The Experience of Receiving a Late Diagnosis for Autistic Young Adults

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The Experience of Receiving a Late Diagnosis for Autistic Young Adults

by

Taylor Schembri-Mutch

A THESIS
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Abstract

Autism spectrum disorder (ASD) is a neurodevelopmental disorder which presents with deficits in social communication and restricted, repetitive patterns of behaviour. ASD is estimated to occur in 1 in 59 individuals, with the average age at diagnosis being 53 months. Yet, many individuals are missed as children and diagnosed later in life. As a result, adults are now diagnosed more often than youth and/or children. Despite this, little is known about the experience of receiving a late ASD diagnosis. A qualitative inquiry was conducted to better understand the experience of diagnosis and what it is like to be undiagnosed vs. diagnosed with ASD. Eight participants were interviewed and their responses analyzed using interpretive phenomenological analysis. Results identified 29 themes across three different levels. Level 1 themes represented pre-diagnosis and post-diagnosis timeframes and were broken down into Level 2 themes. The pre-diagnosis Level 2 themes were circumstances leading to diagnosis, hidden diagnosis, alternative identities, and potential negative outcomes of not having an ASD diagnosis while the post-diagnosis Level 2 themes were settling into diagnosis, potential benefits of receiving an ASD diagnosis, potential negative outcomes of an ASD diagnosis, and desires. Some Level 2 themes were further broken into more detailed Level 3 themes which communicated the nuances in experiences for each of the participants.

Keywords: autism spectrum disorder (ASD), diagnosis, qualitative research, adults
Preface

This dissertation is original, unpublished, independent work by the author, T. Schembri-Mutch. The experiments reported in Chapters 1-5 were covered by Ethics Certificate number REB 18-1302, issued by the University of Calgary Conjoint Faculties Research Ethics Board for the project “The Experience of Late Diagnosis for Young Adults on the Autism Spectrum” on July 08, 2019.
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I would also like to acknowledge the role my dogs have played in the completion of this dissertation. To Chowie and Blue, thank you for all the hours you spent sitting beside me as I continually wrote, edited, and re-wrote every portion of this dissertation. Chowie, you have been present for all my degrees. You almost did not make it to the end of this dissertation, but fortunately your fighting spirit prevailed and you encouraged me to type on.

Lastly, and most importantly, I give thanks to my husband who has supported all my academic dreams from the very beginning. You put your career on hold to prioritize mine and you picked up and moved your entire life to be with me during internship. I am forever grateful to have found such a wonderfully understanding spouse to spend the rest of my life with.
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Potential negative outcomes of not having an ASD diagnosis

Falling through the cracks

Negative treatment experiences

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This dissertation is a qualitative investigation of the experience of receiving a late diagnosis for autistic young adults. One of the main goals of this dissertation is to allow autistic adults the opportunity to share their first-hand perspectives regarding receipt of their autism spectrum disorder (ASD) diagnosis. This first chapter provides an overview of the dissertation, while chapters two, three, four, and five discuss the literature review, methods, results, and discussion sections, respectively.

This chapter provides a brief introduction to differing views regarding diagnosis. It defines key terms used throughout the dissertation and briefly describes ASD and its relation to diagnosis. A rationale for the current study is then provided, followed by the research purpose and objectives. Next, the study’s significance and implications are discussed. In alignment with qualitative traditions, the researcher’s interest, assumptions, and experience are presented as related to the current study. The chapter then concludes with an overview of the dissertation and its successive chapters.

**Definition of Terms**

To enhance clarity and understanding throughout the reading of this dissertation, relevant key terms are defined below.

(1) *diagnosis* – For the purposes of this investigation, a diagnosis will be defined as the formal identification of a condition via a diagnostic title associated with a particular symptom cluster and other diagnostic criteria.

(2) *mental disorder* – For the purposes of this study, the term mental disorder will be used to describe any diagnosis defined as such in the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5; APA, 2013).*
(3) **neurodevelopmental disorder** – Neurodevelopmental disorders are defined by the APA (2013) as a group of conditions that manifest during the developmental period and which are characterised by personal, social, academic, and/or occupational impairments in functioning.

(4) **autism spectrum disorder (ASD)** – ASD is a neurodevelopmental disorder characterized by deficits in social communication and interaction, in combination with the presence of restricted, repetitive patterns of behaviour, interests, or activities (APA, 2013).

(5) **experience** – This term references phenomena that a participant has encountered outwardly or undergone internally.

(6) **late diagnosis** – For the purpose of this study a late diagnosis will be defined as a diagnosis that was received at or after age 12.

(7) **identity-first language** – A language style in which the disability precedes the personhood-noun, such as autistic person (Gernsbacher, 2017). This language style is used throughout the dissertation, as evidence demonstrates that it is preferred by the majority of autistic individuals (see CASDA, 2020; Sinclair, 1999)

**Views on Diagnosis**

Various disciplines in psychology have differing views regarding diagnosis, which has resulted in tension between the disciplines. Awareness of this tension and the differing views regarding diagnosis in the field of psychology are important because they can influence clinical practice. Reasons for and against diagnosis often include arguments related to the medical model, language use, service access, pathologization, and stigma. While individual practitioners
can acknowledge the benefits and consequences of diagnostic practice, it is useful to examine opposing interpretations and persuasions to gain a better understanding of the divergent views.

Those in support of diagnostic labelling often note that the medical model provides a language system that allows for efficient communication of clinical concerns (Ben-Zeev et al., 2010; Strong, 2012; Volkmar & Reichow, 2013). A well-known and frequently used diagnostic tool, the *Diagnostic and Statistical Manual of Mental Disorders (DSM)*, was designed to improve communication regarding different types of conditions (APA, 2013). This language system has also improved research utility by grouping disorders by associated symptoms, which contributed to the development of evidence-based approaches to treatment for those disorders (Ben-Zeev et al., 2010; Strong, 2012). Access to services and funding opportunities is another strong argument for diagnostic labelling as they are often dependent on official diagnoses.

Those against diagnostic labelling often cite concerns regarding the over-pathologization of human behaviour via diagnostic labels. Application of the medical model in the field of psychology implies that the individual with a diagnosis is disordered and thus efforts should be undertaken to ameliorate that disorder (Wakefield & Schmitz, 2010). This focus neglects to consider environmental, sociocultural, and sociopolitical sources of impairment (Sinacore-Guinn 1995; Strong, 2012). Other arguments against diagnostic labelling question and critique the pathologization of natural human concerns (Elkins, 2009; Strong, 2012) and variations or eccentricities in the human condition (Ben-Zeev et al., 2010). Still other arguments focus on the subjectivity of psychological diagnoses as there are no laboratory tests that can identify mental disorders (Rogler, 1997; Wakefield & Schmitz, 2010). Lastly, arguments regarding stigma and labelling are often used to refute diagnostic practice as it has been reported that diagnoses can have catastrophic effects on those diagnosed (Ben-Zeev et al., 2010; Milton, 2012).
Mental Health and Mental Disorder

Much of the tension regarding the benefits and consequences of diagnosis has arisen within the mental health field, and many of these arguments can be applied to different clinical populations and mental disorders. Concerns regarding labelling, stigma, and service access are applicable across diagnoses, including ASD. Although ASD is classified as a neurodevelopmental disorder in both the DSM-5 (APA, 2013) and the International Classification of Diseases (ICD; WHO, 2019), it is still considered a diagnostic entity. Further, ASD has been linked to poorer mental health outcomes, with high incidences of co-occurring mental health disorders (Eaves & Ho, 2008; Howlin & Moss, 2012; Stewart et al., 2006), making the link between ASD and mental health more apparent.

While research has been conducted on the process of diagnosing ASD (i.e., Baird et al., 2011; Bastiaansen et al., 2011; Howlin & Moore, 1997), little research has focused on the experience and/or meaning of diagnosis for autistics. Researchers have reported that receiving an ASD diagnosis in adulthood can have a substantial emotional impact (Huang et al., 2020); yet we lack an understanding of this impact and how it relates to labelling, stigma, and service access. Further, Bailey (2019) indicated that there is often a reluctance to both give and receive an ASD diagnosis in adulthood, despite some autistic individuals preferring a diagnosis (Schembri, 2017). Given this range of perspectives in the literature and practice, there is a need to investigate what diagnosis means to autistic individuals.

Autism Spectrum Disorder

ASD is a neurodevelopmental disorder that presents with varying symptomology and degrees of impairment (Morrison, 2004). According to the DSM-5, autistic individuals present with persistent deficits in social communication in combination with restricted, repetitive
patterns of behaviour (APA, 2013). ASD was originally termed Kanner’s syndrome and included an inability to form social relationships, with an insistence on sameness (Kanner, 1943). Since this initial conceptualization, the concept of ASD has undergone many revisions and is now represented as a spectrum disorder. ASD is often diagnosed through comprehensive diagnostic evaluation (Adreon & Durocher, 2007; CDC, 2015) and is currently estimated to occur in 1 in 59 individuals (Baio et al., 2018). This prevalence rate is much higher than previous estimates, which is due in large part to changes in awareness and conceptualization (CDC, 2012; 2014; King & Bearman, 2009; VanBergeijk et al., 2008). Further, clinicians are now better able to identify and diagnose autistic individuals who present without intellectual disability (Adreon & Durocher, 2007). While the average age at diagnosis is 53 months (CDC, 2014), many individuals are missed as children and instead diagnosed later in life. In fact, adults are currently being diagnosed more often than youth and/or children because our ability to identify those previously missed is increasing (Bailey, 2019).

Available research pertaining to ASD and diagnosis indicates that concerns regarding stigma and access to services are widespread. Stigma is a prominent concern for autistic individuals and it has been found that others can hold negative attitudes towards autistic people (Mogenson & Mason, 2005). Concerning stereotypes associated with ASD include beliefs that individuals are odd and/or dangerous and that they cannot marry, work, or obtain an education (Kinnear et al., 2016; MacLeod et al., 2013). However, an ASD diagnosis may in some cases reduce stigma by providing a frame of reference to understand the diagnosed (Butler & Gillis, 2011; Schembri, 2017). Additionally, parents of autistic children reported that an ASD diagnosis afforded access to services for their children (Abbott et al., 2012; Shattuck & Grosse, 2007), which has resulted in clinicians reporting pressure to provide diagnoses so clients can receive
interventions (Hodge, 2005; Shattuck & Grosse, 2007). As such, there are a mix of benefits and other consequences to receiving an ASD diagnosis (Calzada et al., 2012; Haertl et al., 2013).

Research Aims

This research aimed to invite autistic individuals to participate as experts in their own lives by asking them to contribute their first-hand experiences in receiving an ASD diagnosis. This aim was met in two ways. First, individuals were asked to participate in one-on-one interviews to share their experiences with the researcher. Second, they were asked to participate in member checking to confirm the researcher’s interpretation of their exemplars. The researcher felt compelled to include autistic individuals in her research because first-hand perspectives of autistic individuals have not traditionally been sought or amplified. Instead, the focus has often been on investigating the ideas and opinions of family members, care providers, and/or clinical researchers (DePape & Lindsay, 2016; Nicolaidis et al., 2019). Further, autistic adults have expressed dissatisfaction in being disregarded as experts in their own lives (Gillespie-Lynch et al., 2017; MacLeod et al., 2013; Nicolaidis et al., 2019), which has prompted new research trends that advocate for the inclusion of autistic individuals (Canadian Autism Spectrum Disorder Alliance, 2020; Nicolaidis et al., 2019; Pellicano et al. 2018) in ASD-based research.

Another aim of this research was to gain an understanding of the dual perspectives of what it is like to be undiagnosed vs. diagnosed with ASD. The only way to glean an understanding of both these perspectives is to ask people who have received a late diagnosis as only they know what it is like to have undiagnosed ASD while still experiencing ASD symptoms and then receive said diagnosis. These same individuals can also share their experience of receiving an ASD diagnosis and what that diagnosis means to them. As such, the following research questions form the basis of this investigation: (1) What is the experience of a late
What does a late ASD diagnosis mean to those who receive one?

**Significance and Implications**

This research can benefit autistic individuals and those who work with them. By understanding the experience of receiving a late ASD diagnosis for autistic young adults, it is possible to examine personal perspectives regarding diagnosis. Understanding how autistic individuals perceive and relate to their diagnosis can contribute to the current literature regarding the utility of diagnosis. Further, it may be possible to decrease the number of individuals who experience self-stigma or other challenges in relation to their diagnosis while also improving the appropriateness of assessment and intervention supports and services provided to this population. Ideally this research will contribute to the literature regarding diagnosis, which has been considered stigmatizing (Ben-Zeev et al., 2010), with some professionals advocating for a reduction of diagnostic practice (e.g., Khoury et al., 2014). This study is also significant for the field of counselling psychology as it sheds light on divergent views on diagnosis in the field.

**Dissertation Overview**

Chapter two of the dissertation begins with a review of current views on diagnosis. These views are then related to ASD, with a thorough definition and discussion of the condition. Use of language with autism populations is also highlighted. Chapter three then discusses the research methodology and methods for the present study. Smith et al.’s (2009) interpretive phenomenological analysis (IPA) and its use are explained. Chapter 4 delineates the results of the study and chapter 5 concludes the dissertation with a discussion of the findings in light of the existing literature. Research implications, study limitations, and suggestions for future research are also emphasized.
CHAPTER 2: LITERATURE REVIEW

This chapter seeks to highlight the different perspectives regarding diagnosis and diagnostic labelling in the field of psychology. This chapter introduces ASD by reviewing its history, how it is identified, use of language, and its incidence rates. A review of the literature pertaining to ASD and diagnosis is followed by a focus on stigma and access to services. As limited literature investigates first-hand perspectives of autistic individuals (DePape & Lindsay, 2016), the review synthesizes available literature while making efforts to include first-hand perspectives whenever available.

Current Views on Diagnosis

The various disciplines in psychology (e.g., clinical, counselling, school, health, industrial/organizational) hold differing views on the purpose, role, impact, and utility of clinical diagnosis, which has resulted in tension within the broader field of psychology. Awareness of these views can influence clinical practice and the supports/services provided to clients. The differing views on clinical diagnosis have been well explored in the field of mental health; as such, this review will focus on this perspective.

Many mental health practitioners find diagnosis to be useful and beneficial (e.g., Robertson & McDonald, 2015), though others believe it to be a detriment with profound negative consequences such as stigma and labelling (e.g., Ben-Zeev et al., 2010; Eriksen & Kress, 2005). Some have even called for a broad reduction in diagnostic practice across different clinical labels (e.g., Khoury et al., 2014). However, many practitioners are located in between these opposing views and acknowledge the various potential outcomes of diagnostic practice. This section of the review will highlight some of these perspectives by discussing the medical model, stigma and labelling, and access to services.
Medical Model

It is difficult to discuss the conceptualization of diagnosis without first considering the medical model. Although reference to the medical model is pervasive in psychology, many psychologists have struggled to define it (Elkins, 2009). The medical model, also known as the disease model, has been defined as “a model of health which suggests that disease is detected and identified through a systematic process of observation, description, and differentiation, in accordance with standard accepted procedures, such as medical examinations, tests, or a set of symptom descriptions” (Swaine, 2011, p. 114). Additionally, Elkins (2009) suggested that the medical model is used in psychological contexts to diagnose an individual based on symptoms and then select a treatment designed to cure that individual of their illness. Using the medical model and the term disorder implies that there is a dysfunction within the individual that results in impairment and that this dysfunction should be cured (Wakefield & Schmitz, 2010).

Essentially, this perspective regards disorders as conditions in need of elimination or at the very least remediation.

By describing symptoms and disorders, the medical model offers an efficient way for clinicians to communicate clinical concerns by creating a language system that identifies and classifies diagnostic entities (Ben-Zeev et al., 2010; Strong, 2012; Volkmar & Reichow, 2013). Diagnostic systems have been created to identify and label different mental disorders to aid with this language system. In fact, the DSM was initially designed “to improve communication about the types of patients cared for” (APA, 2013). Two of the most well-known diagnostic tools available to psychological practitioners in North America are the DSM and the ICD, which are used to classify “mental disorders” (APA, 2013, p. xli) and “diseases, disorders, injuries and other related health conditions” (WHO, 2019, para. 6), respectively. The DSM has emerged as
the “standard reference for clinical practice in the mental health field” (p. xli), at least in North America, and the *ICD* has served as the “foundation for the identification of health trends and statistics globally” (WHO, 2019, para. 2) in much of the rest of the world. The language system provided by the medical model, and in part by these diagnostic classification systems, can be utilized by individuals who wish to share their conditions and associated symptoms with others, and by psychologists when communicating with other professionals (Larsson et al., 2012; Robertson & McDonald, 2015; Strong, 2012). The medical model has also been viewed as beneficial to the field of psychology, and has served as a universal language system that has provided research utility by defining disorders and their associated symptoms that in turn has supported efforts to develop evidence-based approaches to treatment (Ben-Zeev et al., 2010; Strong, 2012).

Although the medical model is widely used, it is not without criticism. According to Swaine (2011), there are three main criticisms of the medical model:

(1) it supports the false notion of dualism in health, whereby biological and psychological problems are treated separately; (2) it focuses too heavily on disability and impairment rather than on an individual’s abilities and strengths; and (3) it encourages paternalism within medicine rather than patient empowerment. (p. 114)

Like Swaine, some clinicians and researchers, including counsellors and counselling psychologists, have been cautious about use of the medical model. Counselling psychologists have often rejected the medical model and its focus on psychopathology because this perspective can clash with the views of practitioners who believe that an individual’s concerns do not occur in isolation and instead can exist outside of a person, between persons, and within them (Sinacore-Guinn 1995; Strong, 2012). Further, some practitioners believe that the medical model
detracts from the view of the person that encapsulates the environmental, sociocultural, and sociopolitical causes contributing to distress (Sinacore-Guinn, 1995). Strong (2012) also noted that the medical model can conflict with psychologists’ theoretical orientation and approach to treatment. For example, narrative practitioners, who talk in discourses and constructed perspectives rather than in terms of diagnosis, and treatment protocols have found it difficult to account for clients’ concerns in labelling terms that reference symptoms and diagnoses. Additionally, family therapists focus on the family as a dynamic social system rather than individuals in isolation.

Both Elkins (2009) and Strong (2012) have questioned the pathologization of natural human concerns (e.g., bereavement) and have claimed that medicalization of these concerns changes the way we understand and address them. This falls in the tradition of Thomas Szasz, which goes as far back as the 1960s. Ben-Zeev et al. (2010) also spoke against pathologizing language being used to frame common human behaviours, arguing that not all eccentricities related to affect, interpersonal functioning, and/or coping should be regarded as disorders. Rogler (1997) emphasised this point by highlighting the impact that social norms and research trends have on diagnostic criteria. Kawa and Giordano (2012) supported this statement and reminded readers that homosexuality was a diagnosable DSM condition that is now viewed as a normal variation of sexual orientation and not a pathology. Wakefield and Schmitz (2010) have further referenced the evolving editions of the DSM and ICD in which new disorders are identified, old ones are abandoned, and previously existing ones are merged into new categories as additional support for the perspective that some diagnostic criteria are socially constructed. The authors also noted that drastic changes in incident rates (see Kessler et al., 2005) of mental disorders cannot be fully explained by changing DSM criteria and instead may have something to do with
the way a disorder is measured by specific people at specific times. Of course, incident rates
could also reflect societal changes in stressors and mental health.

Although a universal language system has helped describe certain groups of people and
their associated concerns, there is a certain amount of subjectivity in the identification and
labelling of mental disorders. Unlike pure laboratory tests that are used to identify physical
conditions to a relative degree of certainty (e.g., a pregnancy test), the identification of mental
disorders is often subjective (Rogler, 1997), meaning that determination of a diagnosis is
dependent on various factors. This lack of certainty or positive confirmation regarding of the
presence of a mental disorder has brought the field of psychology under much scrutiny. In
Wakefield and Schmitz’s (2010) book chapter regarding the measurement of mental disorders,
the authors stated that there is no gold standard that can be used to identify the true presence of a
mental disorder and that we must instead make judgements based on available symptomology.
The authors further noted that the understanding of what differentiates a mental disorder from
normal everyday distress is unclear, as each diagnosis has arbitrary boundaries. Moreover,
conceptual validity of diagnoses is difficult to obtain because some symptoms present in
response to environmental stressors as well as to genuine mental disorder (e.g., symptoms of
sadness can occur in both depression and grief), resulting in false positives for diagnoses.

**Stigma and Labelling**

While arguments have been made for and against the medical model, Ben-Zeev et al.
(2010) offered an argument against diagnostic practice based on stigma and labelling. The
authors claimed diagnoses can have catastrophic effects on personal identity due to the stigma
surrounding them. Milton (2012) agreed with Ben-Zeev et al. and noted “to be defined as
abnormal is potentially to be seen as 'pathological' in some way and to be socially stigmatised, shunned, and sanctioned” (p. 885).

Three types of stigma regarding mental illness have been identified: public-stigma, self-stigma, and label avoidance (Corrigan et al. 2004; Corrigan & Watson, 2002). Public-stigma occurs when groups sanction a stereotype against a different group of people, whereas self-stigma refers to a loss of self-esteem and self-efficacy resulting from internalized public-stigma (Ben-Zeev et al., 2010; Corrigan & Watson, 2002). Label avoidance occurs when people fail to seek out mental health services to avoid being assigned a stigmatizing label (Ben-Zeev et al., 2010). Diagnoses can lead to public-stigma when a negative belief/stereotype about a group exists (e.g., people with mental disorders are dangerous) that can progress to prejudice when agreement with the negative belief results in an emotional response (e.g., fear) and then ultimately to discrimination when there is a behavioural response to that emotion (e.g., not hiring people with mental disorders out of fear; Corrigan & Watson, 2002). Based on Corrigan & Watson’s (2002) conceptualization, public-stigma occurs when specific beliefs about groups are present and then acted upon. However, Ben-Zeev et al. (2010) pointed out that since diagnosis is a classification initiative, being assigned a diagnostic label groups people together and opens them up for stereotyping.

While the impact of public stigma related to mental health concerns is damaging, the impact of self-stigma can be just as great (Ben-Zeev et al., 2010). Corrigan and Watson (2002) have stated that public-stigma can transition to self-stigma if it is perceived that the negative response to their diagnostic label is legitimate. The authors further suggested that collective representations (i.e., cultural stereotypes, sociopolitical ideology, and the perceived place of the diagnostic group in society) have influenced the appraisal of stigma in specific circumstances.
The authors acknowledged that public-stigma does not always translate to self-stigma; in fact, some people have resisted self-stigma by forcefully reacting to public-stigma as a social justice issue. Regardless, others believe that diagnostic labels historically hurt individuals by encouraging self-fulfilling prophecies when people agree with the negative stereotypes surrounding their diagnostic label. This self-prejudice can then result in behavioural responses such as failing to pursue work or housing opportunities (Corrigan & Watson, 2002; Eriksen & Kress, 2005).

