASD Diagnosis	
	Theme 1.1: What's going on?
	Theme 1.2: Parent Experience of the diagnostic process
	Theme 1.3: Experience of finding out my child has ASD
Theme Cluster 2ND – Reasons for Non-Disclosure	
	Theme 2.1ND: Will there be a need?
	Theme 2.2ND: Labelling
	Theme 2.3ND: Don't want to give child an excuse
	Theme 2.4ND: Unwanted attention from others
Theme Cluster 3ND – Reasons for Disclosure Considered	
	Theme 3.1ND: Child asking questions
	Theme 3.2ND: Understanding
	Theme 3.3ND: Fear that they will find out another way
	Theme 3.4ND: Medical reasons
Theme Cluster 4ND – Potential Outcomes of Disclosure for Child	
	Theme 4.1ND: Parent perceived outcomes
	Theme 4.2ND: Uncertain of the response, understanding, or impact
Theme Cluster 5ND – Where are we now?	
	Theme 5.1ND: Conversations with child
	Theme 5.2ND: Parent feelings about the decision process
	Theme 5.3ND: Parental disagreement about disclosure
Theme Cluster 6ND – Decision about Disclosure in the Future	
	Theme 6.1ND: Not yet, but eventually
	Theme 6.2ND: We would disclose if child could understand
	Theme 6.3ND: Uncertainty
	Theme 6.4ND: Non-disclosure or the absence of a decision
Theme Cluster 7ND – What might our process be?	
	Theme 7.1ND: How to disclose
	Theme 7.2ND: When to disclose
	Theme 7.3ND: Supports

Appendix E – Disclosed Participant Conceptual Framework

Common Theme Cluster 1 – Journey of Receiving the ASD Diagnosis	
	Theme 1.1: What's going on?
	Theme 1.2: Parent experience of the diagnostic process
	Theme 1.3: Experience of finding out my child has ASD
Theme Cluster 2D - Leading up to Disclosure	
	Theme 2.1D: Planning and researching
	Theme 2.2D: Conversations without attaching a label
	Theme 2.3D: On the same page and accepting of the diagnosis
Theme Cluster 3D - Reasons for Disclosure	
	Theme 3.1D: Never thought not to disclose: It's not a secret
	Theme 3.2D: Just another part of who they are
	Theme 3.3D: Child was asking questions, and aware of their differences
	Theme 3.4D: Fear they would find out another way
Theme Cluster 4D - Process of Disclosure	
	Theme 4.1D: When disclosure occurred
	Theme 4.2D: How and the narrative of disclosure
	Theme 4.3D: Factors influencing child's understanding
	Theme 4.4D: Resources to support disclosure
	Theme 4.5D: Parent feelings about disclosure
Theme Cluster 5D - Advice to Others Considering Disclosure	
	Theme 5.1D: How parents present information
	Theme 5.2D: Normalize the process
	Theme 5.3D: Process, prepare, and access resources