While Ben-Zeev et al. (2010) have expressed substantial concerns regarding the stigma associated with diagnostic practice, they also acknowledged that some diagnostic labels can offer reprieve, normalization, and a shared sense of community for those with similar conditions. Mogensen and Mason (2015) supported this statement when they concluded that an ASD diagnosis can be liberating as it has enabled those who have been diagnosed to understand themselves better by gaining personal insight, reframing problems, and highlighting a common identity with others. Schembri (2018) replicated similar findings in an unpublished case study of attention-deficit/hyperactivity disorder (AD/HD) in which it was indicated that the AD/HD diagnosis allowed the participant to better understand herself and her limitations. These findings seemingly counter some of Ben-Zeev et al.’s (2010) initial concerns about self-stigma and support notions that diagnoses may provide individuals with a frame of reference for understanding themselves.

Access to Services

Another benefit provided by diagnosis is access to funding and non-financial supports (e.g., accommodations, equipment, supports at school/work/in the community, sick leave, and disability benefits). Diagnostic labels have assisted clients in accessing services and funding that
are dependent on specific clinical labels (MacCulloch, 2010). As a researcher and clinician, the writer can attest to the truthfulness of this statement in a Canadian context as she has worked in environments where clients needed a formal DSM diagnosis to access free mental health services and treatments. As psychological services are generally not a free health service for individuals in Canada (Domene & Bedi, 2013), access to funding and services can be of utmost importance to clients and practitioners. Further, many clinicians have noted clients needed to receive treatment for identifiable diagnoses to obtain financial reimbursement from insurance providers (Eriksen & Kress, 2005; 2006; Sinacore-Guinn, 1995; Strong, 2012). Since a lack of finances has presented a barrier to accessing psychological services, disengagement from the medical model, and therefore diagnostic labelling, can create financial barriers for clients. MacCulloch (2010) further cautioned against the use of diagnostic labels as gatekeepers to services and claimed that such an approach allows diagnostic tools such as the DSM to determine who can and cannot access services while simultaneously disempowering practitioners from deciding who needs care and intervention services.

**Mental Health to Mental Disorder**

While there is disagreement regarding diagnosis in the field of mental health, one can see how some of these arguments are relevant to numerous clinical populations, including those outside the field of mental health. Use of the medical model, concerns regarding stigma and labelling, and access to services are all valid considerations that can be applied to a variety of different clinical diagnoses/mental disorders and are of relevance to the current study. Although ASD is considered a neurodevelopmental rather than a mental health disorder, it is useful to examine the different perspectives on assigning an ASD diagnosis.
ASD is a diagnostic entity in both the *DSM* and *ICD*, which are considered the standards of reference for diagnostic practice in the field of mental health (APA, 2013; WHO, 2019). Further, autistic individuals have been found to have poorer mental health outcomes, with high incidences of co-occurring mental health concerns when compared to non-ASD populations (e.g., Eaves & Ho, 2008; Howlin & Moss, 2012; Stewart et al., 2006), making the link between ASD and mental health rather apparent.

The majority of ASD research has focused on the biology and/or causes of autism (Pellicano et al., 2018) while neglecting the first-hand experiences of autistic individuals as being worthy of investigation (Gillespie-Lynch et al., 2017; Milton, 2012). Some research has been conducted on the diagnostic process to understand how to diagnose ASD efficiently and effectively (i.e., Baird et al., 2011; Bastiaansen et al., 2011; Howlin & Moore, 1997). Yet, scant research has focused on the *experience* and/or meaning of diagnosis for this population. Available research has indicated that receiving an ASD diagnosis in adulthood has a significant emotional impact (Huang et al., 2020), but we lack an understanding of this impact and how it may relate to previously mentioned topics such as stigma and access to services. Despite the misgivings of some clinicians around providing ASD diagnoses (Bailey, 2019), some research findings indicate that autistic individuals may prefer a diagnosis (i.e., Schembri, 2017). As such, there is a need to investigate what diagnosis means to autistic individuals. Accordingly, the history of ASD, its current clinical description, incidence rates, and the concept of receiving an ASD diagnosis later in life will be discussed.

**Autism Spectrum Disorder**

ASD is a neurodevelopmental disorder with highly varying degrees of impairment and manifestation (Morison, 2014). To be diagnosed as autistic via the *DSM*, an individual must
present with both “persistent deficits in social communication and interaction across multiple contexts” and “restricted, repetitive patterns of behaviour, interests, or activities” (APA, 2013, p. 50). While the deficits in social communication must be manifested through impairments in social-emotional reciprocity, nonverbal communicative behaviours, and peer relationships, the restrictive/repetitive patterns of behaviours can manifest through motor movements, insistence on sameness, fixated interests, or hyper-/hyporeactivity to sensory input (APA, 2013). According to the *DSM-5*, the severity level of the social communication impairments and the restricted, repetitive behaviours must be specified when diagnosing ASD (APA, 2013).

**History of ASD**

In 1943, autism was initially termed Kanner’s syndrome and described as an inability to develop social relationships with an accompanying insistence on sameness (Bowler, 1992; Kanner, 1943). Since then, the labelling and conceptualization of Kanner’s syndrome has evolved to include terms such as early infantile autism, Asperger’s syndrome/disorder1, autistic disorder, pervasive developmental disorder, and ASD. These changes have emerged from new realizations regarding the causation, manifestation, identification, and treatment of ASD as reflected in the consecutive editions of the *DSM* (APA, 1980; 1994; 2000; 2013) and *ICD* (WHO, 1978; 2016; 2018) frameworks.

Prior to the publication of the *DSM-5* (APA, 2013), autism was identified as one of five pervasive developmental disorders defined as a “severe and pervasive impairment in several areas of development: reciprocal social interaction skills, communication skills, or the presence of stereotyped behaviour, interests, and activities” (APA, 2000, p. 69). This conceptualization

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1 While Asperger’s is referred to as a disorder in the *DSM*, it is referred to as a syndrome in the *ICD*. This dissertation utilizes both terms to encapsulate both terminologies.
included autistic disorder, Asperger’s disorder, and pervasive developmental disorder – not otherwise specified (PDD-NOS); it also extended to conditions such as Rett’s disorder and childhood disintegrative disorder (CDD). As Rett’s disorder and CDD are no longer considered part of the autism spectrum, they will not be discussed here. However, autistic disorder, Asperger’s disorder, and PDD-NOS are understood to be part of the autism spectrum and will be reviewed briefly.

According to the *DSM-IV*, autistic disorder was defined as a profound impairment in social interaction and communication skills, with a restriction in interests and activities and the presence of restricted, repetitive, and/or stereotyped patterns of behaviour (APA, 2000). Asperger’s disorder was introduced in the *DSM-IV* (APA, 2000) as a distinct disorder characterized by impairments in social interaction, with accompanying restricted patterns of behaviour, interests, and/or activities (VanBergeijk et al., 2008). Although the two diagnoses were viewed as falling under the same umbrella of pervasive developmental disorders, the key diagnostic difference was the lack of marked impairments in communication skills, self-help skills, and cognitive impairment in Asperger’s disorder (Safran, 2001). Lastly, PDD-NOS was conceptualized as a severe and profound impairment in at least two criteria affecting social interaction, communication skills, or stereotyped behaviours that were atypical or subthreshold for another diagnosis (APA, 2013).

As the differences between these three disorders were often challenging to appreciate clinically, debate arose as to whether they could be differentiated reliably and whether they represented unique conditions (Safran, 2001). As a result of this debate and careful review of the literature, the disorders were unified under an autism spectrum framework (Hofvander et al., 2009) in the *DSM-5* and *ICD*, meaning the disorder is considered to affect individuals differently
and to varying degrees. The spectrum terminology refers to a range of criteria presentations and a continuum of symptoms varying from mild to severe (Adreon & Durocher, 2007). As indicated in the opening of this section, the current *DSM-5* diagnostic criteria for ASD specify that an individual must present with “persistent deficits in social communication and social interaction across multiple contexts” as demonstrated by impairments in social-emotional reciprocity, nonverbal communicative behaviours, and ability to make and maintain peer relationships (APA, 2013, p. 50). Individuals must also currently, or by history, demonstrate at least two of four specified “restricted, repetitive patterns of behaviour, interests, or activities” (APA, 2013, p. 50).

**Identification of ASD**

An ASD diagnosis is usually reached through comprehensive diagnostic evaluation and developmental screening completed by specialists (e.g., psychologists; developmental pediatricians; neurologists; psychiatrists) or interdisciplinary teams of professionals from various specialties (e.g., psychology, medicine, speech-language pathology, occupational therapy; Adreon & Durocher, 2007; CDC, 2015). ASD diagnoses are also commonly informed by clinical tools (e.g., structured observation, interview, and/or rating scales). In general, a comprehensive ASD assessment should include investigation of: (a) core autism signs and symptoms (i.e., diagnostic criteria); (b) early developmental history; (c) any relevant behavioural concerns (d) home and community functioning; (e) physical and mental health history; (f) other neurodevelopmental conditions; and (g) sensory differences (National Institute for Health and Care Excellence, 2014).

**Incidence Rates**

ASD is currently estimated to occur in approximately 1 in 59 individuals according to U.S. statistics (Baio et al., 2018), which demonstrates a dramatic increase in occurrence
compared to prior estimates that placed prevalence at 1 in 69 (CDC, 2014) and 1 in 88 (CDC, 2012). While many factors have contributed to increased prevalence rates, changes in awareness and conceptualization of ASD have been paramount (CDC, 2012; 2014; King & Bearman, 2009; VanBergeijk et al., 2008). Changes in diagnostic practice have also increased incidence by improving clinician ability to identify autistic individuals who do not have intellectual disability and who may have been previously overlooked (Adreon & Durocher, 2007). However, it is also possible that environmental conditions have contributed to increased prevalence.

**Age at Diagnosis**

Although the average age at diagnosis is 53 months (CDC, 2014), many autistic individuals are identified later in their lives. This is because changes to diagnostic criteria and the way we view ASD have allowed us to identify individuals who were missed as children (Bailey, 2019; Huang et al., 2020). In fact, adults are currently being diagnosed more often than children or adolescents (Bailey, 2019). Lai & Baron-Cohen (2015) referred to these individuals as the “lost generation” as they went undiagnosed until adulthood, largely because adults often experience barriers to accessing diagnoses. However, Bailey (2019) has also claimed that some individuals go undiagnosed due to a reluctance to either give or accept an ASD diagnosis.

Individuals who are diagnosed later in life tend to have less severe forms of ASD, often without significant language impairments or intellectual disability (Bailey, 2019; Emerson, 2016). Thus, it is logical to conclude that the experience of ASD for those diagnosed later in life will differ from those who were diagnosed earlier in life or who have more severe presentations. Individuals who are diagnosed later in life are a unique population as they have experienced longer periods of time without an ASD label despite presenting with signs and symptoms of ASD during much of their lives. As such, these individuals can provide a unique perspective
regarding what it is like to receive an ASD diagnosis, what that diagnosis means to them, and how that diagnosis has affected their life. Individuals who are diagnosed early in life will have a limited ability to remember and reflect on the time in their life before the diagnosis and are therefore not able to provide this unique perspective.

Use of Identity-First vs. Person-First Language

The use of language in reference to clinical conditions has been a source of poignant discussion. As Kenny et al. (2015) noted, “the language we use has the power to both reflect and to shape people’s perceptions” (p. 1). The use of language to describe groups of people has been such a pressing matter that advocacy groups and psychological associations have set standards for the use of such language when referring to different groups of people (e.g., APA, 2010, 2020; Kenny et al., 2015). However, recent publications have re-visited this conversation with different findings (e.g., Gernbacher, 2016, 2017; Kapp et al., 2012; Kenny et al., 2015). According to Gernsbacher (2017), person-first language is defined as “the structural form in which a noun referring to a person or persons (e.g., person, people, individual, adults, or children) precedes a phrase referring to a disability (e.g., person with a disability)”, whereas identity-first language occurs when “the disability, serving as an adjective, precedes the personhood-noun (e.g., disabled person)” (p. 759).

In 2010, the APA’s Publication Manual indicated that researchers should be sensitive to labels and suggested that one way this could be accomplished was to “put the person first.” It was specifically noted that this solution was “preferred when describing people with disabilities” (p. 72). According to Gernsbacker (2017), person-first language was supposed to be used with all groups of people to denote linguistic equality between different groups of individuals – disabled or not. However, it was found that person-first language was used more frequently to refer to
those with disabilities than to those without disabilities, and thus negated the chief purpose of person-first language (Gernsbacher, 2017). It was also used most often when referring to those with more stigmatized disorders (i.e., neurodevelopmental disorders; Gernsbacher, 2016). For example, person-first language was used to refer to intellectually disabled individuals 93% of the time and autistic individuals 75% of the time; however, it was used to refer to gifted individuals less than 1% of the time (Gernsbacher, 2016).

In terms of the autism community, Kenny et al. (2015) noted there is disagreement on how autism should be described that is complicated by changes in the conceptualization of ASD and the way it is perceived and understood, in addition to differences in people’s social and ideological beliefs about ASD. As a result of this disagreement, Kenny et al. polled 3470 autism community members in the United Kingdom to discern which terms are preferred to describe autism; the most highly endorsed terms were “autism”, “on the autism spectrum”, and to a lesser extent “autism spectrum disorder” (p. 5). Kenny et al. also found that the way in which one was associated with autism influenced the preferred terminology. The term “autistic” was endorsed more often by autistic adults and family members/friends, while “person with autism” was endorsed more often by professionals (p. 5). Kenny et al. also found that among autistic adults, autism is viewed as inseparable from the person and therefore identity-first language was preferred. Autistic adults also took a disorder vs. difference approach to autism conceptualisation where they viewed autism as a different way of seeing the world but still acknowledged that having a disability allows them to access services within a neurotypical-centric world. Autistic adults in Kenny et al.’s study similarly indicated that the notion of the autism spectrum has trivialized the unique difficulties that autistic individuals have, and that terms such as high- and low-functioning are highly misleading. However, professionals in the autism community have
presented differing views on autism. According to professionals, the person should always come first. Professionals also noted that although autism can be disabling, the current language is overly deficit-focused and should instead be emphasizing unique qualities and celebrating strengths. Family members in Kenny et al.’s study were the most divided group; some felt that autism was an intrinsic part of their family member while others felt that autism did not define the individual. Most family members viewed autism as a difference rather than a disorder but noted that we should not downplay the impact of autism on functioning or the variability across the spectrum.

In a personal account regarding the use of person-first language, Sinclair (1999) noted that the use of person-first language has suggested that autism can be separated from the person when it cannot. Sinclair observed that we do not hesitate to label important aspects of people’s lives and personalities (e.g., being a parent, catholic, male, generous, loving) and has not understood why autism should be different than any of these other labels. Sinclair further stated that the use of person-first language diminishes the autism part of his own life, which he views as problematic since he believes that autism encapsulates the way his brain works and is thus an essential feature of his personhood. Sinclair further observed that person-first language contributes to stigma by implying there is something bad about having autism as person-first language is often used to separate negative characteristics from a person.

Based on this evidence, APA (2020) has refined their statement on language used to describe those with disabilities and encourages writers to honor the language preference of the group being investigated/worked with. APA has further noted that the use of person-first language and/or identity-first language is acceptable until you know the language preference of the group you are investigating and has clarified that mention of a disability should only occur
when it is relevant, with an added caution that negative and condescending terminology should be avoided at all costs. CASDA (2020) has also published a guide on preferred language for those who work with the autistic community. In their statement, CASDA provided some guiding principles on language that should be avoided which includes: (1) terms such as ‘living with autism’, (2) references to autism as a burden or something that individuals are a victim of, (3) reference to autism as a disease, (4) use of the term ‘mentally handicapped’, (5) reference to comparison groups as ‘normal’ or ‘healthy’, and (6) reference to low or high functioning autism. APA has also made similar statements to CASDA stating that terms such as “high functioning”, “low functioning”, and “special needs” (p. 137) should specifically be avoided. Based on these findings the author has decided to prioritize use of identity-first language throughout this dissertation.

**ASD and Diagnosis**

While the majority of ASD research has focused on the underlying biology and causes of autism (Pellicano et al., 2018), trends are changing to include efforts to improve services across the lifespan and/or the utilization of participatory research models (Nicolaidis et al., 2019; Pellicano et al., 2018; Tesfaye et al., 2019). In fact, the Interagency Autism Coordinating Committee (2017) has advocated for a shift in the way ASD research is approached, and recommended that current research trends have more immediate and direct ramifications on the daily lives of autistic individuals, with a specific focus on services in adulthood. Nicolaidis et al. (2019) agreed with this statement and noted that there is a substantial need for researchers to “promote the inclusion of autistic adults in research” (p.1). While this approach is a welcomed change, qualitative studies that investigate the experience and meaning of ASD diagnoses are lacking. The first-hand perspectives of autistic individuals have traditionally been excluded from
research, with the focus instead being on the ideas and opinions of family members, care providers, and/or clinical researchers (DePape & Lindsay, 2016; Nicolaidis et al., 2019). In fact, when DePape and Lindsay (2016) conducted a synthesis review on published qualitative research that investigated the first-hand experiences of autistic individuals, they were only able to find 33 articles published between 1980 and 2014. This is concerning, as evidence points to both the importance of including the first-hand perspectives of autistic individuals (Hurlbutt & Chalmers, 2002; Jones et al., 2001) and the dissatisfaction that autistic adults experience when disregarded as experts in their own lives (Gillespie-Lynch et al., 2017; MacLeod et al., 2013; Nicolaidis et al., 2019). While additional qualitative research regarding the experience of ASD has emerged since DePape and Lindsay’s published article (e.g., Cai & Richdale, 2016; Cullen, 2015; Knott & Taylor, 2014; Mogensen & Mason, 2015; Schembri, 2017), the body of research examining how autistic individuals view their diagnosis is limited and there is even less information regarding those who have been diagnosed later in life. The lack of first-hand perspective is troubling, as participants in such studies have referred to the impact of diagnosis on their life even though most of these investigations have not specifically focused on this topic (e.g., DePape & Lindsay, 2016). As such, this portion of the chapter will review current perspectives of ASD diagnosis while highlighting research that prioritizes the first-hand experiences of autistic people when possible. Extant research regarding ASD diagnoses focuses on stigma and access to services. While this dissertation focuses on research articles prioritizing the first-hand perspective, this is in no way meant to diminish the value of autobiographical writings by autistic authors [see Longtin & Bell Opila (n.d.) for a list of autistic autobiographies].
Stigma

Research with autistic individuals has supported the contention that stigma is a prominent concern for this population and that others may hold negative attitudes towards autistic people (Mogenson & Mason, 2005). Stereotypes associated with ASD include beliefs that individuals cannot marry, hold jobs, get an education, or are unusual, dangerous, mentally ill, and/or have intellectual disability (Kinnear et al., 2016; MacLeod et al., 2013). Consequently, many autistic individuals have been reluctant to share their diagnosis for fear they will be assigned inaccurate attributions and/or treated differently (Humphrey & Lewis, 2008; Mogenson & Mason, 2005). In an investigation with autistic post-secondary students, one student was reluctant to tell family members of her diagnosis for fear they would assume that she had an intellectual disability, while another indicated she did not share her diagnosis with instructors for fear they would fail her due to beliefs that autistic people cannot work in her field of study (Schembri, 2017).

While research findings have suggested that autistic people experience stigma (e.g., Kinnear et al., 2016; Obeid et al., 2015), Butler and Gillis (2011) contended that Aspies\(^2\) are stigmatized because of their behaviours rather than because of stereotypes regarding the diagnostic label. In their investigation, Butler and Gillis compared stigma scores on different vignette descriptions in a between-subjects experiment organised in a two (Asperger’s label vs. no label) by three (descriptions of social behaviours indicative of Asperger’s vs. milder social deficits vs. control) design. Results indicated that vignettes with the Asperger’s label were given lower stigma scores than vignettes with no label, which implied that participants attributed less stigma to those with an Asperger’s label. A positive correlation between behaviours and

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\(^2\) The term Aspies is the identity-first term used to refer to people with Asperger’s disorder, a term that was coined by Aspies themselves.
stigmatization also offered evidence that it is the behaviours which are stigmatizing and not the
Asperger’s label. As such, Butler and Gillis concluded that when individuals have a diagnostic
label, others are less likely to assume they are at fault for their behaviours.

Although the approach to ASD diagnosis has prompted concerns about stigma, in some
cases a diagnosis may reduce self-stigma by providing individuals with a new framework for
understanding themselves and/or others who have been diagnosed. In support of this proposition,
Schembri (2017) investigated the barriers to success for autistic post-secondary students and
found that individuals who received an ASD diagnosis outside of childhood perceived the
diagnosis as beneficial because it provided them with a way to understand themselves. A
diagnosis offered them an explanation for their experiences, behaviours, and differences. This
explanation allowed participants to externalize their concerns by viewing them as separate from
their sense of self. Participants in Schembri’s investigation explained that growing up knowing
something was amiss while lacking a way to label that experience was particularly difficult. One
participant shared that growing up autistic but not having a name for it was an emotionally and
psychologically awful experience. This participant knew that something was different but did not
have a way of conceptualizing or understanding that difference because he did not have a name
for it. This finding has also been emphasized by Haertl et al. (2013) in which the lived
experience of ASD and its effects on relationships, socialization, and occupational participation
were investigated. In this research, six autistic adults without co-occurring intellectual disability
referenced knowing that they were different from others despite not having an official label for
that difference. Participants in Haertl et al.’s investigation also noted that they previously felt out
of place or like a “misfit” and were relieved by their diagnosis (2013, p. 32).
Participants in MacLeod et al.’s (2013) investigation of six higher-education students and their relation to the Asperger’s label also identified benefits of a diagnosis. Participants in this study noted that an ASD diagnosis provided them with a way to connect with other autistic people and gain insight/understanding about themselves. Some participants even noted that ASD was a central and important part of their personal identity. These findings indicated that rather than being harmful, an ASD diagnosis could potentially reduce self-stigma by allowing autistic people to form a new identity explaining why they are different or fail to fit in. However, some participants in MacLeod et al.’s study indicated that they did not see benefits to diagnosis and that they chose not to interact with other autistic individuals because they viewed autistic people as antisocial, which may indicate that autistic individuals can hold stigmatizing views towards other autistic individuals. For others, the stigma was associated with the words ‘autistic’ and ‘autism’, which they strongly associated with low intellectual disability in contrast to the conceptualization of Asperger’s (Schembri, 2017). The combination of these findings is supported by both Calzada et al. (2012) and Haertl et al. (2013). Calzada et al.’s investigation of 10 families regarding the utility of an ASD diagnosis suggested both advantages and disadvantages of diagnosis. Advantages included increased understanding and support whereas disadvantages included stigma and the label’s inefficiency at clearly communicating their child’s specific concerns. Further, Haertl et al. found that an ASD diagnosis could elicit feelings of both relief and frustration. In this study, participants communicated that they were relieved by their diagnosis because they always knew they were different. Yet, participants also felt discouraged because to them the diagnosis also meant that being ‘normal’ would never be a possibility as there is no known cure for ASD. Researchers and clinicians have also argued that ASD diagnoses are beneficial and that even diagnoses given later in life can assist with adjustment.
This is because adults without a diagnosis who meet criteria for ASD typically experience multiple challenges and perceived failures in their lives, which are experiences that the ASD diagnosis can help explain (Bailey, 2019), providing a psychological buffer to self-stigma.

Huang et al. (2020) conducted a scoping review regarding the first-time assessment and diagnosis of autistic adults. They found 82 studies across 13 countries; the majority of which (72.6%) were quantitative in nature. Huang et al. found 17 qualitative studies that described the experience of receiving an ASD diagnosis, though most of this research was conducted in the United Kingdom and may not be fully applicable in a Canadian context. In their review, Huang et al. concluded that autistic adults frequently described feeling different from their peers and reported experiencing social isolation and/or bullying prior to their diagnosis (see Hickey et al., 2018; Lewis, 2016; Punshon et al., 2009). Huang et al. also concluded that some adults expressed relief and happiness upon receipt of the diagnosis while others expressed negative reactions (see Jones et al., 2014, Lewis, 2016; Punshon et al., 2009). As some of these studies are closely related to the current investigation, they will be described in more detail.

Lewis (2016) conducted a qualitative study investigating the experience of receiving an ASD diagnosis as an adult by analysing open-ended online surveys. Six themes were found: feeling different from others, riding an emotional rollercoaster, striving to accept themselves, strategizing to improve their lives, maintaining normalcy, and wandering into the future. In the theme of feeling different from others, most participants reported that they had a negative self-image prior to the diagnosis because they thought something was wrong with them. However, this was not the case for all participants, as some interpreted this difference in a more positive light such as uniqueness. In terms of the theme riding an emotional rollercoaster, the authors reported that accepting the diagnosis took time, especially if the diagnosis came as a surprise.
However, some participants expected the diagnosis and were unphased when they received it. Regardless, most participants reported feeling relief when they received their diagnosis, as it helped to legitimize their experiences. With the third theme, striving to accept themselves, the authors noted that the participants needed time to re-evaluate how they viewed themselves and their self-concept. For the theme of strategizing to improve their lives, participants reported that knowledge of their diagnosis helped provided them with ‘tools’ that were beneficial to daily life. Within the theme of maintaining normalcy, participants reported having many ASD related challenges; despite this, the participants did not view themselves as disabled. Lastly, for the theme of wandering into the future, participants reported that they had concerns regarding their futures, particularly because others did not understand their diagnosis and because there was limited support available for autistic adults.

Punshon et al. (2009) interviewed 10 adult Aspies and extracted six themes: negative life experiences, experiences of services (pre-diagnosis), beliefs about symptoms of Asperger syndrome, identity formation, effects of diagnosis on beliefs, and effect of societal views of Asperger syndrome. Mostly notably, participants reported negative life experiences prior to their diagnosis, which led to the development of specific beliefs related to their Asperger symptoms (e.g., negative experiences with peer groups led to beliefs that the individual was ‘different’). The authors stated that these beliefs influenced individual self-identity, a conclusion which aligned with Corrigan et al., (2004) and Corrigan and Watson’s (2002) views on how self-stigma is formed. Hickey et al. (2018) conducted a similar study, interviewing 13 autistic adults over the age of 50. The authors derived three themes from their analysis including difference, life review, and longing for connection. Participants in this investigation reported being aware of their personal challenges and noted that they made attempts to reduce these challenges so that they
could fit in socially. Importantly, the authors noted that the receipt of a formal diagnosis allowed participants to externalize personal challenges and thus explain these challenges with their diagnosis rather than relating them to their self-concept.

Eaves and Ho (2008) found that 25% of caregivers of autistic young adults reported ignorance of ASD in others, as well as unhelpful or harmful attitudes towards autistic people. Alarmingly, nearly 30% of the participants recalled a specific individual exerting a negative/harmful influence on their autistic family member. Kinnear et al. (2016) also explored stigma for families of autistic individuals and found that several factors contributed to stigma for these families including the typical physical appearance of their child (nonvisible disability), their child’s socially inappropriate behaviour, and a general lack of ASD knowledge. Kinnear et al. stated that people often make assumptions about behaviours of autistic children by assuming that these behaviours equate to a lack of behavioural management on behalf of the parents. This assumption caused concern given that many autistic individuals lack physical or visible markers to indicate a disability, which leads people to conclude that their potentially atypical behaviours are a deliberate choice or an act of will. Rosqvist (2012) and Haertl et al. (2013) also emphasized this point and referred to ASD as an invisible disorder because those with the disorder look like their neurotypical peers, but behave differently.

Abbott et al. (2012) interviewed nine parents/caregivers of autistic children and found that although receipt of an ASD diagnosis can be difficult for parents, it can also provide them with a framework for understanding their child. Parents in Abbott et al.’s study indicated they felt relief upon receipt of their child’s diagnosis as it provided them with an explanation for their child’s behaviour. Some parents even stated they felt vindicated upon receiving the diagnosis. However, some reported feelings of upset, shock, and disbelief when given the diagnosis. In
another study, parents of autistic children noted experiencing distress, confusion, and despair because they could not fully understand their child and/or their limitations; however, most indicated that the ASD label helped them to understand their child and access the support they needed (Midence & O’Neill, 1999). Parents also reported that receipt of their child’s diagnosis alleviated feelings of guilt and shame as some parents felt responsible for their child’s difficulties. As such, it can be concluded that families and caregivers of autistic individuals have also expressed mixed concerns regarding stigma and ASD.

**Access to Services**

Parents of autistic individuals found that the diagnosis afforded access to services for their children (Abbott et al., 2012; Shattuck & Grosse, 2007). In fact, researchers have indicated that there is very little that parents and service providers can do to address a child’s difficulties until an official diagnosis is received (Hodge, 2005). For instance, highly effective intensive early intervention therapies that promote improved outcomes for autistic individuals (Edwards & Chatham, 2011) typically require an ASD diagnosis for service access (Hodge, 2005). As such, some professionals have reported feeling pressured to provide or alter diagnoses so clients can receive access to treatment (Hodge, 2005; Shattuck & Grosse, 2007). Diagnoses can also benefit autistic adults, as post-secondary students who were diagnosed later in life could then be granted access to educational accommodations which they previously did not have access to (Schembri, 2017). Further, participants in Haertl et al.’s (2013) investigation found that once diagnoses were received, the services provided were more aligned with the specific needs of autistic individuals. Lastly, Bailey (2019) suggested that an ASD diagnosis given in adulthood is beneficial as it allows clinicians to: (a) develop a treatment plan based on knowledge of autistic adults; (b) look
for and treat common co-occurring clinical conditions; (c) assess appropriate ASD interventions; and (d) provide ASD related information to relevant family members.

Summary

American statistics indicate that incidence rates for ASD have increased to 1 in 59 (Baio et al., 2018), meaning more people are being diagnosed than ever before. Currently these diagnoses are being provided more often for adults than children or adolescents (Bailey, 2019; Huang et al., 2020). Despite increases in incidence rates, not all practitioners view diagnostic labelling as a useful and advantageous practice. This view of diagnosis has relevance to ASD, as some practitioners have misgivings about providing ASD diagnoses (particularly in adulthood; Bailey, 2019). Arguments against diagnosis tend to focus on stigma and the effect that stigma can have on those diagnosed (e.g., Kinnear et al., 2016; Obeid et al., 2015). Even with the varying opinions that clinicians may hold towards diagnostic practice, there is limited literature examining the first-hand experiences of receiving an ASD diagnosis and what that diagnosis means to recipients. Additionally, the literature investigating the experience of a late ASD diagnosis is especially scant. However, knowledge regarding the experience and meaning of an ASD diagnosis can help inform views on diagnostic practice, heighten self-understanding among autistic people and allow them to contribute their own expertise regarding their day-to-day lives, and further contribute to autism literature. Accordingly, this is an important area of knowledge and inquiry. Emerging from this literature review, the questions proposed for the present investigation were: (1) What is the experience of a late diagnosis for autistic young adults? and (2) What does a late ASD diagnosis mean to those who receive one?
CHAPTER 3: METHODOLOGY

The first section of this chapter describes the underlying assumptions of the research design utilized in this study. Following, the study’s methodology and methods are reviewed.

Assumptions Inherent in the Research

Since qualitative researchers are involved in the interpretation and organization of their research data, they are often considered key instruments in the research process. As such, it is imperative that researchers position themselves within the research by examining and articulating their philosophical assumptions and interpretive frameworks prior to engaging in a research project (Creswell & Poth, 2018). Researchers must also acknowledge their exposure to and understanding of the existing literature, and their personal beliefs and assumptions regarding the proposed research topic. As research is value-laden, biases are often, if not always, present in the research (Creswell & Poth, 2018). To understand the role of values in research, researchers must acknowledge and state their axiological assumptions and the way these assumptions may influence the research (Creswell & Poth, 2018). This process of acknowledgement allows the researcher and arbitrators/readers of the research to gain insight into how the researcher’s assumptions and values interact with the research process from design to implementation. The present inquiry had several underlying assumptions that influenced its inception and subsequent data collection and analysis; these are examined below.

Background and Relation to the Research

The researcher previously worked as an Early Intervention Therapist with young autistic children and their families in the home and community. Following this work, she began her Masters of Science degree in Counselling Psychology at the University of Calgary. During this training, the researcher was exposed to specific values and beliefs regarding ways to approach
diagnosis in the field of counselling psychology (as explained in the literature review) that have shaped and influenced the researcher’s approach to diagnosis and diagnostic labelling.

Then, while preparing to identify a research topic for her thesis, an opportunity related to research with autistic young adults in post-secondary education presented itself. With increasing numbers of autistic post-secondary students (Alcorn MacKay, 2010) and few guidelines informing how to best support these students, the need for appropriate services for autistic students was identified at the University of Calgary (M. Cole, personal communication, August 4, 2016). As such, the researcher was offered the opportunity to engage in a research project to investigate the barriers to educational success for autistic post-secondary students. This project provided an opportunity to expand upon the researcher’s interest in ASD and incorporated a desire to work with young adults. While the findings of that study identified many barriers to success for autistic post-secondary students, participants also indicated that failing to receive an ASD diagnosis during early childhood was detrimental to their sense of self (Schembri, 2017). One participant offered a poignant description of what it was like to grow up without a diagnostic label, which is shared below:

**Interviewer:** Is there anything else, now that we’ve been chatting for a little bit, that you can think of? That might be important to share about your experience of having autism?

**Participant:** It sucks, it absolutely sucks. Like, every day of your life knowing that there was something wrong, or growing up and not being able to have a name to it, but knowing that something was wrong, and never being able to name what was wrong with you. It was awful.

**Interviewer:** Yes, so going undiagnosed for so long was especially awful?

**Participant:** Yeah. And it would lead to like many different, like, awful thoughts about yourself.

**Interviewer:** So sometimes negative thinking and negative thoughts towards yourself can be...

**Participant:** Um, from the first, from the ages of five till thirteen, I didn’t believe I was human. Like, the way I was treated in classes, and like my own understanding of how, like, my self-perception was. I knew there was something wrong with me. I could never name what was wrong with me
because there was nothing that I could see as different to the other people, so like, the only conclusion I could ever come up with was, “I’m not one of these people, I’m something...just a freak.” (p. 113).

This revelation of the damage that can come about by a lack of diagnosis and its corollary that diagnosis can be cathartic and offer a frame of reference or understanding for those being diagnosed was new to the researcher, as she had been trained in a discipline of psychology that traditionally challenged the medical model and its emphasis on diagnostic labelling and pathology (Larsson et al., 2012; Sinacore-Guinn, 1995). As such, the researcher wanted to investigate the experience of receiving an ASD diagnosis later in life. To assist with this endeavour, the author wrote her doctoral candidacy field-of-study paper on the current views of diagnosis in the field of counselling psychology. This research paper set the foundation for the researcher’s background and understanding of diagnoses and diagnostic labelling in psychology. To ensure that her previous experiences and axiological values regarding diagnostic labelling did not skew or bias data collection and interpretation, the researcher sought to investigate all perspectives regarding diagnosis by investigating both the hindering and helpful aspects of accessing an ASD diagnosis.

Assumptions

Several assumptions were made about the means to approach this investigation, the language to use, the diverse cognitive abilities of autistic individuals, and the value that diagnosis can play in a person’s life. As such, the researcher has described each assumption she held and, when possible, her attempt to constrain those assumptions.

The researcher designed the project with the impression that a qualitative approach was the best way to conduct this study. The researcher believed that it was optimal to speak directly to autistic individuals and gain a first-hand account of their experiences to understand the
experiences of autistic individuals fully. Additionally, as autistic individuals have communicated that being disregarded as experts in their own lives was both dissatisfying and problematic (Gillespie-Lynch et al., 2017; MacLeod et al., 2013; Nicolaidis et al., 2019), the researcher felt an ethical duty to conduct the study from a first-hand perspective. While quantitative research can provide many valuable insights, such an approach was thought to detract from the spirit of this research that aimed to facilitate autistic individuals having their voices heard in a research format. Based on this assumption, the researcher decided not to engage in quantitative or mixed methods approaches and to focus solely on a qualitative approach.

Due to the researcher’s previous research with autistic post-secondary students, she assumed that most research participants would find the concept of diagnosis, and thus the receipt of a diagnosis, to be a beneficial and validating experience. The researcher assumed that the receipt of a diagnosis would allow participants to externalize their concerns and thus be beneficial to their sense of self. To mitigate this assumption and lessen its influence on the research design and analysis, the researcher purposely sought out multiple perspectives/views regarding diagnostic labeling. She intentionally worded her recruitment scripts/flyers to be open ended by inviting individuals to share their experience with diagnosis. This approach presumably decreased risk of a skewed participant pool of primarily individuals with positive experiences within the sample. The interview questions were designed to be open ended and revolved around both potential positives and negatives associated with receiving a diagnosis. The researcher was also careful not to impose her beliefs on participants by asking questions in a non-leading manner. For example, the researcher aimed to ask participants if their sense of self has changed since receiving the diagnosis instead of asking if it changed in a positive way. Participants were then invited to expand upon their response to this open inquiry.
Based on the researcher’s exposure to literature on the use of language (as described in the literature review), the researcher assumed that autistic individuals prefer identity-first language and so incorporated this terminology in this document. Finally, the researcher also assumed that prospective participants would present with a range of full-scale intelligence quotient (FSIQ) estimates. As autistic individuals have been frequently diagnosed with an accompanying intellectual impairment (APA, 2013), it is important to discern FSIQ for the sample. Many studies indicated that autistic individuals with higher cognitive functioning have better long-term outcomes (e.g., Billstedt et al., 2005; Farley et al., 2009; Henninger & Taylor, 2012; Howlin & Moss, 2012; Levy & Perry, 2011); as such, it can be concluded that those with higher FSIQ scores will likely have qualitatively different experiences regarding what it is like to receive an ASD diagnosis. Based on these assumptions, the researcher decided to assess FSIQ as part of the inclusion/exclusion criteria for the present study.

**Epistemological and Ontological Frameworks**

Qualitative researchers are typically required to state their epistemological and ontological frameworks explicitly prior to beginning data collection (Braun & Clarke, 2013). This process has been essential to conducting trustworthy research, and failure to distinguish between ontology (the nature of reality) and epistemology (our ability to understand that reality) can result in methodological conflict (Tebes, 2005). The primary investigator approached the research from an ontological viewpoint of critical realism. Braun and Clarke (2013) indicated that critical realism is a “theoretical approach that assumes an ultimate reality but claims that the way reality is experienced and interpreted is shaped by culture, language, and political interests” (p. 329). In this sense, everyone may experience the same or a similar reality, but the nature of that reality is influenced through different experiences. As such, critical realists have assumed
that data can inform us about reality but have also anticipated that the data collected is not a direct mirror of an individual’s experience (Harper, 2012). As a critical realist, it is the researcher’s job to move beyond the data and draw on additional evidence to explain the data further (Harper, 2012). For the proposed research, it was assumed that autistic individuals are knowledgeable about their experiences with diagnosis but they may be unaware of some of the factors that shaped those experiences.

The researcher approached the research with an epistemological perspective of contextualism that “assumes that meaning is related to the context in which it is produced” (Braun & Clarke, 2013, p. 328). Contextualism is highly aligned with the ontological approach of critical realism as both state that the nature of reality/how we come to know that reality is dependent on context (e.g., culture and/or language). This approach has presumed that knowledge can emerge from multiple contexts and can reflect the researcher’s positions (Braun & Clarke, 2013; Madhill et al., 2000). As such, according to this epistemology, no single approach can access an ultimate truth, as everyone’s truth may be different depending on their context (Tebes, 2005). Despite this, knowledge and different truths can be valid or true in specific contexts (Tebes, 2005). Thus, the researcher must obtain subjective evidence from participants by becoming “close” to them so they can begin to “know what they know” by supporting this knowledge with exemplars from the gathered evidence (Creswell & Poth, 2018, p. 21). In this investigation, the researcher became close to participants during the interview process and then attempted to consolidate and translate their knowledge during the data analysis.

**Methodological Overview**

In contrast to quantitative approaches, qualitative methodologies offer the opportunity to explore deeper understanding of personal experiences, perceptions, and meanings held by
individuals. Rather than transforming participant information into quantifiable data for analysis, qualitative research has drawn on observations and descriptions to understand and interpret meaning/import of the data gathered (Braun & Clarke, 2013), which makes qualitative methodologies uniquely suited for the “empathic” exploration of events that attempt to understand and relay experiences (Yardley, 2000, pp. 215-216). Qualitative methodologies often involve detailed investigation of intersecting aspects of the topic of study, whereas quantitative approaches often focus on isolated variables (Yardley, 2000). As such, the knowledge gathered from qualitative investigations can contribute to general understandings and applications.

Several qualitative methodological approaches were considered for the proposed study. Grounded Theory (GT) was considered as a potential approach, as psychologists originally utilized it to gain in-depth perspectives of service users’ experiences (Rennie et al., 1988). As the aim of the current research was to understand the experience of a late diagnosis for autistic young adults, this method might appear to be a good fit. However, the prevailing aim of GT is to contribute to the development of a theory that may provide a framework for explanation regarding a specific process or action (Creswell & Poth, 2018). As one of the aims of this research was to translate the voice of autistic individuals into research findings by highlighting their unique experiences, the researcher sought to provide a detailed focus on the perspectives of autistic individuals rather than develop a conceptual model from a larger group of individuals. Additionally, GT’s use of larger samples is less likely to produce a detailed and nuanced account of each individual participant (Creswell & Poth, 2018), which was an aim of this research. For these reasons, GT was deemed unsuitable for the present study.

The Enhanced Critical Incident Technique (ECIT) was also considered as a methodological approach for this study. ECIT was primarily considered because: (1) it is often
used as an exploratory technique for research topics that have seldom been investigated, (2) it has a been adapted for use in counselling psychology research and therefore offers a goodness-of-fit for the researcher’s primary field of study, and (3) it focuses on events of critical importance to participants (Butterfield et al., 2009). While these elements make ECIT suitable for this investigation, there were other elements of ECIT that made it unsuitable for use with autistic populations and this particular research context. ECIT stresses a highly structured interview approach that limits data collection to dualistic responses with the addition of wish-list items (Butterfield et al., 2009). This limitation was problematic for autistic individuals who may struggle with restricted lines of questioning due to potential difficulties with communication. This assertion was supported in Schembri’s (2017) investigation in which a participant communicated they can identify things that are problematic for them but struggle to identify what they want or need. Further, ECIT explores all content areas with the same level of detail for each participant (Butterfield et al., 2009), which would have proved troublesome since autistic individuals will have highly diverse experiences/concerns, thus making it difficult to explore content areas that may not be relevant for each participant. Lastly, autistic individuals can present with cognitive inflexibility and may struggle to engage in conversation they do not deem personally relevant. This contention was again supported in Schembri’s (2017) investigation where it was found that participants were more verbose when addressing topics they considered relevant and appeared more withdrawn or disinterested when the researcher probed for information they did not deem important or relevant. Following careful consideration and consultation, Interpretive Phenomenological Analysis (IPA) as outlined by Smith et al. (2009) was deemed the most suitable methodological approach to meet the objectives of the study.
Theoretical Foundations of IPA

The theoretical underpinnings of IPA draw upon three philosophical frameworks: phenomenology, hermeneutics, and idiography. Though inspired by phenomenological concepts, the goals of IPA are rooted in different qualitative aspirations (van Manen, 2017). IPA diverged from the Husserlian view of phenomenological inquiry by incorporating the theoretical underpinnings of hermeneutics and idiography. As such, this form of inquiry is often used to investigate participants’ reactions to and how they make sense of their experience (Smith, 2011). According to Smith et al. (2009) “IPA is a qualitative research approach committed to the examination of how people make sense of their major life experiences” (p. 1). Therefore, the main goal of IPA is to explore the lived experiences of research participants and allow them to narrate their experience through research findings (Alase, 2017).

Phenomenology

Phenomenology was originally intended as a philosophical practice rather than a research endeavour (Giorgi, 2000; Smith et al., 2009); it evolved over time and the philosophical framework has been applied to different fields of research. Husserl’s phenomenology embodied a shift away from logical empiricism and served as a protest against dehumanisation in psychological research (Giorgi, 2005; Wertz, 2005). Phenomenology emerged as a response to positivism, and warns against constructivist approaches as the aim of research is to observe and report the phenomenon exactly as it appears (Husserl, 1962). The key component of Husserl’s phenomenology is description without understanding/interpretation, which is achieved through direct replication of phenomena as they appear in consciousness (van Manen, 1990).

Husserlian phenomenology views experience as a first-order knowledge system, whereas science is considered a second order system (Smith et al., 2009). As such, phenomenology is
concerned with how elements, events, and experiences show or reveal themselves (Husserl, 1962), with the aim of phenomenology being the rigorous and unbiased study of things as they appear (Dowling, 2007). Explanations of phenomena are not imposed prior to the phenomena being understood (Dowling, 2007). Instead, phenomenology, with its emphasis on lived experience, attempted to focus on the primitive form of what is immediate in our consciousness before we apply understanding (Caelli, 2000). Husserl (1962) claimed that knowledge both begins with and remains within experience, while further contending that experience and perception of experience are the same. In this form of phenomenology, experience is considered the central source of knowledge (Dowling, 2007). This perspective aligns with IPA as its framework considers experience a central source of knowledge.

Bracketing, which is also referred to as phenomenological reduction, is a process of rigorous self-reflection (Hein & Austin, 2001). This process was originally referred to as *epoche*, which translates as refraining from judgement (Giorgi, 2005; Moustakas, 1994). By engaging in bracketing, researchers attempt to move towards a transcendental attitude that results in reduction as the researcher suspends their beliefs to attend to the phenomenon as experienced by the participant (Hein & Austin, 2001). It was thought that one could uncover new and/or forgotten meanings of experience by returning to and re-examining experiences without pre-established perspectives (Laverty, 2003). This view of bracketing is fundamentally different from an IPA orientation, as Smith (1996) did not believe it possible to fully bracket one’s assumptions. Instead, Smith et al. (2009) have incorporated interpretation into their understanding of knowledge and, as such, brought elements of hermeneutics into the philosophical underpinnings of IPA.
Hermeneutics

Although phenomenology and hermeneutics both have focused on experience, the two philosophies are distinct (Laverty, 2003). Phenomenology can be seen as purely descriptive in offering rich understanding whereas hermeneutics has acknowledged that it is interpretive (Smith et al., 2009). Heidegger, who was once a phenomenologist, initiated a variation of hermeneutics that shifted the focus from the understanding of phenomena to the understanding of *Dasien* or “mode of being human” (Laverty, 2003, p. 24). According to Laverty (2003), Heideggerian hermeneutics diverged from Husserlian phenomenology when it was asserted that consciousness could not be separated from the world view, but instead was a compilation of historically lived experience. This view differed from Husserlian phenomenology, as it acknowledged that everyone is constantly situated in cultural, social, and historical contexts. These constantly evolving contexts provide individuals with understandings from which they cannot detach, meaning that our context provides us with additional information that we use to understand events and experiences. As such, it is believed that individuals cannot refrain from interpreting experiences (Laverty, 2003). Hermeneutics has also been used to interpret texts and, in this vein, one must consider that a text is shaped by the writer’s linguistic community (Smith et al., 2009). As such, an interpretive analyst can offer additional insights to the text that the original author could not. This perspective relates to IPA which asserts that researchers offer interpretations of phenomena that participants cannot (Smith et al., 2009).

Gadmar was another philosopher who contributed to the development of hermeneutics. He aimed to move Heidegger’s work from theory to applied practice (Laverty, 2003). Like Heidegger, Gademer asserted that phenomenological bracketing was an impossible practice and emphasized the importance of history and tradition, and their effects on interpretation (Laverty,
Gadamer also articulated a cycle where, as people read text, they engaged in a dialogue between what they brought to the text and what the content of the text brought to them (Smith et al., 2009). This cyclical analysis relates hermeneutics to IPA as Smith et al. (2009) have claimed that the relation between previous understanding and new phenomena as described by others helps to elaborate or thicken our understanding of the phenomena.

**Idiography**

Idiography has demanded a detailed focus on the particular, which according to Smith et al. (2009) refers to a focus on the individual and is the opposite of nomothetics (claims made at the group or population level). Idiography aimed to restore the scientific study of the individual rather than the accumulated average of the individual illustrated across a pool of participants (Molenaar, 2004). While idiography has generally avoided universal generalizations by focusing on the singular, it has not fully eschewed generalizations (Smith et al., 2009). Instead, generalizations are developed cautiously through analytic induction. This philosophical framework has re-inserted humanity into scientific psychology by straddling the divide between nomothetics and case study (Molenaar, 2004; Smith et al., 2009). The particular can be utilized in IPA in two ways. In the first, the particular refers to the intricate detail seen in IPA data analysis (Smith et al., 2009). In the second, it is referring to the understanding of how a particular phenomenon is understood by a specific group of people (Smith et al., 2009). Smith and colleagues explained that the relation between IPA and both phenomenology and idiography is highly complex:

On the one hand, experience is uniquely embodied, situated and perspectival. It is therefore amenable to an idiographic approach. On the other hand, it is also a worldly and relational phenomenon, which offers us a concept of the person which is not quite so
discrete and contained as the typical understanding of an ‘individual’. Dasein is not the assemblage of dispersed and disparate personae commonly posited by social constructionism – but it is thoroughly immersed and embedded in a world of things and relationships. Because Dasein’s experience is understood to be an in-relation-to phenomenon, it is not really the property of the individual per se. However, a given person can offer us a personally unique perspective on their relationship to, or involvement in, various phenomena of interest. (p. 29)

**Conducting IPA Research**

The following section describes how to plan and conduct an IPA research project using the framework developed by Smith et al. (2009), including a description of how to collect, analyze, and write up IPA data.

**IPA Research Questions**

In IPA, research has generally focused on a person’s experience and/or their understanding of a particular phenomenon (Smith et al., 2009). Thus, IPA is frequently used to examine experiences that are of existential import to participants. Common topics in IPA research include illness experience and psychological distress (Smith, 2011). As it is believed that data generated via IPA research can inform us about how an individual makes sense of their world, research questions generally focus on people’s understanding of their world. Smith et al. (2009) claimed that questions in IPA should be open, exploratory, and directed towards meaning, as opposed to closed, explanatory, and directed towards causality. IPA can also be used to answer theory-driven research questions; however, Smith et al. have noted that theory questions should be secondary to the direct experience as communicated by participants.
**Participants**

Smith et al. (2009) noted that participant samples are selected purposively as the aim is to recruit individuals who have experienced a specific phenomenon. As such, Smith and colleagues recommended that homogeneous groups of participants be recruited through referrals from various “gatekeepers” (p. 49). Smith et al. indicated that participant selection should represent a specific perspective rather than a specific population. As IPA analysis is a rigorous endeavour that requires detailed analysis, studies often utilize small sample sizes. Such sample sizes are acceptable if the sample is sufficient for the potential of IPA to be realized (Smith, 2011), meaning the sample should be capable of providing a detailed account of first-hand experiences with a specific phenomenon. Further, the main aim of analysis is to obtain quality within the sample, rather than quantity; therefore, IPA researchers opt for fewer yet more detailed collections of data (Smith et al., 2009). Smith et al. have recommended a typical sample size of three when undergraduate or master’s level research is conducted. Three interviews are useful as they will allow for three separate case studies, and allow for the analysis of similarities and differences between the cases. Smith et al. further recommended four to ten interviews for IPA conducted by professional doctorates. This sample size range is recommended as it is “more problematic to try and meet IPA’s commitments with a sample which is ‘too large’, than with one that is ‘too small’ (Smith et al., 2009, p. 51) and because “successful data analysis requires time, reflection and dialogue” which larger data sets prohibit” (Smith et al., p. 52). The implication is that both sample sizes can offer meaningful research findings, but that larger sample sizes are more complex to analyse and therefore should only be taken on by more experienced researchers.
Collecting Data

Data collection in IPA is intended to afford participants the opportunity to offer rich and detailed accounts of their experiences (Smith et al., 2009). As such, flexible in-depth semi-structured interviews are the most common data collection method as initial questions can be modified in response to participant statements (Smith, 2011; Smith et al., 2009). Smith and colleagues indicated that interview questions should be descriptive, narrative, structural, contrasting, evaluative, circular, and/or comparative, but that they should never be over-emphatic, manipulative, leading, or closed. Interviews are commonly audio recorded and transcribed verbatim so they can be subjected to scrutiny and intensive analysis.

Analysis

Smith and colleagues (2009) stated that there is no single approved method for working with data, but contended that the chosen approach must be flexible enough to move data from the descriptive to the interpretive. According to Smith (2011), IPA involves a detailed investigation of each interview followed by a search for patterns across the different cases. Smith et al. described typical analysis as focused on a line-by-line investigation of data, followed by identification of emergent themes. Researchers then engage in a dialogue with the data that allows them to develop an interpretive account of each participant’s experiences. Finally, the relation between the individual themes is illustrated and a full narrative account is written. Smith also stated that analysis should be concerned with similarities and differences within the sample so that the researcher can present common themes while also illustrating individual experiences. Smith et al.’s (2009) step-by-step recommendations for IPA analysis are conveyed below.

Step 1: Reading and re-reading. According to Smith et al. (2009) the initial step of data analysis involves immersion of oneself in the data. First, it is recommended that one listens to the
audio recording of the interview and then reads and re-reads the individual transcript. The goal in this step is to slow down and focus on the participant. During this step, the researcher also makes notes about their initial thoughts of the transcript.

**Step 2: Initial noting.** In this step, Smith et al. (2009) instructed researchers to increase familiarity with the transcript by identifying the specific ways each participant talks about the phenomenon in question. There are no rules about what to comment on in each data set; however, it is useful to keep in mind that the aim of this step is to create a detailed set of notes regarding the data. Smith et al. further noted that steps one and two often merge into one another as the researcher starts writing more elaborate notes on the transcripts while reading each interview. Smith et al. indicated that researchers can comment on similarities and differences, repetitions, amplifications, and contradictions when making initial data set comments. Smith and colleagues also suggested utilizing descriptive, linguistic, and conceptual comments. Descriptive comments are exploratory observations that describe content and focus on key words, phrases, or explanations, and are concerned with taking things at face value while highlighting a participant’s thoughts and experiences. Linguistic comments are comments concerned with use of language. Here, researchers can attend to pauses, laughter, repetition, tone, and use of metaphor. Lastly, Smith and colleagues described conceptual comments as interpretive while investigating the transcripts at a conceptual level. At this point the researcher begins to interpret additional meaning and context that may apply to the participant’s statements, whereas descriptive and linguistic comments are focused on taking participant statements at face value.

Stage two of data analysis includes trial and error combined with discussion, reflection, and refinement of ideas. Smith et al. (2009) also acknowledged there are elements of personal reflection present in conceptual coding and recognised that the interpretations researchers
develop will inevitably draw on their own experience and/or knowledge. To assist with this, Smith et al. recommended that researchers employ strategies to assist in de-contextualizing data. For example, they suggested reading a paragraph backwards sentence by sentence.

**Step 3: Developing emergent themes.** The next step that Smith and colleagues (2009) highlighted involves the development of emerging themes. To do this, the analyst must examine the new larger data set including all their initial commentary. When looking for emergent themes, the analyst must reduce the volume of detail (i.e., condensing individual transcripts and initial notes into themes) while maintaining complexity by mapping interrelations, making connections, and highlighting patterns between the initial notes and the transcript (Smith et al., 2009). During this stage, it is important to reduce detail so the reader can get a sense of the themes without being overwhelmed by the data; however, one also wants to maintain complexity so the experience of each individual is not lost in the analysis. By necessity, this stage of the analysis takes the researcher farther away from the descriptive experience of the participant by incorporating interpretation.

**Step 4: Searching for connections across emergent themes.** In step four, Smith et al. (2009) advised researchers to use the themes generated in step three to create a map indicating how the themes fit together. To assist at this stage, Smith and colleagues highlighted ways researchers may look for patterns and connections between emerging themes. Some of the strategies outlined by Smith and colleagues include the use of abstraction (developing super-ordinate themes to explain the relation between related themes), subsumption (when an emergent theme is given super-ordinate status to bring together related themes), polarization (oppositional relations), contextualization (identifying the contextual or narrative elements in the analysis such as cultural themes or key life events), numeration (frequency data of themes), and function
(listing the function of the theme within the data). It should also be noted that themes generated from step three may be modified, combined, or discarded during this stage.

**Step 5: Moving to the next case.** Smith and colleagues (2009) indicated that the next step in data analysis involves moving through each transcript and repeating the entire process. During this step it is important to treat each case as its own by attempting to bracket emergent ideas from the analysis of the previous cases. Nonetheless, it is acknowledged that bracketing is difficult and that the researcher will be influenced by previously uncovered themes.

**Step 6: Looking for patterns across cases.** The last step that Smith and colleagues (2009) outlined for data analysis involves looking for patterns across all cases in the data set. To do this, researchers should ask how one case supports or illustrates a theme in another case. During this stage of the data analysis, one can also reorganize or re-label emergent themes. The purpose of the step is to enhance the levels of interpretation within the analysis, with the aim to move towards a deeper, more detailed recounting of all transcripts. To ensure adequate analysis, Smith et al. suggested at least three levels of interpretation (e.g., examining content, contrast, use of metaphor, and/or detailed micro-analysis of text) to ensure that the analysis is moving from descriptive to interpretive.

**Writing**

While definitive guidelines on documenting an analysis do not exist in IPA, Smith et al. (2009) provided helpful tips on reporting results. It is essential that written findings provide a detailed and narrative account of each participant’s experience with a phenomenon that is both comprehensible and systematic. The purpose of the write up is to provide an account of the data and to offer interpretation of what the data are saying. Smith et al. further indicated it is beneficial to move directly from data analysis to writing the findings, as doing this allows the
researcher to maintain momentum gained while conducting the analysis. Smith et al. also stated that research themes should be communicated clearly and concisely. To assist with this, it is recommended that themes are placed in a table with a short description defining each one. From here, the researcher should take each theme and describe it in more detail. Evidence from different participants is then displayed verbatim to support each theme.

**Strengths and Limitations of IPA**

Although IPA is well suited for this research project, all research methodologies have limitations. To start, IPA has been criticized for drawing on many different theories and methodological approaches. Some have criticized IPA for attempting to unify seemingly incompatible philosophies (e.g., pure phenomenology and hermeneutics). van Manen (2017) agreed with this assertion and was adamant that IPA should not be referred to as phenomenology due to its incorporation of interpretation. The practice of ‘theory blending’ in applied psychology has been referred to as syncretism (Corey, 2013). However, in qualitative research, this practice has been referred to as pragmatism (when a researcher is not fully aligned with or committed to a particular framework but instead selects the most appropriate one to use based on their research; Creswell & Poth, 2018). Resulting, areas of qualitative approaches may overlap with another.

Another aspect of IPA that can be subject to criticism is the use of extremely broad research questions. When using the exploratory questions favoured by Smith et al. (2009), researchers are often unaware of what they will unearth while conducting their research. This approach makes it difficult for researchers to define their research before it has concluded; however, this critique has been applied generally to qualitative research and is not solely attributed to IPA. While IPA utilizes broad research questions, the participant selection process is very detailed, which opens IPA up to more scrutiny. Smith et al. stated that participant samples
should be selected purposively so that “they ‘represent’ a perspective, rather than a population” (p. 49). While this allows for an intentional focus on specific phenomenon, this approach could be considered overly selective. For instance, a researcher may end up with a skewed pool of participants that produces a restrictive view of the phenomena if they are overly discriminating in their participant selection process.

Some may also consider the lack of a priori bracketing as a weakness of IPA because of beliefs that applying personal interpretation to data communicated by participants moves the research too far from the description of the phenomena. This can be problematic, as allowing values and assumptions to guide the research process has the potential to skew the research outcome. Further, some might consider the steps for conducting data analysis as outlined by Smith et al. (2009) to be overly restrictive. With this restrictiveness, it could also be argued that IPA is aligned with quantitative research or nomothetics, making it unappealing for those desiring a purist qualitative approach.

Lastly, IPA may be considered less appropriate for use with autistic populations due to its emphasis on language (Howard et al., 2019). Since deficits in the social use of language is identified as part of the core symptomology of ASD in the DSM-5 (APA, 2013), this is a very real concern. To conduct an IPA investigation with autistic participants, one must ensure that participants can engage in a verbal interview. Additionally, Dewinter et al. (2017) noted that despite having well-developed language capabilities, some autistic individuals may struggle to communicate rich verbal data to the interviewer because they may have limited expressive language and/or overly formal approaches to verbal interaction. As such, it is imperative that the researcher screen each participant’s capacity to participate in the research (i.e., with a screening interview) prior to scheduling an interview.
IPA was deemed suitable for this research project because it allowed for and encouraged close relationships between the researcher and the participants (Smith et al., 2009) that could support participants to contribute in a safe and trusting environment. This relationship also allowed participants to open up and share their experiences, and kept research from being detached and conducted from afar. In carrying out close research, the researcher could glean a true reflection of what a phenomenon or experience was like for participants. This suited the investigation, as participants were asked to talk about personal and/or emotional experiences which they may have been reticent to share if they did not feel allied with the researcher. Further, as IPA examines experiences from the viewpoint of the participant, it often examines phenomena that are of existential importance to the participant, thereby allowing participants to contribute to a field of research in which they have a vested interest (Smith et al., 2009). This approach afforded participants an opportunity to not only engage in research but also to ensure that their first-hand perspective was communicated and incorporated into said research. Howard et al. (2019) noted that IPA “views participants as the experts of their own personal and social worlds and seeks to establish an equality of voice between the researcher and researched” (p. 1) and that “IPA necessitates a respect for the participant and their perspective” (p. 4). These perspectives are extremely important for the population under investigation, as autistic individuals have historically been excluded from offering their own perspective and viewpoints in research. This exclusion has devalued autistic individuals as experts in their own lives and has subsequently limited our understanding of what it is like to live with ASD. Howard et al. (2019) further noted that IPA is highly suitable for ASD research as it can “illuminate autistic experiences in a way that other qualitative approaches do not” (p.4).
IPA was also deemed to be well suited to the present research given its flexible approach that can be utilized with different groups of people. Smith et al. (2009) noted that that there is no single way to conduct interviews and work with data, and contended that a “healthy flexibility” must be utilized (Smith et al., 2009, p. 79). This flexibility makes it easy to apply methodological modifications to suit the needs of the participants and enhance their ability to participate. This flexibility is important as the needs of autistic individuals are highly diverse (VanBergeijk et al., 2008). IPA was also viewed as a suitable approach for the population in question as its flexible approach and ability to modify research questions allowed the researcher to assist autistic individuals to participate in the interview to their fullest abilities (e.g., by rephrasing questions). This approach was deemed critically important as autistic people have “persistent deficits in social communication” (APA, 2013) and may require re-wording or paraphrasing of questions to understand and respond to different questions.

Another strength of IPA was its alignment with the field of counselling psychology. Indeed, IPA originally emerged as a psychology-centered qualitative approach that enabled those in the field of psychology to use a methodology aligned with their viewpoints and assumptions (Smith et al., 2009). As the researcher has been trained in the field of counselling psychology and desires a methodology that allows for alignment with the values and beliefs inherent in her field, IPA offers a well-suited fit. Further, IPA aligned with the researcher’s epistemological and ontological frameworks. Contextualism and critical realism align with IPA as these frameworks acknowledge both the reality that participants communicate and the value of the researcher’s interpretation, as participants may be unaware of the socio-cultural influences that guide their experience and the communication of that experience. IPA aligns with this viewpoint as it merges experience/description (phenomenology) and interpretation (hermeneutics).
Research Setting

This section of the chapter describes in detail how the research was conducted.

Participant Recruitment

Once ethics approval from the Conjoint Faculties Research Ethics Board (CFREB) at the University of Calgary was granted, participants were recruited in the following ways (see Appendix A for recruitment documents):

1) Prospective participants who were identified as meeting criteria for the study by staff at the University of Calgary; Mount Royal University; Southern Alberta Institute of Technology; Bow Valley College; Autism Spectrum Education, Research, and Training group; Ability Hub, and/or other local ASD related agencies were verbally or electronically (i.e., via email) informed that a study regarding autistic individuals was being conducted at the University of Calgary. Prospective participants were informed that their decision whether to participate in the study would in no way affect their relationship with any of the aforementioned institutions. Interested individuals then initiated contact with the researcher by email.

2) Prospective participants were invited to disseminate the study information to others who might be eligible to participate. Participants were informed they were in no way required to inform others of the study, nor would their decision whether to share this information impact their relationship with the researcher or any of the aforementioned institutions.

3) Information pertaining to the study was included in poster advertisements, newsletters, and/or blog posts sent out by local post-secondary institutions and ASD
groups and/or agencies. Prospective participants then emailed the researcher if they were interested in obtaining further study information.

4) Eligible participants from a prior study who had previously consented to be contacted regarding future ASD research opportunities were also contacted via email.

**Inclusion and Exclusion Criteria**

Inclusion criteria were pre-specified to ensure that the participant pool represented a specific perspective as required by Smith et al. (2009). All eligible individuals must have received an ASD diagnosis or any of the previously used autism spectrum diagnoses (i.e., Autism, Asperger’s, or PDD-NOS). As the researcher was investigating the experience of receiving a late ASD diagnosis, participants must have received a late ASD diagnosis, which was defined as at age 12 or after. Most individuals begin grade 7 (typically the beginning of junior high) at age 12 or 13, which would mean that those who did not receive a diagnosis prior to age 12 would have experienced their entire elementary years without a diagnosis and thus would be able to reflect on what it was like to attend elementary school without a diagnosis. Additionally, participants must have received their diagnosis at least 6 months prior to their participation in the study. This was believed to allow reasonable time for adjustment to and reflection on their diagnosis. Individuals also had to be between 18 and 35 years of age at the time of participation. The minimum age was 18 years so that participants would have greater ability to reflect on what the diagnosis meant for them in their adult life (e.g., potential effect on their identity, school accommodations, and employment opportunities), while the maximum age of 35 years was selected to ensure that only the perspective of autistic young adults was attained. While the perspective of older adults might be valuable, they were excluded for two reasons: (1) The time since diagnosis had the potential to be much greater and thus inhibit their ability to accurately
recall what receiving a diagnosis was like and how it affected them, and (2) it could be argued that receiving a diagnosis outside of young adulthood would make for a qualitatively different experience than receiving one prior to the age of 35. To help ensure that they had the ability to understand and participate in the interview effectively, all participants were required to have a FSIQ of 85 or greater on the Wechsler Abbreviated Scale of Intelligence, Second Edition (WASI-II; Wechsler, 2011). A minimum T-score of 60 on the Social Responsiveness Scale, Second Edition (SRS-2; Constantino, 2012) was also required to provide support of the reported ASD diagnosis. Lastly, individuals had to be able to read and write in English to allow them to complete the demographic forms.

**Procedure**

The research project consisted of three different stages (see Appendix D for the procedure flow chart). Not all prospective participants were eligible to engage in all three stages of the research and were notified of such at the onset of the study. The first stage consisted of a telephone screening interview and other screening process. If prospective participants met inclusion criteria, a face-to-face interview session was conducted (stage 2). After the interview, participants were invited to participate in member checking (stage 3).

**Participant Screening (Stage 1)**

Each phone interview included the communication of details on the research study, the answering of participant questions, and the confirmation of eligibility/exclusion criteria (see Appendix E for the telephone screening protocol). Eligibility criteria for FSIQ and SRS-2 scores were determined in person (before the interview) as these could not be evaluated over the phone. Prospective participants were sent a consent form (see Appendix B for a copy of the consent
form) upon conclusion of the screening interview; ineligible participants were thanked for their time and informed that their involvement in the research project had finished.

**Data Collection (Stage 2)**

Face-to-face meetings were held in private rooms at the University of Calgary (prior to the COVID-19 pandemic). These meetings commenced with the interviewer reviewing the consent form with the prospective participant. Each prospective participant was informed that they were in no way obligated to participate in the study and that they were free to withdraw their consent prior to data collection. Once the consent form was signed, the researcher administered the WASI-II and immediately scored it. All participants demonstrated a FSIQ ≥ 85 and were eligible to proceed to the SRS-2. The researcher then scored the SRS-2 and all participants were subsequently found to meet the minimum inclusion criteria of a T-score of 60 or greater and proceeded to the interview.

The interview was semi-structured in nature (see Appendix F for the interview protocol). Accordingly, the interviewer modified interview questions and/or the order of questions to be responsive to participant needs. The semi-structured nature of the interview was important as autistic individuals can have difficulty inferring what they are being asked and/or may experience problems with social communication, making the semi-structured interview format the most appropriate for this population (APA, 2013; Humphrey & Lewis, 2008; Schembri, 2017). Once the interview concluded, each participant completed demographic forms (see Appendix C for the demographic forms). Each participant was then asked if they had any questions or concerns about the research process. As all participants indicated wanting to participate in member checking, each was informed that they would be contacted by email in a few months, once data analysis was complete.
**Member Checking (Stage 3)**

After data analysis was completed, all participants were sent an email containing a list of the research themes, their definitions, and matching exemplars from their transcript. Participants were then able to read the information and indicate, via a checklist (see Appendix G for an example of the member checking template), if they agreed that their exemplars fit the theme and theme definition generated by the researcher. Three participants responded and the information garnered from member checking was included in the discussion section of the write up.

The type of member checking utilized in this study is similar to Mays and Pope’s (2000) description of participant validation. These authors stated that “respondent validation, or ‘member checking,’ includes techniques in which the investigator's account is compared with those of the research subjects to establish the level of correspondence between the two sets.” However, the member checking in this investigation differed from Mays and Pope’s as participants' reactions to the analysis were not incorporated into the study findings, but rather in the discussion session. This was done because the philosophical tenants of IPA value the interpretations of the researcher (Smith et al., 2009), which would not support the revision of themes based on participant feedback. As such, this adaptation to member checking sought to balance the philosophical tenets inherent in IPA and the researcher’s desire to ensure that the voices and perspectives of autistic individuals were appropriately interpreted and incorporated into the discussion of the results. Resultantly, member checking was used in this research investigation as a part of the process of error reduction. Mays and Pope indicated that viewing member checking in this fashion was appropriate as research findings are written for a wide audience and will invariably differ from the individual accounts participants communicated.
Data Analysis

All interviews were audio recorded, transcribed verbatim by an independent transcriber, and analyzed by the primary researcher. The steps to data analysis directly followed those outlined by Smith and colleagues (2009), as described above. The only adaptation to Smith et al.’s process was that the information garnered from the member checking was also included in the discussion write up.

Trustworthiness of Findings

Several credibility checks were used to ensure credible data were generated.

Reflexivity

To ensure reflective practice, the researcher acknowledged the ways in which both she and the selected research process shaped the data at the opening of this chapter (Mays & Pope, 2000). The researcher acknowledged her prior experiences and assumptions. In this case, the researcher identified her assumptions and made clear her previous experience regarding ASD populations. Although the researcher had awareness of ASD due to her previous knowledge and experiences, she is not a member of the population of investigation. As such, she acknowledges that her interpretation of the results, which were influenced by her experiences and exposure to research and scholarly literature in the fields of autism and counselling psychology, risked not aligning with the interpretation of autistic participants.

Member Checking

Member checking occurred as described above. This stage of the research process enhanced trustworthiness of findings as participants had the opportunity to read the information sent to them and to confirm or disconfirm if the themes and their definitions reflected what they had intended to communicate in their exemplars. Information gained from member checking was
included in the discussion portion of the write up. This approach acknowledged potential discrepancies between what the participants intended and the meaning interpreted by the researcher, thereby enhancing trustworthiness of themes and acting as a process or error reduction (Mays & Pope, 2000).

**Yardley’s Criteria**

Yardley (2000) presented four principles to assess the quality of qualitative research – intentionally applied in an open ended and flexible manner. Smith et al. (2009) argued that IPA is uniquely situated and designed to meet all four principles. As such, this section of the chapter reviews each of Yardley’s (2000) principles and indicates how the present study met each.

**Sensitivity to context.** Sensitivity to context should occur in the planning stage, through data collection and analysis, and in the research write up. In the planning stages, sensitivity can be demonstrated by understanding the body of relevant literature, the sociocultural setting, and the prevailing ethical issues present for the specific topic (Yardley, 2000). To do this, the researcher conducted a thorough literature review pertaining to the topic of study and considered the sociocultural and ethical issues relevant for this research. Currently, there is an underwhelming amount of autism research utilizing the first-person expertise of autistic people, as most current research focuses on the opinions of researchers, clinicians, and family members. The researcher sought to address this issue by conducting a purely qualitative study that intentionally and accurately represented the voices and experiences of autistic people.

When discussing sensitivity to context regarding data analysis, Yardley (2000; 2017) cautioned that one must not impose pre-determined categories on the data to show sensitivity to it, but instead let the data speak for itself by focusing on the meaning generated by participants. To accomplish this, the researcher strove to suspend her previous knowledge while analyzing the
data. She did this by considering multiple explanations and interpretations of the data in addition to contextual factors. Further, the researcher believed it was her ethical obligation to engage in member checking as voices of autistic people have not been well utilized in autism research. Emergent themes and definitions were sent to the participants and they could agree or disagree with the researcher’s interpretation and comment about ‘why’ or ‘why not’. These comments were then included in the discussion, ensuring the participants’ experiences were represented accurately.

**Commitment and rigour.** According to Yardley (2000; 2017), commitment and rigour can be demonstrated through detailed and exhaustive data collection and analysis. To have good rigour a data sample must be “complete” in its ability to supply enough information for a thorough analysis (Yardley, 2000, p.212). While IPA does not employ the concept of thematic saturation, it demonstrates rigour through the attentiveness taken in data collection and analysis (Smith et al., 2009). To do this, the researcher sought to set up a comfortable and empathic environment in which each participant felt capable of sharing. The researcher also ensured that participants felt that they could contribute to the interview process safely without fear of judgement, and in interviews, probed for more fulsome information. At the end of the interview, participants were also given the opportunity to share anything they felt was important for the researcher to know about. This opportunity generated rich data as the participants seemingly did not feel that their answers needed to be constrained by the research question and achieved the balance between closeness and separateness that Smith et al. (2009) contended is essential to comprehensiveness in data collection. The researcher also demonstrated commitment and rigour in the data analysis by being systematic and thorough. As Smith et al. recommend, the researcher intentionally paid attention to the idiography inherent in IPA analysis. This focus on the
particular resulted in a detailed and rigorous analysis that one could argue is only possible with a
small sample size as is recommended by IPA.

**Transparency and coherence.** Transparency and coherence refer to the reader’s ability
to see how the researcher interpreted the data (Yardley, 2017). For an analysis to be transparent
and coherent it must be persuasive in nature, while also being clear and logical (Yardley, 2000).
Readers must understand how and why the researcher developed each theme and, in a sense,
must be convinced that the research recreates the reality of the participants who experience that
phenomenon (Yardley, 2000). Smith et al. (2009) noted that the writer must clearly articulate
each of the steps taken to demonstrate transparency in the data analysis. The writer accomplished
this by detailing Smith et al.’s steps to data analysis and then following them. Smith et al. argued
that emergent themes must be tied together in a logical manner and adhere to the principles of an
IPA approach for the written analysis to be coherent. The writer upheld the philosophical tenets
of IPA (i.e., phenomenology, hermeneutics, and idiography) when conducting her analysis, and
incorporated each of these elements in a logical and concise manner.

**Impact and importance.** Yardley (2000) contended that one of the most important
aspects of quality research is its impact or utility. Yardley (2000; 2017) also stated that all
research should generate knowledge that has utility and/or can influence the actions/beliefs of
people. Yardley (2000) further elaborated that the only way to evaluate the value of research is to
focus on the objectives of the analysis, what the research is intended for, and/or the community
the findings are relevant to. IPA meets the need for utility as it is of unique import to the
participants of the inquiry (Smith et al., 2009). Of note, this study is of import as it is one of the
few studies investigating the first-hand perspectives of what it is like to receive an ASD
diagnosis later in life. As this topic is under-researched in ASD, this study demonstrates utility
and novel ideas regarding the experience of receiving a diagnosis, which is applicable not only to members of this population, but also to others who receive a diagnosis later in life.

**Ethical Considerations**

Below is a description of the ethical considerations for the study.

**Informed Consent**

Once prospective participants indicated they were interested in participating in the study and it was determined they met eligibility criteria during the telephone screening interview, an electronic copy of the consent form was sent to them for their review. Then, the details of the study were fully explained at the beginning of the in-person interview and all participants were encouraged to ask any clarifying questions about the consent form or the research process. The researcher then endeavoured to ensure that each participant clearly understood the consent form and provided additional information on specific details regarding confidentiality so that each participant was aware of what would happen to their personal information and data. Further, each participant was reminded that, based on the inclusion/exclusion criteria of the WASI-II and SRS-2, not all prospective participants would necessarily be eligible to participate in the interview. Despite this condition, no participants were excluded based on scores on these protocols. During this stage, participants were made aware that they could withdraw from the study at any point prior to data collection for any reason, without penalty or consequence.

**Monitoring for Safety and Needs**

To minimize any confusion and to address potential discomfort, participants were advised at the initial information sharing, during the consenting processes, and at the beginning of the in-person interview, about the aims of the study, the requirements of participation, and potential risks related to participation. All participants had experienced an ASD assessment prior to
receiving their diagnosis; hence, it was presumed that the expectations for study participation may have been viewed as relatively comparable to their prior diagnostic assessment experiences. Participants were informed that participation in the study could take approximately two and a half hours, and were advised that they could request breaks at any time. Breaks were also offered after the completion of the WASI-II and SRS-2.

It was anticipated that the content of the interviews could potentially elicit some emotional response. If this occurred, the researcher planned to consult with the participant to determine if they should continue participation. Participant options during times of emotional upset included taking a break from the interview, rescheduling the interview, withdrawing from the study, or continuing the interview without a break. As the researcher has completed a Master of Science in Counselling Psychology and was trained in interviewing and rapport building skills, she possessed the skills to manage and process emotions that might arise during the interview session. Moreover, the researcher has previously worked with autistic individuals and was knowledgeable about this population's needs. To ensure appropriate handling of participant concerns, the interviewer planned to record and then report any notable instances to her research supervisor. To further ensure the safety of participants, a resource sheet was given to everyone during the face-to-face meeting. This sheet informed participants about where to obtain psychological and/or ASD related community services. In a few instances, participants indicated interest in looking for more specific resources (e.g., AD/HD coaching) and the researcher provided information on how to obtain those resources. No participants experienced obvious emotional upset or distress throughout the interview process. However, one prospective participant arrived at the face-to-face meeting quite dysregulated. The prospective participant was upset regarding the length of time it would take to participate in the research and did not
consent to be audio-recorded or to have any information obtained in the face-to-face meeting used for research purposes. As a result, the participant was advised they were not eligible to participate in the research. This incident was recorded and the primary researcher consulted with her supervisor regarding the event. It was determined that appropriate steps had been taken during the informed consent process and that the researcher had provided the prospective participant with the consent form ahead of time, explained the details of the study in email communications, and verbally tried her best to explain the study parameters during the telephone screening interview. This incident demonstrated how the steps taken to protect participants were able to identify and prevent further distress, yet that clarity and support for participants are important.

Considerations for those who may have had specific needs were also put in place to maximize the ability of prospective participants to engage in the study. Interviews were conducted in fully accessible locations. Additionally, assistance from the researcher was offered if they had difficulties with reading or writing; no participants required this assistance.

**Data Storage**

To ensure confidentiality, all documents related to the research were anonymized and stored securely with access only being granted to the research team. Participants' names were never directly linked to the data, as their names were only present on a master sheet\(^3\) and consent form. Once all data was collected and member checking was complete, the master sheet was shredded. Further, the consent forms were stored separately from the master sheet in a locked

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\(^3\) The master sheet linked the participants with their assigned identification and contained information pertaining to the dates each participant participated and the extent of their participation (i.e., phone interview, WASI-II, in person interview). The purpose of this sheet was to organize and connect participant data to de-identified data for the purpose of contacting participants regarding member checking, gift-card draws, and/or clarification on responses.
filling cabinet, making it impossible to connect data back to individual participants. If participants mentioned their own names during an interview, the pseudonym selected by the participant on the consent form was transcribed in place of their name. Further, other potentially identifying information (e.g., name of workplace or autism agency) was left out of the transcription.

Audio files and electronic data were stored on a password-protected and encrypted USB drive. Both the USB device and all paper materials associated with the study remained in a locked cabinet when not in use. Only the primary researcher had access to this cabinet. At the conclusion of data collection, anonymized records were transferred to the University of Calgary where they were stored in a locked research cabinet (paper documents) and on an encrypted research drive on the University of Calgary mainframe computer until time of destruction, which is planned to occur ten years after data collection. At that time, all paper documents associated with the study will be securely shredded and all electronic files, including email communications, will be deleted. An independent transcriber and the research supervisor had access to the audio files and transcripts; they were required to sign a confidentiality agreement outlining their confidentiality responsibilities.

Confidentiality

As all participants were drawn from the autism community in Calgary, multiple steps were taken to maintain participant confidentiality. For example, participants did not receive information or exemplars from other participants’ interviews during member checking. This was done to ensure that no participants could be recognized from their exemplars, as it is possible that others in the community may identify that individual or situation when talking about one’s experience in a small community.
Compensation

On the consent form participants were asked if they would like to be entered into a draw to win one of two gift cards valued at $25 for participating in the interview and/or member checking portions of the study. Participants indicated their desire to be entered in the draws by checking the appropriate box on the consent form and by providing their email address so they could be notified if they were selected for the draw. Participants were able to enter a gift-card draw for both the face-to-face meeting and the member checking portions of the research process (if a participant engaged in both the interview and member checking they could enter both draws; however, participants could only win once). As 8 participants were recruited, the odds of winning either draw were 1:4 for the interviews and 1:3 for member checking (given that no participant was permitted to win the draw twice). Selected participants were contacted by email to organize mailing of the gift card. Privacy was maintained as the winners of each gift card were kept confidential, with only members of the research team having knowledge pertaining to draw winners. Additionally, parking/transit/driving expenses incurred by participants while attending the interviews were reimbursed to a maximum of $10.00 per participant, as per the average cost of parking at the University of Calgary according to daily and hourly parking fees; participants were asked to provide their receipt to be reimbursed and were given cash in hand.

Benefits of Research

The findings of this research can benefit autistic individuals and the institutions/agencies who work with them. By better understanding the experience of a late ASD diagnosis for autistic young adults, it is possible to decrease the number of individuals who experience self-stigma or other challenges in relation to their diagnosis while also improving the appropriateness of assessment and intervention supports and services provided to this population. Further, this
research may enhance diagnostic services for autistic individuals. As IPA in general, and this study specifically, examined phenomena of existential import to participants (Smith et al., 2009), this approach allowed participants to contribute to a topic in which they have a vested interest. Further, sharing of assessment and diagnosis experiences was likely to be validating and/or affirming for autistic people. This is especially important when considering ASD populations, as autistic individuals have not traditionally been invited to share their first-hand experiences in ASD related research. This investigation further allowed participants to confirm trustworthiness of the findings via the invitation to participate in member checking, which optimized accurate interpretation of first-hand perspectives. The risks (e.g., cognitive fatigue and/or emotional upset) associated with participating in this research were considered equivalent to those associated with general clinical practice when conducting history taking and diagnostic evaluation. As such, it is believed the benefits associated with the study outweigh potential risks.

This research will hopefully contribute to the literature regarding diagnosis of ASD. This is crucial as diagnoses have generally been considered stigmatizing (Ben-Zeev et al., 2010), with some researchers/clinicians calling for the reduction of diagnostic practice (e.g., Khoury et al., 2014). This study was also significant for the field of counselling psychology as it shed light on two divergent views of diagnosis in the field. The first view is that diagnosis is not aligned with the field of counselling psychology because it cannot be aligned with the values and assumptions to which some in counselling psychology ascribe (e.g., challenging the underlying principles of the medical model). The second view is that assessment and diagnosis are both practical and useful to the profession, with some counselling psychologists believing that diagnosis can be aligned with the values inherent in their field. While many practitioners’ beliefs fall somewhere between these views, examining these perspectives has contributed to the literature regarding
diagnosis in ASD populations and offer knowledge based in a Canadian counselling psychology context.

Summary

Few studies utilize the perspectives of autistic individuals, and investigation of the experience of receiving a late ASD diagnosis is exceptionally rare. Moreover, information that is reflective of the first-hand perspectives of autistic individuals is exceedingly valuable (Hurlbutt & Chalmers, 2002; Jones, et al., 2001); the field continues to under-explore the first-hand expertise that autistic individuals can offer about their lives and perspectives. Autistic young adults who receive a late diagnosis of ASD are in a unique position to offer their perspective about both what their lives were like before and after receiving their diagnosis. Information specifically focusing on this perspective and duality will help to bridge a substantial gap in the literature.
CHAPTER 4: FINDINGS

This chapter reviews the results of the study by beginning with a description of the research participants. Each theme is then presented with in-depth descriptions and verbatim quotes for illustration. Given the breadth in presentation in the autism spectrum, a range of quotes has been selected to demonstrate the variability of exemplars within each theme.

Participant Characteristics

The sample consisted of eight participants (three males, three females, one transgender male, and one non-binary person who was assigned female at birth) aged 18-31 ($M = 25.25$, $Mdn = 25.5$). Age at time of diagnosis ranged between 12-29 years ($M = 20.38$, $Mdn = 21.5$). Time since diagnosis ranged from approximately nine months to approximately 16 years (time is approximate as participants did not always recall the exact date of their diagnosis; $M = 4.94$, $Mdn = 2.5$). Most of the sample was White (87.5%), with one individual identifying as Japanese and White. Five (62.5%) individuals indicated they had an ASD diagnosis, while two (25%) indicated an Asperger’s diagnosis, and one (12.5%) a PDD-NOS diagnosis. FSIQ scores ranged from 104-123 ($M = 114.13$, $Mdn = 115.5$), while SRS scores ranged from 60-90+ ($M = 76.63$, $Mdn = 78$).

All participants indicated having multiple other diagnoses (see Table 1), including AD/HD (e.g., inattentive, combined presentation), learning disorder (reading, written expression), Tourette’s disorder, oppositional defiant disorder (ODD), generalized anxiety disorder, social anxiety disorder, panic disorder, agoraphobia, bipolar I disorder, cyclothymia, major depressive disorder, persistent depressive disorder (dysthymia), posttraumatic stress disorder (PTSD), obsessive compulsive disorder (OCD), trichotillomania, excoriation disorder, body dysmorphic disorder, insomnia, binge eating disorder, anorexia, gender dysphoria,
developmental coordination disorder, obsessive compulsive personality disorder, borderline personality disorder, alexithymia, and sensory modulation disorder.

Table 1

Co-Morbid Conditions

<table>
<thead>
<tr>
<th>Condition</th>
<th>Number</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>AD/HD – Inattentive</td>
<td>1</td>
<td>12.5</td>
</tr>
<tr>
<td>AD/HD – Combined</td>
<td>5</td>
<td>62.5</td>
</tr>
<tr>
<td>Learning Disorder – Reading</td>
<td>1</td>
<td>12.5</td>
</tr>
<tr>
<td>Learning Disorder – Written Expression</td>
<td>2</td>
<td>25</td>
</tr>
<tr>
<td>Tourette’s Disorder</td>
<td>1</td>
<td>12.5</td>
</tr>
<tr>
<td>Oppositional Defiance Disorder</td>
<td>1</td>
<td>12.5</td>
</tr>
<tr>
<td>Generalized Anxiety Disorder</td>
<td>5</td>
<td>62.5</td>
</tr>
<tr>
<td>Social Anxiety Disorder</td>
<td>2</td>
<td>25</td>
</tr>
<tr>
<td>Panic Disorder</td>
<td>1</td>
<td>12.5</td>
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<tr>
<td>Agoraphobia</td>
<td>1</td>
<td>12.5</td>
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<td>Cyclothymia</td>
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<td>Bipolar I Disorder</td>
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<td>12.5</td>
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<tr>
<td>Major Depressive Disorder</td>
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<tr>
<td>Persistent Depressive Disorder</td>
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<tr>
<td>PTSD</td>
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<td>OCD</td>
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<tr>
<td>Body Dysmorphic Disorder</td>
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<td>Trichilomania</td>
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<td>Excoriation</td>
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<tr>
<td>Insomnia</td>
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<td>25</td>
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<tr>
<td>Binge Eating Disorder</td>
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<td>12.5</td>
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<td>Anorexia</td>
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<tr>
<td>Gender Dysphoria</td>
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<tr>
<td>Developmental Discoordination Disorder</td>
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<td>Obsessive Compulsive Personality Disorder</td>
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<td>Borderline Personality Disorder</td>
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<tr>
<td>Alexithemia</td>
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<tr>
<td>Sensory Modulation Disorder</td>
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Findings

This section of the chapter reviews the findings from the data analysis. The first portion of this section describes the audio and transcribed data, while the latter describes the themes that emerged from the data analysis.
Audio and Transcriptions

Interview duration ranged from 25-66 minutes ($M = 45$, $Mdn = 41$); transcription files ranged from 19-83 pages ($M = 43.25$, $Mdn = 31.5$). The transcriptionist transcribed the audio recordings verbatim, and used // to indicate laughter and (( to indicate portions of the audio file that were inaudible. Portions of the transcript that could be considered identifiable personal information (e.g., participant name, name of city, name of resource/service centre) were omitted during the write up. In the exemplars, the interviewer is identified by I in italic text, while each participant is identified by P in standard text. During the interviews, the interviewer used acknowledging phrases to communicate to the participants that she was listening and understood the information being conveyed (e.g., yeah, mhm, okay). These phrases were transcribed verbatim but have been left out of the final write up to increase readability and to reduce interruption of participant exemplars. During the data analysis, some exemplars met criteria for more than one theme; these have been double coded and appear in multiple themes.

Thematic Findings

Three levels of themes emerged during the data analysis (see Figure 1). The two Level 1 themes represented different time frames: pre-diagnosis and post-diagnosis. All themes in the pre-diagnosis category reference the period in each participant’s life prior to receiving their diagnosis, whereas the post-diagnosis category refers to the period of time after they received their diagnosis. Each Level 1 theme was then broken into four Level 2 themes: pre-diagnosis (circumstances leading to diagnosis, hidden diagnosis, alternative identities, and potential negative outcomes of not having an ASD diagnosis) and post diagnosis (settling into diagnosis,

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4 All theme titles derived from this research will be written in italics to prevent confusion with theme titles identified in other literature as references in the introduction and discussion.
potential benefits of receiving an ASD diagnosis, potential negative outcomes of an ASD diagnosis, and desires. Four of the Level 2 themes were then broken down further into Level 3 themes: potential negative outcomes of not having an ASD diagnosis (falling through the cracks, negative treatment experiences, overlooking or misattributing ASD symptoms, lack of understanding and confusion, blaming self, and relationship difficulties), potential benefits of receiving an ASD diagnosis (access to supports; confirmation, validation, or explanation; action-based self-awareness; ASD is less stigmatizing; landing ground or starting point; enhanced or improved view of self; and improved relationships), potential negative outcomes of an ASD diagnosis (assumptions, stigma, and stereotyping; diagnosis can lead to excuses; dislike for ASD supports or services; and improved awareness can lead to shame), and desires (to be treated equally, but with understanding and respect; specialized research; access to supports and resources; earlier diagnosis; accurate representation of diversity; perspectives on language and labelling; easier access to assessment; and better clinical training and knowledge). A total of 29 themes/subthemes emerged from the analysis. Each of the themes/subthemes is accompanied by a definition and exemplars that elucidate its relevance (see Table 2). While many of the themes applied to many or all the participants, some experiences were more unique and were thus only relevant for a few (see Appendix H to see which themes apply to individual participants).
Figure 1. Theme levels and titles for the experience of a late ASD diagnosis.

Table 2

Theme Table

<table>
<thead>
<tr>
<th>Level 1 Theme</th>
<th>Level 2 Theme</th>
<th>Level 3 Theme</th>
<th>Definition</th>
<th>Supporting Exemplar</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre-Diagnosis</td>
<td>Circumstances Leading to Diagnosis</td>
<td>---</td>
<td>The circumstances that led an individual to seek out an ASD diagnosis</td>
<td>I: Who initiated the referral for the assessment? P: Um… I believe that was the Government of Alberta. Because I was in the process of trying to get into the AISH program. So they, they made me go through several hoops with different psychiatric situations and...</td>
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<tr>
<td>Hidden Diagnosis</td>
<td>---</td>
<td>Any instance where an ASD diagnosis has been hidden from an autistic person</td>
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<tr>
<td>Alternative Identities</td>
<td>---</td>
<td>The development of alternative identities to help explain ASD symptom presentation</td>
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<tr>
<td>Potential Negative Outcomes of not having an ASD diagnosis</td>
<td>Falling Through the Cracks</td>
<td>Missed opportunities or a lack of supports because no ASD diagnosis was in place</td>
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</table>

**I:** Okay. Yeah, okay. And so you were applying for AISH...were you off of work or...?

**P:** Yeah, I was just having a rough go of things, so... helpful to have that support.

**P:** And that my parents kept it from me. Uh... the diagnostician, the psychologist, advised my parents not to tell me about it.

**I:** So how did you understand yourself before the diagnosis then?

**P:** That I was just the odd-ball kid. Like just the classic, stereotypical kind of weird, likes to stay inside and read books all day.

**P:** I wish I could think of more things, but um... I honestly wish that I was diagnosed a lot early than I was, because maybe – maybe – my
parents would have been more proactive with getting me into some kind of… I don’t know, program to help me figure things out, because I mean, if I had learned a lot of the skills that I have now, back when I was younger and more impressionable, it would have made a large difference I think.

### Negative Treatment Experiences

| I: Do you think if you got the autism diagnosis earlier in life, before these other diagnoses, would that have changed anything for you? | P: Hell yeah //. It would have made things a lot easier.

I: Yeah. In what way?

P: Um… well for one, not being – having pills shoved down my throat at age 6.

### Overlooking or Misattributing ASD Symptoms

| P: Um… and so I – when I was meeting with [NAME OF |
A lack of understanding and/or confusion regarding autism symptoms that can result from not having an ASD diagnosis

I: Okay. Do you think your life would be different if you never received a diagnosis?
P: I think it would. Like, I’m not sure I could articulate how it would be different, but I think I would just be trying a
<p>| | | |</p>
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<tbody>
<tr>
<td>Blaming Self</td>
<td>When autistic individuals believe they are at fault for their difficulties because they do not know they have ASD</td>
<td><em>lot harder to sort of make sense of the way that I relate to the world and I would sort of always have a mystery around me.</em></td>
</tr>
<tr>
<td></td>
<td></td>
<td><em>Blaming Self</em></td>
</tr>
<tr>
<td></td>
<td><em>I: What did being mislabeled early in life result in?</em></td>
<td><em>P: Just me basically feeling like I was a freak. Like I was wrong in some way. When I was just a kid trying to be a kid and parents and teachers basically saying, ‘oh you’re doing this not right, you’re not doing this.’</em></td>
</tr>
<tr>
<td>Relationship Difficulties</td>
<td>Difficulties trying to understand, establish, or maintain relationships</td>
<td><em>P: I was just bullied constantly. Like, through the whole thing. But I didn’t really understand even that I was getting bullied - for a lot of it. I just… kind of… it just turned into like, I deserve this because I’m a bad person, thing.</em></td>
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<tr>
<td>Post-Diagnosis</td>
<td>Settling into Diagnosis</td>
<td>The time it takes to adjust to</td>
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<tr>
<td>Potential Benefits of Receiving an ASD Diagnosis</td>
<td>Access to Supports</td>
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<tr>
<td>Access to intervention, treatment, services, or opportunities as a result of an ASD diagnosis</td>
<td>about the diagnosis I was ignorant about what that diagnosis meant. And that’s really what harmed me. I was ignorant about the fact that it was happening in general.</td>
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</table>

I: Did your life change in any substantial way? Like any other ways?

P: I mean I got more help in school

I: More help in school?

P: Because they finally gave me the supports that I needed. Extra time in tests and you know, some kind of like – access to the – they called it the [NAME OF RESOURCE CENTRE] in high school. Uh… it was a specialized sort of study area where you could get help from people there that were – there’s just more of them than anywhere else in the school.
**Confirmation, Validation, or Explanation**  
Receipt of an ASD diagnosis provides confirmation, validation, and/or explanation of why an individual is the way they are.

**ASD is Less Stigmatizing than Other Diagnoses**  
The view that ASD is a less stigmatizing compared to other diagnoses.

**Landing Ground or Starting Point**  
An ASD diagnosis  

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**I:** So since receiving your diagnosis, has the diagnosis changed the way that you view yourself?  
P: Um… not really, I think it’s more confirmed a lot things that I noticed when I was younger. Just growing into adulthood it sort of confirmed a lot of things that like, ‘oh that’s why I reacted in that way,’ or ‘oh that’s why I have this particular little behavioural quirk that people would’ve picked up on.’

P: It just helps to explain a lot of things and a lot of people are more sympathetic towards a kid that is like, ‘oh the kid is autistic,’ as opposed to ‘oh the kid is AD/HD’ or ODD or the kid is – for a bizarre reason – oh they’re schizophrenic at age 6.
<table>
<thead>
<tr>
<th>Action-based self-awareness</th>
<th>An increase in self-awareness after receiving an ASD diagnosis</th>
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</thead>
<tbody>
<tr>
<td>Enhanced or Improved View of Self</td>
<td>A positive change in the way autistic individuals view themselves after receiving an ASD diagnosis</td>
</tr>
</tbody>
</table>

**I: Has the diagnosis benefited you in any way?**
P: It has, not necessarily in terms of like I guess a tangible way, but more just in – in the sense that it’s helped me mentally and its sort of, just with self-understanding and self-awareness.

**I: Now that you have this new label, has anything changed for you?**
P: I think so, I think it’s – I think it’s allowed me to sort of perceive myself in a – in a favoured way. In a more sensitive way to myself, because before I
was – if I was doing something wrong I would feel that was bad. Whereas if I was doing something wrong now I would just… in certain situations I would be able to say, ‘well it’s just because I’m different.’

<table>
<thead>
<tr>
<th>Improved Relationships</th>
<th>An improvement in personal relationships after receiving an ASD diagnosis</th>
</tr>
</thead>
</table>

P: Um… because before it was really difficult to navigate making friends. But now I sort of understand the stages of going through like, OK now we sort of are past the pleasantries stage, now let’s get a little bit more like, emotionally connected and things like that.

<table>
<thead>
<tr>
<th>Potential Negative Outcomes of an ASD Diagnosis</th>
<th>Assumptions, Stigma, and Stereotyping</th>
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</table>

P: So then it almost makes you seem like less of a person to them because then they immediately think of the classic autism person who can’t verbalize anything, sits around flapping their arms, screaming, very
低智商，这就像……
不，那不是我，
但有一些
相似之处，但
不像你想象的
那么多，而且
有一种非常负面
的倾向。

对Autistic
诊断会带来借口

一个诊断可以
导致借口，这些借口
有潜力限制
自闭症患者

P: 有些人
会说，他们会
说，‘哦，你有
这个，所以你
会当盾牌。

对Autistic
的厌恶

对Autistic
的厌恶

P: 我其实
不喜欢
ABA
培训的
大部分
。因为……它不
适用。
我唯一
发现它
适用的
地方，
就在
几周前
的
相亲。

改善
意识
可以
导致
guilt

改善
理解和
自我
意识
可以
导致
关于
当前
症状
呈现
或
过去行为的
羞愧

P: 是的，就像
……有一个
例子，
这个女孩
走过来
拥抱我，
然后
走了，
我非常
幸福。
我想那是
great。
但是
再想想
它，就像……
it was a dare. People were trying to make fun of me //. I: Yeah, yeah. That’s really frustrating. P: So like… I mean, thankfully I was oblivious so it didn’t really hurt at the time, but it’s still… it’s – it’s odd to look back and understand – I: And have that awareness? P: Yeah. Ignorance is bliss //.

Desires

To be Treated Equally, but with Understanding and Respect

A desire to be for others to treat autistic people the same as non-autistic people, while still understanding and respecting autistic differences

P: Um… if I had control over the way people viewed me I guess it sort of depends. Because I want people to see me… as an equal in sort of all respects. Um… but I also want people to understand that I don’t necessarily see the world the same way that they do. And I – I would want people to sort of be sensitive to that.

Specialized Research

A desire to have research investigate

P: Um… I hope you guys just keep doing more
different aspects of ASD research into it because there needs to be more research shown that it’s like, hey autism is a spectrum and there are people that are lower functioning, high functioning, sort of in the middle, and like… it doesn’t mean that the person is like a whole other species of person, is what I seem to have been encountering where it’s just like, like everyone is a little bit different in their own ways, like, perhaps not everyone has autism, but everyone does have slight little peppering’s of similar traits, and it’s good that we’re doing research into this and I hope that you have good success with this research initiative because like, it needs to be done. And I’m sure a lot of it is common
sense to some researchers in the field, but common sense doesn’t get published as papers, you have to have data.

P: Um… I suddenly do see a large difference between supports when I was, you know, 15 – a teenager, and now that I’m 24. It dries up a lot, and you go basically anywhere online, and most of it is stuff with development and, you know, beginner social skills and all that stuff, there’s not much for… anyone who has tried to //, go past that or managed to go past that.

I: Yeah. So I’m hearing that there is a lack of supports for adults – P: Yes.

I: And the type of supports don’t necessarily meet your needs? P: Yeah.
<table>
<thead>
<tr>
<th>Earlier Diagnosis</th>
<th>A desire to be diagnosed earlier in life</th>
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<tr>
<td><strong>I:</strong> Do you think if you got the autism diagnosis earlier in life, before these other diagnoses, would that have changed anything for you?</td>
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<tr>
<td><strong>P:</strong> Hell yeah //. It would have made things a lot easier.</td>
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<tr>
<th>Accurate Representation of Diversity</th>
<th>A desire for ASD to be accurately represented as a spectrum condition</th>
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<tr>
<td><strong>P:</strong> Um… also like, a lot of TV shows and things that are coming out these days, I’m not sure are helping it. Because it is so different for everyone. They’re taking very classic symptoms and I’ve watched those because I think it’s funny what they think of most people. Um… it would be nice to see a TV show with a girl that’s autistic.</td>
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<tr>
<th>Perspectives on Language and Labelling</th>
<th>Preferences regarding language and labelling used to describe ASD</th>
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<tbody>
<tr>
<td><strong>I:</strong> As a person who has been given a few of these labels do you find any of this labelling helpful?</td>
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<tr>
<td><strong>P:</strong> I find it more harmful than</td>
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<tr>
<td>Easier Access to Assessment</td>
<td>An expressed desire to be diagnosed with ASD at an earlier age</td>
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P: When you have to do it as an adult – like, to get my diagnosis, was I think – between having to commute, because I had to come to [CITY] to go to a specialist um…

helpful. Um… uh… yeah, the idea that I’m a disorder is – is simply wrong. I mean, we don’t have to look back very far to see when gay people were considered a disorder. And now it’s obviously very wrong to think of it that way. It’s just normal variation. I feel the same way about neurodivergence. I have a different way of perceiving the world. And so when I’m labelled as a disorder and these sorts of things – and the way that they – that they try to classify it that way.
and then go through with a clinical psychologist a whole battery and interview of like, two days of testing straight - Um… which is exhausting on me, but it’s like… that was probably close to $5,000. To get a diagnosis. And it’s like, we know that people who are autistic, whether they’re diagnosed or not //, but people who have these traits are more likely to be unemployed. And so, there are so many barriers to accessing diagnoses once you’re an adult.

<table>
<thead>
<tr>
<th>Better Clinical Training and Knowledge</th>
<th>A desire for health professionals to have better understanding of ASD</th>
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<tbody>
<tr>
<td>P: Um… and a lot of people, I’ve even – people like doctors, psychiatrists – don’t understand it. Don’t know how to treat it. Don’t know how to diagnose it. Um… and it’s really frustrating.</td>
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Pre-Diagnosis

This Level 1 theme refers to the time period that occurred prior to each participant’s diagnosis. This category consists of four Level 2 themes and related sub-themes. The Level 2 themes present in this category are: circumstances leading to diagnosis, hidden diagnosis, alternative identities, and potential negative outcomes of not having an ASD diagnosis.

Circumstances Leading to Diagnosis. This theme refers to the circumstances that led an individual to seek out an ASD diagnosis. In each instance the participant or one of their caregivers sought an assessment because the participant was displaying ASD symptoms or experiencing difficulties in their daily lives. In the excerpt below, the participant’s teachers noticed symptoms that were reminiscent of ASD and helped initiate an assessment referral.

I: Who initiated the referral for an assessment for a diagnosis, do you know?
P3: I think uh… my teachers did.
I: Teachers? Okay. Yeah. And do you know why they did this?
P3: Um… it more specifically said in my file, because I wasn’t really making friends in school. I tended to engage in a lot of repetitive tasks. And would get hyper-focused on one thing. It was like tunnel vision over here – like really concentrating, but no work was getting done.

While in the previous example a teacher picked up on and noticed the participant’s ASD symptoms, in the below example, a friend of the participant had an ASD diagnosis and recommended the participant get assessed as they shared similar symptom features.

P4: Because [FRIEND] had been diagnosed by this doctor with autism and she noticed that I exhibited a lot of the same symptoms so she was like, ‘hey you should go see this guy.’

In another example, the participant was aware they may have ASD and thus initiated the referral on their own. In this example, the participant was experiencing multiple concerns and often ended up in the hospital because she lacked appropriate treatment.

I: Who initiated the referral for an assessment for a diagnosis?
P7: Me.
I: Yeah? And how come?
P7: I knew that I… I knew that I probably had an autism – or probably should have – an autism diagnosis. I have worked in education for almost 10 years now. I’ve worked with a lot of kids who are autistic. And um…it’s kind of funny like, when you’re autistic you kind of – you know you’re not quite the same as everybody else. Like, you know you’re different, but you don’t really know why. Um…and I knew that I was having issues with – I had a lot – I was dealing with a lot of sensory overload. I had um… mine started out with getting a lot of other mental health diagnoses that didn’t really quite fit. Um… where like, parts of it fit… um… but… it didn’t quite encapsulate everything that was going on. And, uh… one of the things that is talked about in the autism community, um… is autistic burnout. And that was definitely what I was going through. But I didn’t have a name for it, I didn’t know what it was. But it was like I wanted out of my situation in a lot of cases, and that would end in like, hospitalization. So like, I’ve been in the hospital over 10 times. For like, months and months at a time. Pretty much spent all my teens in the hospital. And it was just like, it was kind of like ‘enough is enough’ like, I need to do something to be able to get the support that I need. Or at least have it on paper //.

Hidden Diagnosis. This Level 2 theme refers to any instance where an ASD diagnosis has been hidden from an autistic person. Three separate exemplars from the same participant describe how parents hid an ASD diagnosis from their child following the recommendation of a clinician. The participant then recalled how being deceived about their diagnosis resulted in feelings of anger, with the participant noting they wished they were told about their diagnosis when it was assigned. The participant also noted later in the interview that the deception caused them to think that having an ASD diagnosis was a bad thing.

I: When you found out about the diagnosis, did it change the way you view yourself?
P3: Um… no, mostly it made me angry that somebody thought this about me without talking to me about it. And that my parents kept it from me. Uh… the diagnostician, the psychologist, advised my parents not to tell me about it.

P3: Which led to a lot of misunderstanding about what it actually was.
I: Yeah, yeah. Were you angry about – more about the diagnosis itself or not being told?
P3: I was angry about the deception. Like absolutely. That’s the thing that made nothing else going, because I’m like – ‘if this had any sense to you, you would’ve just told me,’ kind of attitude.
I: Yeah. Do you think anything would’ve changed if you had just been told when you were actually diagnosed?
P3: I think a lot of things would’ve changed.

P3: It especially creates this kind of idea that there is something wrong with the diagnosis, not only creating the ignorance about self, but creating a negative image about that self.
I: Mhm, yeah. So withholding the diagnosis kind of makes it seem like the diagnosis itself is wrong or bad?
P3: It makes it seem like the diagnosis is a bad thing. That it’s bad to be considered this kind of person.

In the next exemplar another participant recalled an instance where they knew about someone else’s hidden diagnosis and stated how if they were in the same situation it would leave them with feelings of confusion.

P4: Um… her little cousin was diagnosed with autism very, very young. And her aunt chose to withhold this diagnosis from the cousin and, it’s – it’s been years since that happened and my friend who is also autistic is just like, ‘I just wish I could tell him, I feel like it would be so helpful and I feel like he would be able to understand himself so much more.’
I: Mhm, yeah. So you think that not having a label to understand yourself can be problematic?
P4: It’s not not having a label. It’s just having a label that is hidden from you.
I: Yeah, yeah. So this kind of… hidden label… how could that be difficult or problematic?
P4: Um… it’s interesting because I feel like if I was – if I was in the little cousin’s position I – I would notice parents – like my parents and other people’s – like other adults – treating me differently than other children. I would – I would never understand why.

Alternative Identities. This theme references the development of alternative identities to explain ASD symptom presentation. These alternative identities are not harmful in nature and therefore are not considered a potential negative outcome of not having an ASD diagnosis. However, each of these identities was developed because an individual was not aware that they had ASD. Some participants reported being a “weird”, “odd”, or “quirky” individual and further stated that identifying this way was adaptive as it helped them understand themselves and view
themselves in a more positive light. In the first exemplar, a participant explained how labelling themselves as the quirky one allowed them to find humour in their differences.

P6: And I had like, a few good friend groups, but I was always the quirky one, I laughed at my weirdness, I laughed at whatever, and every time I did something wrong, they’d laugh at me and I’d just laugh with them.

Another participant stated that viewing themselves as an ‘odd-ball’ was beneficial.

I: Yeah. Okay. So understanding yourself as kind of the ‘odd-ball’ would you say that this is a positive or a negative thing?

P1: It’s a positive thing. I know that traditionally people don’t like that label slapped on them, but I’m sort of the opposite of – sure, you can put another label on and then it just helps me understand more things and gives a bit more of a clinical perspective for folks who are trying to help with my mental health to give them more data. Because more data is always good.

Other participants identified with the diagnostic labels they had previously been assigned. In the example below, a participant explained how they used their diagnoses to understand themselves, but also noted that the addition of the ASD diagnosis increased their personal understanding.

I: How did you understand yourself before the diagnosis?

P1: Ah… that I mainly was just suffering from depression, and generalized anxiety, and possible post-traumatic stress, and then with the autism lumped on there it helped to sort of encapsulate everything, as to make sense as to why I react to certain things in different ways.

Other participants self-identified/presumed that they had ASD, despite not having an official diagnosis. This demonstrates an alternative identity because this identity was not, at the time, officially available to them. In the example below the participant noted that because they already suspected they had ASD, receiving the official diagnosis did not change the way they viewed themselves.

P7: So… yeah. So, and yeah, it’s – my, my husband knew too. Like we knew – we’d known this already for like, probably 5 years. Like we knew that was most likely um… that I probably did have autism.
I: So did the diagnosis change the way you view yourself?
P7: No, I knew I was – I knew.
I: Yeah, OK. So you already had this idea that you had autism?
P7: Yeah.

**Potential Negative Outcomes of not having an ASD Diagnosis.** This theme refers to any potential negative outcome that can occur because a person does not have an ASD diagnosis. This theme consists of six Level 3 themes titled: *falling through the cracks, negative treatment experiences, overlooking or misattributing ASD symptoms, lack of understanding and confusion, blaming self, and relationship difficulties.*

**Falling Through the Cracks.** This theme refers to missed opportunities or a lack of supports that occurred because no ASD diagnosis was in place at the time. Participants noted that a lack of supports could present in a variety of different ways. One participant recounted that although a lack of treatment was beneficial because it encouraged them to work extremely hard, it also meant they missed out on earlier intervention therapies.

I: Yeah, the benefit is that you – I think, if I’m understanding correctly, that you had to work really hard to kind of get where you are. But the harm was that you missed out on these other opportunities.
P6: Yeah, like I could’ve had earlier intervention.

Others related that a lack of an ASD diagnosis resulted in hospitalizations because they did not have appropriate treatment or support for their concerns. The same participant also related that a lack of diagnosis changed her educational experience. In this example the participant fell through the cracks because her concerns were overlooked and she received no treatment other than hospitalization.

I: So do you think your life would be different if you were diagnosed earlier?
P7: Probably. Yeah.
I: What would have been different?
P7: Oh my god… um… //. Like, I probably wouldn’t have spent all of my teenage years in the hospital. I probably would’ve done schooling a lot differently. I
probably wouldn’t have gone to public school. Which would’ve been a positive thing for me. Um… because I just – I was just bullied constantly.

Others also reported being unable to access ASD-related opportunities (e.g., specific camps, workplaces, or social opportunities) without a diagnosis. In the example below, a participant recounts how they would have been able to attend organized school outings with other autistic children if they had a diagnosis. When reflecting on this loss, the participant noted they felt aspects of grief in relation to missing out on these opportunities.

P6: There is one part where like, there was this aspect of grief of like, ‘oh I could’ve gone out with all the other special needs or autistic kids in my school. I could’ve gone swimming, I could’ve had all this social integration from an early age.’

**Negative Treatment Experiences.** This theme refers to a dislike for treatment experiences prior to an ASD diagnosis. In the first example, a participant was diagnosed with AD/HD and ODD as a youth, which resulted in the used of stimulant medications as his only form of treatment. The participant held a great dislike for this treatment approach and believed that his treatment would have been approached differently had he previously received an ASD diagnosis.

*I:* Do you think if you got the autism diagnosis earlier in life, before these other diagnoses, would that have changed anything for you?

P1: Hell yeah //. It would have made things a lot easier.

*I:* Yeah. In what way?

P1: Um… well for one, not being – having pills shoved down my throat at age 6, hopefully. And just a little bit more understanding from adults that I’m just a kid who has problems and not a problem to be dealt with. Because unfortunately that was sort of the way I was dealt with, like ‘oh you’re just – you have this.’ Instead of you are this, you have this, so then you just treat the problem with a solution and that’s the end of it. Whereas autism is meant to be a lifelong thing that can’t be cured, because that’s a little bit more of a healthy mindset towards people because we’re not broken machines. We’re people that have problems that some are conquerable, some are not.

P1: I just kept falling through the cracks. And at least autism is the nice net at the bottom to go like, ‘well you didn’t meet these diagnostic criteria or you just fell through for whatever reason,’ so… somewhere to land at least.
I: Yeah, do you think that if you had received an autism diagnosis earlier in life instead of an AD/HD or ODD, do you think that would’ve changed anything in way of your relationship with your parents?

P1: Yeah, because they wouldn’t have shoved pills down my throat right away. They would have – I hope – at least pursued alternative methods of treatment or just living in general.

Another participant reported that she was often treated with cognitive behavioural therapy (CBT) when she accessed treatment options prior to her ASD diagnosis, which she did not find helpful. One could presume that if she had the ASD diagnosis prior to engaging in mental health treatment, a different approach may have been utilized or offered.

P7: Um… a lot of like, even clinical psychologists are not really trained well on a lot of it. So like, even though I had… what was frustrating for me is like, I… would go through – and I’d been through like, tons and tons and tons of psychologists and like, they’d always, they love – because psychologists love CBT for whatever reason, they love it. And I don’t, because it’s a lot of like, how to – ‘how do you feel about this and, what’s the effect, and that…’, and I – I don’t know how I feel most of the time. Um… and I can’t really tell. I know frustrated but I don’t really know why I’m frustrated a lot of the time.

Overlooking or Misattributing ASD Symptoms. This theme refers to a failure to consider that an individual’s symptom presentation was related to ASD. In some instances symptoms were ignored, and in others, misattributed to other diagnoses. In the first exemplar a participant was assigned multiple different diagnoses, but noted that none of those diagnoses fully covered the extent of her concerns. Later in the interview, the same participant shared she had been diagnosed with anorexia, but noted that her presentation was drastically different from others with the same diagnosis.

P7: Um… mine started out with getting a lot of other mental health diagnoses that didn’t really quite fit. Um… where like, parts of it fit…but… it didn’t quite encapsulate everything that was going on.

P7: And it’s like, OK well, you know, instead of like… you know, I had an anorexia diagnosis for a long time. And so, but what I was doing… that was basically just not eating, because I was so stressed out from all of my social interaction during
the day and everything that was going on and all the sensory overload and stuff like that, so it was like, ‘I need to get out of this situation,’ and the only way that I knew how to get out of that situation was to be pulled from my life and be stuck in a hospital.

P7: I noticed there’d be girls who were like, really afraid of eating certain foods. Because of like, calories or because of fat content. And I’d like, I was never like that. It was kind of like, ‘what if this is expired? What if the texture is wrong? What if it feels wrong in my mouth? This is not a chicken finger.’

In an example also illustrated in Table 2, a participant noted that her report cards had comments that were indicative of ASD symptomology but that people attributed these symptoms to AD/HD instead. This misattribution of symptoms is similar to one of the exemplars from the negative treatment experiences theme where the individual was diagnosed with and then subsequently treated for AD/HD and ODD.

P5: Um… and so I – when I was meeting with [NAME OF PSYCHOLOGIST] I had to send her a bunch of report cards with teacher comments and she was laughing - she was like, it was so obvious but nobody clued in. Because there would be comments like, “[participant] won’t stop re-arranging her pencil crayons and like stuff like that.” Or coming up to me and being like, did you know the pattern in the carpet is like this?” // Like stuff like that, but no one ever like thought anything, they just thought I was AD/HD or something like that.

Lack of Understanding and Confusion. This theme refers to a lack of understanding and/or confusion regarding autism symptoms that can result from not having an ASD diagnosis. The confusion resulted from individuals experiencing and/or displaying signs and symptoms of ASD without having a label to explain and/or externalize those symptoms. All eight participants had exemplars in this theme.

In the first example, a participant reported that dealing with constant mystery regarding oneself is unhelpful. This participant also related that if one has a diagnosis and is aware of that diagnosis, then there is an option to improve upon or do something about it.
I: So do you think that withholding or not giving a person an ASD diagnosis – can that hinder some people?

P2: I feel like that would hinder someone more than anything. Yeah, I… even if… people can learn to live with anything, but living with an eternal question mark in your head is never going to help. At least one way you have the option of improving, the other one you don’t.

Another participant stated that they were unable to understand themselves prior to their diagnosis, which resulted in being easily influenced by others in their life.

I: Okay. How did you understand yourself before the diagnosis?

P4: I didn’t // in a way.

I: // Okay.

P4: Um… I mean, before I – before I sort of got to see a psychiatrist and sort of figured out what was up with me. I just sort of knew that something was wrong, but I couldn’t articulate what it was.

I: So what was that experience like? Knowing that something was wrong and not being able to articulate it?

P4: It was challenging, and I feel like it was a lot easier for me to be influenced by other people’s view of me.

Another participant related a similar experience, where they experienced many struggles and knew something was off, but did not have a way to conceptualize and/or understand their experiences.

I: How did you understand yourself before your diagnosis?

P6: I don’t think I did //. Like… it was just… I knew I had all these struggles. I mean, I was getting frustrated before as well. Especially within grade 8. But like, there’s just these – like there was something missing. But I was not aware of what that – like, I could not figure it out.

Finally, other participants recalled that they had a difficult time understanding specific ASD symptoms. These participants referred to not understanding sensory concerns, behavioural differences, and/or social deficits. Meanwhile, another participant was confused as to why non-ASD-specific treatment was not alleviating her concerns.

Blaming Self. The exemplars in this theme all relate to self-blame that occurred when participants believed they were at fault for their difficulties because they did not know they had
ASD. It seems that many participants internalized their difficulties and/or symptom presentation when they lacked a label to help externalize their concerns. Many participants reported believing they were at fault for their difficulties because they were not understanding others and/or not working hard enough. In the first example a participant specified this precise sentiment.

**I:** How did you view yourself before the diagnosis?
**P2:** It was… It was confusing I guess? I mean it was… a lot of unknowns. I thought I was just… like it was actually my actions, or I was just not getting something not understanding or not working hard enough or a lot of the things that happen when you don’t know.

In another example, a participant clearly stated that they thought something was wrong with them and therefore blamed themselves because they did not have a label to help understand their symptoms.

**I:** Because you would have had Asperger symptoms before the diagnosis. So how did you make sense of those symptoms?
**P5:** I didn’t.
**I:** Yeah. Did you have any thoughts or feelings about those symptoms?
**P5:** Um… I think I probably just took it down on myself. Like being like, “well something’s wrong with me,” or I don’t know – I don’t know, like getting self-angry or something and not understanding it.

**I:** That makes sense. So you kind of took out maybe your frustrations on yourself? Or like…?
**P5:** Like, “oh it’s my fault” kind of. “Oh it’s my fault” //.

In the last example a participant related that they thought they were a bad person before they received their diagnosis due to the severe bullying they experienced.

**P7:** But I didn’t really understand even that I was getting bullied for a lot of it. Um… I just… kind of… it just turned into like, an ‘I deserve this because I’m a bad person’, thing. So like, my self-esteem was very, very low and it’s still – I’m trying to recover from that. Like, it’s just… it’s just – it’s always been low, because I always felt like I was doing something wrong. Or I did something wrong. Or it was my fault because I was such – I was so different from everybody else. I’m like, ‘why can’t you just be like everybody else?’ And… I couldn’t.

I: So before you knew you had autism, you kind of viewed yourself as a bad person?
**P7:** Yeah, that – it developed – I guess it kind of developed into that.
**Relationship Difficulties.** This Level 3 theme refers to difficulties trying to understand, establish, or maintain relationships. Many participants reported not understanding how to make and maintain friendships, being the victim of bullying, not fitting in, and not understanding others. In the first example, a participant reported notable relationship difficulties with different teachers at his school. It seems these difficulties occurred not only because the participant was struggling with ASD symptoms, but because without a label to explain them the teachers misinterpreted these symptoms as bad behaviour. These experiences were so salient for one participant that he was able to recall them with clarity years later as an adult.

**I:** Did you notice that you were struggling with certain things or that certain things were easier?

**P2:** School. School was horrible.

**I:** Yeah? What about school?

**P2:** Ugh… I was always that kid that was isolated. Like, they sat you at a desk, apart from the class, away in the corner. And uh… I don’t know how many times I was dragged in front of my class in Grade 6 by my teacher, [NAME OF TEACHER], he would just stand me there and berate me for minutes in front of everyone about not finishing homework, or not being fast enough, or – oh my god it was horrible.

**I:** Yeah, so you were always being told you’re not doing X, Y, or Z.

**P2:** Yeah, that – my response to any situation like that I just shut down. Like, I wouldn’t say anything, I wouldn’t speak, I wouldn’t respond. I would just stand there and stare at him, and of course that just made it worse. And then I did the same thing in Grade 8. I didn’t bring in an essay for my – to my English teacher and… I mean… she kept… kept asking me where it was and I just sat there staring at her, I couldn’t say anything. I was just mute, and I mean… yeah… it was weird.

In a second example another participant recalled how she was often taken advantage of by others because she did not understand their intentions.

**I:** Mhm, yeah. OK. Has your life changed in any substantial way since receiving your diagnosis?

**P5:** Um… not too crazy. I suppose… I guess just understanding why I kind of got like used by people before. Or like those kind of things, was like… OK maybe // you know, like, just understanding it versus everyone’s a horrible person //.

**I:** Yeah, yeah. Can you give an example of like ways that you were used before?

**P5:** Um… I suppose not understanding intentions of people? Um… I’d get like, lied to a lot, I suppose… and like more upset about that then other people do, just
because it is like, more intense I guess. So like, “oh if you give me this money I’ll pay you back,” and like not understanding that maybe they’re not the most trustworthy person. Stuff like that.

In another example a participant reported workplace relational difficulties that made it difficult to find and maintain employment.

P8: And I – I should also say that you know, even at jobs, I had issues with jobs. Like, like working – like, I remember – pretty much every job I’ve ever worked at uh… I – I never knew when things had to get completed. It was always like, you know, I worked at a golf course for a few years when I was in high school. And I was like, you know, I – I don’t know when to go pick the short range. I don’t know when to, you know, do these various tasks. And it was like I needed to have like a list of things done. And – and it’s not that I’m not a hard worker or anything. I actually probably work harder than most people, but I have to have an idea of – of what I’m supposed to do. And so like, I – I had trouble with those types – sorts of things in jobs that I was working, throughout all different jobs. I also worked at department stores and stuff like that. And, you know, I consistently had these issues, and it was like, you know, with instruction and with engaging with customers. I remember one boss I had was saying like, you know, “you’re not smiling enough at the customers.” And, you know, you’re not offering them – the – the – the taster and this stuff. And I’m just like, “I hate doing that, don’t make me do that.” And I never understood what was going on and they just thought I was being lazy or I was being insubordinate or something like that. And – and so like, I really… and – and I see why the unemployment rate for us is very high. And I think that’s why actually. Because we – we’re often forced to behave in a certain way and it really drains our – our energy. And so like, we’re good at certain jobs, but those kind of jobs that are available to everybody, that we often are forced to take up, like, I – I struggle with those.

Another participant reported struggling to understand expectations in romantic relationships prior to her diagnosis.

P7: I mean, the first two years of us dating, I didn’t even realize we were dating.
I: Mhm //.
P7: // and so like, lack of awareness. Um… and he, um… like, you know, he would text me or something like that – this is back in a few days, right? And – so he would text me, and I’d get back to him like, two weeks later, which I didn’t really see an issue with. Um… // he’s patient. He is very patient. He’d be like, “hey, want to like, hang out or do something?” And I’d be like, “no, I’m playing boggle online right now; I’m busy.” And like, not understanding that that was like, an issue. Not understanding that like, I guess not really considering his feelings. Like, I didn’t – I wasn’t intentionally trying to like, push him away. But it sort of - I guess - would be perceived like that? Um… and then a lot of our dates were me
like, playing video games, and he’d sit and watch. And he’d gently like, “can we
go do this? Could we maybe go do that?” I’m like, “no, I’m playing my game.” //
and – but he’s – he’s really patient and I’ve come a long way with a lot of stuff
too. But he’s learned like, unless he like, tells me, I don’t know.

Post-Diagnosis

This Level 1 theme refers to the period that occurred after each participant’s diagnosis.
This category consists of four Level 2 themes and their associated sub-themes. The Level 2
themes are settling into diagnosis, potential benefits of receiving an ASD diagnosis, potential
negative outcomes of an ASD diagnosis, and desires.

Settling into Diagnosis. This theme refers to the time it takes to adjust to receiving an
ASD diagnosis. Some participants indicated that they needed time to adjust to their diagnosis
before they could make use of their new diagnostic label. Below a participant reiterated this point
when they explained that because their family was dismissive of the diagnosis, the participant
needed time and encouragement to understand and appreciate what the diagnosis meant to them.

I: Has your sense of self changed since receiving your diagnosis?
P2: Um… since receiving it yes. Yeah. Um… I mean like I said, initially I kind of
dismissed it with my family, because that’s what they did and that’s what I
thought I was supposed to do and I didn’t know any better.
I: Okay.
P2: It was actually my ex-girlfriend that kind of drew me out of my shell and taught
me that, you know, this isn’t something that you should ignore. I mean… she’s
going to school to become a psychologist now so // I mean… makes sense.

Below, a different participant noted not only how it took them time to settle into the
diagnosis but that it took others some time to be accepting of it. However, the participant noted
that coming to terms with the diagnosis was a beneficial process. The same participant related
later in the interview that ignorance of your diagnosis is more harmful than the actual diagnosis,
because it can lead to a lack of acceptance.

I: Yeah, yeah. Fair enough. Did the diagnosis benefit you in any way?
P3: Um… coming to terms with it and understanding that was the diagnosis, my – in my 20s, yes. Definitely. Um… it was really difficult at first explaining that to people around me, because they were like, “what, what, what, no, no, no,” um… but eventually I just persisted and, not even eventually, but just kept persisting past the like… fall outs and everything, and uh… uh… the diagnosis absolutely benefited me, but it was persisting through the bad times through it. Like the rough bumpy patches as, you know, information comes into play, everything gets jostled, but then eventually it settles. Um… getting to the settling part of that uh… definitely was beneficial.

I: So in general, do you think that receiving an ASD diagnosis can hinder some people?
P3: I don’t think it’s the diagnosis that hinders people.
I: What would you say that hinders people then?
P3: Um… more ignorance. Like when I was first told about the diagnosis I was ignorant about what that diagnosis meant. And that’s really what harmed me. I was ignorant about, um… the fact that it was happening in general.

Potential Benefits of Receiving an ASD Diagnosis. This theme refers to any potential benefits that a person may experience because of their ASD diagnosis. This theme is comprised of seven Level 3 themes: access to supports; confirmation, validation, or explanation; ASD is less stigmatizing than other diagnoses; landing ground or starting point; action-based self-awareness; enhanced or improved view of self; and improved relationships.

Access to Supports. The first subtheme in this category refers to access to intervention, treatment, services, and/or opportunities because of an ASD diagnosis. Many participants reported that a receiving an ASD diagnosis increased their ability to access not only supports in general, but also ASD-specific supports that they previously could not access. Examples of different supports included accommodations in educational and/or work settings, funding, interventions (e.g., behavioural intervention), service dogs, and ASD-specific resources and/or support groups. In many ways this theme is the counterpart to falling through the cracks; while some may have missed out on or not qualified for support services because they did not have an ASD diagnosis, a benefit of diagnosis is that it provides access to said services.
A wide variety of exemplars have been chosen to highlight the different types of supports that autistic individuals gained access to once they received their diagnosis. In the first example, a participant offered a very succinct example of how getting a diagnosis allowed them funding.

I: Did your life change in any substantial way after getting a diagnosis?
P1: Ah… yes. Because I was able to get onto the [NAME OF FUNDING PROGRAM] program that helps to reduce my stress immensely.

In yet another example, a different participant related that the diagnosis opened ASD-specific volunteer opportunities that give him great purpose and allow him to connect with other autistic individuals.

P3: Uh… that led me to a lot of the volunteer work that I’m doing right now with [NAME OF SERVICE] and uh… to this project even. Uh… it gave me a huge purpose, more of a calling even. Uh… being able to talk to people about Autism and about how, uh… we interact with people and interact with the world. It really, really opened up a lot to me.

A different participant also stated that the ASD diagnosis allowed access to specific items that assisted her with sensory concerns. The same participant further related later in the interview that the diagnosis also helps her advocate for her right to use these items and supports at work.

P7: So once I had my diagnosis it’s like, no like, you can actually have all these other things. Like, you can have fidgets, and you can have noise-cancelling headphones, and you can have, like… you can wear sunglasses and stuff like that, and it was stuff that like… inherently like, I don’t think of, right? And so it was like, oh – I can do all these other things and it actually like, makes just… your day to day stuff so much easier.

I: So the field of psychology has created labels to help us understand and name conditions for people who might be different from others. So examples would be autism, AD/HD, all these things.
P7: Yeah.
I: So as a person who’s been given one of these labels do you find this labelling helpful?
P7: Yes.
I: Yes. How so?
P7: Um… it just… it… well, it allows you to – I guess, advocate for yourself. It allows you to explain the supports that you need and why you need those
supports. It’s – you know like, I have this diagnosis, this diagnosis, you know, entails this, this, this. It means that I’m going to be, you know, more sensitive to these kinds of things.

Lastly, another participant recounted how he got his ASD diagnosis in his last semester of university. He noted that the diagnosis allowed him access to different services and accommodations at his university.

P8: I got to go to the [NAME OF SUPPORT PROGRAM AT UNIVERSITY] uh… for only once a semester, unfortunately. But like, it was really good. Because I got to be around other people that I felt like I – I could be understood. I didn’t have to go through all the explanation, and all the time. And it just felt really comfortable. Um… as – as fair as relating to other uh… uh… or non-autistics I should say. Referring to non-autistics would be more like…I’m – I’m more um… I’m more aware now of like, myself in relating to them, you know?

P8: And I – I got to have a voice recorder. Uh… and that really helped, because then I if I forgot something I could listen to it back later. And, you know, and – and uh… just those types of things were – were helpful. I got to go and take tests in a special test room that were um… that were better and stuff like that. So, you know, it – it did provide a few things. I – I also got some funding from the government as well.

Confirmation, Validation, or Explanation. This subtheme, which was prevalent for all participants, is considered a benefit because receipt of an ASD diagnosis provided confirmation, validation, and/or explanation of why an individual is the way they are (the way they do things and their reactions to their environment). In some instances, this theme can be seen as the counterpart to the Level 3 theme lack of understanding and confusion; where a downside of not having an ASD diagnosis is not understanding yourself, but the corresponding benefit to a diagnosis is that the diagnosis confirms, validates, and/or explains past and current behaviour or experiences. In the first example, a participant stated that knowing he is autistic prevented a lot of unnecessary questioning about himself. The same participant later explained that confirming a diagnosis and recognizing that someone is different is helpful for others as well because it helps
them understand and accept that others may be different. In this example, the benefit of diagnosis is applicable to both those who are autistic and those who interact with autistic people.

**I:** What about personal benefits?

**P2:** Personal benefits. I mean… I mean, I keep cycling back to my own personal understanding, like… I don’t know if that’s circular, but…yeah. The major benefit was just knowing and not having to wonder. Because I’m really bad at anything that’s open ended.

**P2:** The same reason that uh… we can recognize uh… what piece of that puzzle goes into this position of the pattern. We can recognize that this person stands out. You know? Um… and I think that is a very good thing. Uh… recognizing something is different. That uh… doesn’t have to be a negative thing. You can simply go like, “oh, okay!” and when you know more about that difference, uh… that’s when I think acceptance will really start happening more.

A different participant echoed similar sentiments by stating that getting her ASD diagnosis was a lightbulb moment that helped explain why past events happened as they did. This person also reflected that she used to think she was a horrible person but is now able to reflect and understand that many of her difficulties were related to her ASD symptoms.

**I:** Do you think there’s anything that you want to share with me about maybe the meaning that diagnosis gives your life, or um… if you think it’s important or not important?

**P5:** Um… I think it was important, because it was kind of like, a light bulb going off. And then the more I research the more it’s kind of like, “oh that’s why this is like that” or “that’s why this might have happened.” Um… anything that could have been traumatic that happened and like, well… maybe that’s why //. Instead of just being like, “oh I’m horrible”

Like the previous two excerpts, the following excerpt from a different participant addresses a pivotal moment when receiving an ASD diagnosis was like finally fitting the pieces of a puzzle together. When given their diagnosis, this person was finally able to make sense of their presentation which led to increased understanding of self.

**I:** When you got the diagnosis, did it change the way that you view yourself?

**P6:** Big time //.

**I:** Yeah, yeah //. How?
P6: Things finally made sense. There – like I still talk about this in therapy now. Because nobody talks about it. But… I say like… they use the puzzle pieces saying like, “everyone with autism is unique.” I say it’s all the pieces going together. Because it’s like all these different parts that finally are making sense.

In the last excerpt for this theme a participant related that getting an official diagnosis was a source of relief even though she and her husband suspected she had autism because it confirmed that her social difficulties were warranted.

P7: So… yeah. So, and yeah, it’s – my, my husband knew too. Like we knew – we’d known this already for like, probably 5 years. Like we knew that was most likely um… that I probably did have autism. But just… I don’t know. There’s kind of some… like… relief I guess, in getting a diagnosis. Because at least you know that it – at least it’s not… you know… people just think that you’re really weird all the time // it’s like, “well I’m really weird, but there’s a reason for it.”

**ASD is Less Stigmatizing than Other Diagnoses.** This theme reflects the perspective that that ASD is less stigmatizing compared to some other diagnoses. In the example below a participant noted that the public can be frightened of people with certain diagnoses; however, the participant clarified that she does not think that ASD is one of these diagnoses, and instead believes that ASD is a less harmful diagnostic label. The same participant later explained that she believes a lot of people who receive an ASD diagnosis later in life are often misdiagnosed with other conditions. She believes that the autism label is a healthier label to use for oneself compared to other potential diagnoses.

P5: I only think it’s harmful if they’re like, not… fully aware of it or if it is something that seems to be more shocking to people in terms of like, bipolar or something that some people are afraid of. Like, “oh are they going to snap on me?” kind of thing. Um… and I don’t think autistic is – it’s more considered like, weird versus a dangerous one. So I think people are a lot more like, OK about it //.

I: Yeah. So you think the autism label is less harmful than other like, mental health labels?

P5: Yeah.

P5: Um… or I think a lot of people – uh… the one way that I think it would benefit is a lot of people are misdiagnosed as like, um… borderline personality or like,
other things that I think do have those negative like, relationships with those labels.

I: Yeah, negative kind of stigma around them?
P5: Yeah. When I think that, “oh they’re actually similar to me in many ways – I wonder if they’re ASD?” And that’s like, a healthier umbrella to look at yourself under. Instead of having like, five kind of misdiagnosis. Is that a more negative than one that’s just like… you know, going to be more on a positive side //.

I: Yeah, so… you think that the autism umbrella label, has like, more positive connotation compared to some of the other diagnoses that people can be accidentally given instead of ASD?
P5: Yup, yeah.

**Landing Ground or Starting Point.** This theme reflects that an ASD diagnosis provides a landing ground or starting point from which autistic people can begin to understand themselves and/or their symptoms. Several participants noted that having an ASD label allowed them to learn about their condition. This psychoeducation helped them understand themselves better and provided them with options regarding how to approach different situations. While this theme is aligned with *confirmation, validation, or explanation*, it differs in that it gives autistic people a starting point to learn about their condition. In the first example a participant explained that the diagnosis provided a direct link to personal research. He made this comment while discussing the utility and potential consequences of the ASD label.

P5: It’s just a – basically a – pointing you in the right direction to research more and understand what part of it suits you.

In the exemplar below, a participant discussed how labelling provided structure and expectation regarding his symptoms. Further, this participant reiterated that he can research how others have approached or responded to similar concerns and use that information to prepare accordingly. The same participant reiterated later in the interview that the ASD label serves as a tangible starting point that the participant can use to develop their own understanding further.

I: As a person who has been given one of these labels, do you find this labelling helpful?
P:2 Um… on a whole, yes.
I:  Yes? How so?
P2:  Um… I hate to reiterate myself but it has provided structure and expectation.
I:  Yeah, reiteration is great, it’s helpful, so don’t worry.
P2:  // okay. The structure and the expectation. Like um… at the very least if I don’t know what’s happening I can Google – and there are how many hundreds of thousands of people that have dealt with something before?

P2:  I, uh… other than just um… providing me with um… some sort of starting point with which to begin understanding. Like it’s obviously not a catch all, or a, uh… magic bullet, but it was a starting point and… one of the things I always had a problem with was finding a place to start. Give me like, a piece of paper and I’ll stare at it, but give me something to iterate upon and, you know, I can do it forever.

I:  So the label helps you understand yourself or provide a beginning?
P2:  Yes, it gives me something to latch onto, and then I can move and develop my understanding of myself based on that. I mean, I’m obviously more than just that, but… I mean… knowing this, I can, you know, stand on something and observe and see.

**Action-Based Self-Awareness.** This theme refers to an increase in self-awareness that occurs after receiving an ASD diagnosis. While related to landing ground or starting point, this theme differs as participants utilize the new information they have about themselves in a beneficial way. For example, while the theme landing ground or starting point might highlight different symptom presentations and what to do about them (e.g., they learn about sensory concerns and different tools to assist with these concerns), the current theme reflects an understanding of what they need in specific situations so they can act upon those needs. In the first exemplar, the participant was able to research and understand some of their difficulties in making and maintaining relationships and then used this information to enhance their relationships.

P3:  Because I – especially understanding that I was autistic – allowed me to realize, “OK, so I am just really irritating to some people,” and you can understand how that irritation bothers them. And then you can use that irritation in only appropriate ways, like in friendly ways. So it’s like, “come on, come on,” you know? It’s like, “gee, I wonder why I’m saying this because I know I’m irritating you” //. Um… but uh… it can also allow you to um… you know, uh… control, not eliminate, your personality. Just choose to
engage in those kind of behaviours when you have your own time, you know? Like if you need to make some weird sounds or weird clicking uh… intonations.

In another example a participant spoke about how they used information regarding their sensory differences in a beneficial way. Now that they know about their sensory concerns and how they react to them they can use this information to be better prepared when going to certain events and/or locations.

I:  *Has the diagnosis changed the way that you view yourself?*
P4:  Yes, not necessarily in a negative way, just sort of… it changes the way that I um… approach situations and the way that I reflect on situations.

I:  *Can you explain kind of how you approach or reflect on situations now?*
P4:  Um… I think I sort of um… tend to avoid situations where I might experience like, sensory overload or things like that. Um… or I might come into a situation better prepared for it, for example, bringing like earplugs to a concert.

Lastly, a participant related that she now uses her increased self-awareness to advocate for what she needs in different situations. She was able to reflect on what does and does not work for her and then use the information gained from that reflection in a way that suits her specific needs.

I:  *So would you say that the autism or the Asperger’s label brings meaning to your life then?*
P5:  Um… yeah, I think that’s just back to the more self-aware. So… again, being like, patient with myself and then understanding different things that’ll make day-to-day easier. Um… also helps manage self-care. And when it’s like, “OK I’m just going to take a break or have a day to myself.” And… I don’t know, people always say like, “you should go outside and go for like a walk,” and I’m like working on an art project, and I’m like, “no… this is what I want to do” //. And like, understanding that that’s feeding kind of what I like to do. And it’s OK that I don’t want to necessarily go out with other people or go to the bar. And I suppose some of my other friends, if I just say, “no I don’t want to go to the bar” I don’t have to make up an excuse anymore. They can just be like, “OK.” But they’ll still invite me.

**Enhanced or Improved View of Self.** This theme can be seen as the counterpart to the Level 3 theme *blaming self.* Instead of blaming oneself for symptom presentation and/or difficulties, receipt of an ASD diagnosis can in some cases equate to a positive change in the way
autistic individuals view themselves. Many participants reported feeling less at blame for their concerns after their diagnosis, which led to an improvement in the way they view themselves. In the first example a participant reported that not only did the diagnosis improve his understanding of himself, but it also made him feel more comfortable being himself.

I: Okay. Has there been any change to your sense of self since receiving the diagnosis?

P4: Um… if anything I feel more like myself. Which… it seems strange to say, but it just – it just helps me sort of understand myself a little bit more. And that makes me more comfortable sort of in my own skin.

In another example, a participant stated that getting their ASD diagnosis enhanced their self-esteem. Instead of blaming past experiences on who they are as a person, they now use their diagnosis to explain why they may have had negative experiences in the past.

I: What about your sense of self then? Has that changed since receiving the diagnosis?

P5: Um… it’s made – I think it’s probably improved my self-esteem a little bit. Um… because like, before things would happen – like I had a – like again, I had a lot of other mental health diagnoses as well, and it would’ve like… you know, it’s – now that I have this diagnosis it’s kind of like, it’s sort of like an ah-ha moment //.

Meanwhile, another participant stated that since receiving their diagnosis they have come to realise that they are not deficient, but instead the way society interacts and responds to them is. Instead of engaging in self-blame this participant externalized their concerns by believing society is in the wrong.

P8: And all these different things. And it’s like, you know, I feel like when I got my diagnosis, like I – I’ve actually noticed that most of my experiences in my life haven’t been due to me being deficient. It’s been actually due to the way that I’ve been treated by society. The way I fit into society. It has more to do with that than it does with, um… the way that I am, really. And so… like I feel like I’m – I’m not really disabled for the way that I am. I’m disabled by the way that society has – has positioned me in the world.

Lastly, when asked about any changes to their sense of self since receiving their diagnosis a participant noted how they have integrated their autism into their personal identity.
Instead of resisting their diagnosis this participant accepted it as part of who they are. The same participant then related later in the interview that because of this conceptualization they are often kinder to themselves when they make mistakes.

P6: Oh yeah, things make more sense. Yeah, it definitely changed. Like… I’ve taken it as a part of me. Like I would – I know lots of people how are like, “I wish I didn’t have autism, I wish I didn’t have this.” I’m like, “honestly… it’s a part of me."

P6: I often see myself uh… differently in that respect. Like, like I’ve – I’ve learned not to internalize a lot of these experiences that I feel in my flashbacks and stuff. I don’t – I no longer apologize for the way that I am, or what have you. If I have an issue like, it still feels weird to go through the awkwardness, or to go through the mis-stepping here, or whatever. But it – it’s like I don’t – I don’t feel like, I don’t – I don’t take it personally upon myself anymore. As much as I used to be like, you know, “what did I do? I’m an idiot,” or whatever. And I don’t – I don’t feel like I do that anymore.

Improved Relationships. This theme, which was relevant for all participants, refers to an improvement in personal relationships after receiving an ASD diagnosis and can be seen as the counterpart to the theme relationship difficulties. Participants noted that their relationships with others had improved since receiving their diagnosis. In the first example a participant related that they are now better able to understand how to communicate with others. Further, this participant also related that this improved understanding has made it easier for them to maintain relationships.

I: OK, that makes sense. Has your connection with other people changed since receiving the diagnosis?

P3: Yeah, I think it’s gotten a lot better actually.

I: Yeah. In what ways?

P3: Um… again, it kind of allowed me to understand the different aspects of my own communication and the different aspects of other people’s communication.

I: What about more personal relationships, like relationships with your family or your friends. How have those changed?
P3: Uh... those have changed a lot more for the better. I started understanding how to make friends more easily with that. Again, like you can embrace your weirdness in an appropriate context and appropriate circles, especially when you learn to recognize people who will identify with that kind of quirk as opposed to who will be off-put by it, or just a little too new for them, a little too much for first meeting someone, you know?

I: Mhm, so... understanding the diagnosis has allowed you to connect with people more?

P3: Yeah, very much so.

Another participant related a similar experience and noted that he now better understands social norms, which makes it easier to connect with different people. This exemplar also provides an illustration of a double-coded excerpt where the participant acted on newly gained knowledge as described in the action-based self-awareness theme, which resulted in the benefit of improved relationships.

I: Okay, okay. Has your connection with other people changed at all since receiving the diagnosis?

P4: // You know, it’s interesting. I have like... a small group of friends that I stayed friends with um... after high school, and one by one all of us got diagnosed with autism //. And we’re like, “oh that explains a lot” //. Um... so I feel like, with my core friend group it hasn’t really changed a lot. Um... but in – in the sense that – just meeting new people, and dealing with new people in my life, it has changed a little bit.

I: Yeah, so what has changed?

P4: I feel like now that I know I need to perform the sort of general social norms, whether it be like eye contact or just like making small talk and things like that, I feel like I’m more aware of the fact that needs to be done.

Another participant related that getting her diagnosis allowed other people to understand her better which in turn has enhanced her romantic relationship.

P5: Benefits... Um... relationship wise I think it gives like, my boyfriend more patience as well. Because he has to understand and he’s – we started dated before, and then throughout the diagnosis, and then still dating. Um... but different arguments and stuff he just wouldn’t understand like, why – like, “that’s irrational” kind of thing. And so now if I can explain it to him then he’ll kind of like, “OK this is the way she thinks,” or “It’s more black and white. I’ll just take what she says and like, move on with it.” Instead of trying to convince me – and it’s not going to work.
I: So would you say that the diagnosis has helped other people understand you better as well?
P5: Yup.

Lastly a participant noted that other people are more accepting of them when they know that have ASD. This participant related that autism acts as a ‘key word’ that changes peoples’ perception and makes them more understanding or accepting of difference.

P6: But I think like, people will – are more willing – when they’re willing to accept me with the neurodiversity in mind.

Potential Negative Outcomes of an ASD Diagnosis. This theme refers to any potential negative outcomes that a person may experience once they receive their ASD diagnosis. This Level 2 theme consists of four Level 3 subthemes: assumptions, stigma, and stereotyping;
diagnosis can lead to excuses; dislike for ASD supports or services; and improved awareness can lead to shame.

Assumptions, Stigma, and Stereotyping. This subtheme, which was relevant for all participants, refers to the potential for people to make assumptions or engage in stigma and stereotyping towards autistic people. Participants reported numerous different experiences of stigma and stereotyping, so several exemplars will be shared to highlight the variety of experiences. One common experience reported by participants related to the assumption of intelligence. Many individuals noted that when people find out they are autistic they automatically assume that they have lower intelligence. This assumption then escalates in some cases because people treat the participants differently based on that assumption. In the first example, a participant related how most people he encounters believe that autism equates to lower intelligence and how he must challenge those assumptions. The same participant noted that this is problematic because people can treat autistic individuals differently because of this belief
and then related how this experience has specifically affected him, even when interacting with autism treatment providers.

P1: People’s preconceived notions of autism, the arm flapping, screaming uncontrollably, the traditional low functioning autism, but trying to change that and be like, ‘yeah I know I have autism and I know you think this, but I’m going to direct you to read over here,’ and look into people with a little bit more mental facilities.

I: Do you think that receiving an ASD diagnosis can hinder some people? Just in general, not yourself.
P1: In general, yes it can.
I: How so?
P1: Um… by people getting the diagnosis then being treated as if they’re an invalid.

P1: A lot of the times it feels that if you mention that you have autism or you mention that you have uh… looked into autism, they sort of change gears, and it feels like they almost dumb down for you, which is rather insulting. Because it’s kind of like, “no… just because I have this diagnosis does not exactly mean that I dropped 30 IQ points,” like that’s not how this works.

P1: And this one was specifically for adults with autism, but it looks like we have a mix of low functioning and high functioning and unfortunately they have to cater to the lowest common denominator so a lot of the ways that they try and present things and they talk, with their tone of voice, and their inflection, it’s very much sing-songy almost, like you’re dealing with a kindergartener and it’s kind of like, the rest of us over here are sort of tapping our fingers going, “okay can you talk to us like adults instead of preschoolers? Because this is rather frustrating.” And like even the material they gave… lots of pictures, big words [font size], very simplified language, and it’s like, I appreciate the work they’re doing, it’s good, but it almost feels like there needs to be a split.

I: Two groups?
P1: And ask us like, “are you uh high functioning or low functioning?” because there’s a lot of us that have voiced our concerns of like, “this feels very patronizing. “You’re asking us to describe our mood like, “how’s your mood in the weather?” it’s like, can’t we just say how we’re feeling, instead of trying to come up with an analogy or something? Like… yeah.

I: So the assumption that all people with autism have an intellectual disability you think is very hindering?
P1: Yes.
Another participant reported experiencing stigma from their family regarding their diagnosis. Not only did the family engage in label avoidance by trying to hide the diagnosis, but some family members made disparaging remarks about autistic people. This same participant also related concerns about stigma in the workplace. He reported telling people he was autistic during interviews and believed that sharing this information prevented him from getting a job. As such, the participant related that labelling is not harmful, but the stereotypes that society attaches to those labels are.

P2: But I mean, initially it was – it was weird because everyone seemed kind of weird about it and tried to just ignore and hide everything //.
I: So was there like, maybe a little bit of stigma around the diagnosis?
P2: Oh there still is. Like my brother’s one of those 16 year olds that uh… goes commenting on it //, like ‘you’re so autistic’ or whatever, on his video games when he’s playing, all those things.

I: Um… has the diagnosis harmed you in any way?
P2: Well, it… it’s certainly – just my… naivety I guess, because I … I made the mistake of like, telling people at interviews and stuff. Back when I was trying to apply before I got the job at [NAME OF WORKPLACE].

I: Is there anything about this kind of labelling that you see as harmful?
P2: I mean, yeah… I mean… unfortunately it’s not – not like, not in a clinical sense harmful, but unfortunately it’s just uh… those labels get attached to certain stereotypes and, I mean, those follow you around.
I: Yeah. So, it’s not necessarily that the label is harmful, but stereotypes?
P2: Yes, yes. Society’s interpretation of them uh… just as a general whole, is not exactly on par with the clinical interpretation or definition.

Yet another participant reported discrimination in the workplace with a colleague asking the participant if she was cable of pursing her job because she had autism.

P7: The only one I would say that is – that I ran into an issue with is some stigma around what you are able to do as a person with autism. And like, it’s really silly to me, because there was an administrator who had talked to me and they’re like, “are you sure you – if you have autism you should be a [JOB TITLE]?”
Another person reported a form of label avoidance when they drew attention to the fact that some parents will withhold vaccinations due to the fear that vaccinations cause autism.

P4: It’s this idea that autism is – is this scary thing that needs to be avoided at all costs. Like even – like risking your child’s life so that they don’t have autism. It’s – it’s just unfathomable to me.

I: Yeah. And it sounds like it’s frustrating.

P4: It definitely is. Because like, it’s not – it’s not a demon. It’s not the end of the world. It’s just something that your child has that’s – that’s different about them.

A female participant also noted that there is a lack of understanding regarding what autism looks like in individuals without intellectual disability and what autism looks like in females. She reported that when she shares her diagnosis with others, they often do not believe her. She also reported a specific instance where a friend of hers told her that getting assessed for autism was ‘stupid’ because she did not believe that the participant could possibly have autism based on her presentation.

P5: Because if I just say I’m autistic people are like, “no you’re not.” Or like… all that, kind of, “you don’t look autistic like, what are you talking about?”

P5: There’s the one girl that was like, it was before I was going to – I was like, “oh I think I might be on the spectrum I’m going to go get tested.” And she just looked at me and was like, “that’s the stupidest thing I’ve ever heard you say.”

In a similar case for another participant, support staff at their school even went so far as to refute a participant’s diagnosis by calling the participant’s parents to tell them the diagnosis was wrong. This same participant related that terminology used to describe autism and the autism spectrum can often be used in a derogatory way.

P6: I had this learning support person who was not – she was good for some things, and had she not intervened I might have been in a different place. But like, she was out of line and she called my parents being like, “no [PARTICIPANT NAME] does not have autism.”
P6: I think now it’s becoming a derogatory thing like,” oh that person’s totally on the spectrum.” It’s like calling someone a retard.

**Diagnosis Can Lead to Excuses.** Some participants reported that a potential negative outcome of an ASD diagnosis is that it can lead to excuses and that these excuses have the potential to limit autistic people. One participant commented on how this could be self-limiting, while another talked about the potential risk of accessing too many accommodations, which could hold them back and limit overall adaptive potential. The third example exemplifies how a diagnosis can limit others’ expectations of the autistic individual.

*I:* Any negatives at all that you can see about getting an ASD diagnosis?

P5: Um… I suppose only if people take it so far as using it to limit themselves doing things instead of just continuing to do what they would do.

P5: But were… the other aspect I think of that is like… had they diagnosed me earlier and had I gotten all the support, I’m not sure I would be anywhere near where I am today. Because like, I could’ve ended up at like, an autism specific school //. Because like… I’m that kid that will go after any possible support and am perfectly fine with that. Like, I’ll take any accommodation I can get.

A different participant emphasized this point by stating that his family used his diagnosis as something to excuse and ignore rather than as a starting point to access treatment or services.

P2: I mean um… oddly enough when my family found out about it, they kind of laughed it off and – “now we’ve got a label we can excuse and ignore it.” So that was basically what happened.

While some participants reported that potential for autistic people to use their diagnosis as a crutch, one reported that allistic\(^5\) people can also accuse autistic people of hiding behind their diagnosis as a form of excuse, which is problematic when autistic individuals are using their diagnosis to explain differences and/or advocate for their needs.

P1: Some people like to say, they like, “oh you have that so you hide behind it as a shield.” Like, well sometimes yes, and sometimes no, and sometimes I use it as a

\(^5\) A term that means not having autism (Cambridge Dictionary, 2020)
crutch to help me in situations that otherwise I would fall through on, but – just like anything else in life – it’s another tool to help explain and interact with the world around us. So it’s up for us to use, because it is us.

*Dislike for ASD Supports or Services.* This theme refers to a dislike for ASD-specific supports and/or services. This theme is considered a potential negative outcome of receiving an ASD diagnosis because once the diagnosis was given, ASD-specific interventions were accessed and some participants reported a great dislike for some autism services. In the first example, a participant reported a dislike for applied behaviour analysis (ABA) therapy which is commonly used with autistic populations.

P6: Now I actually don’t like the ABA training for the most part /. Because… it’s not applicable. The only place I’ve ever found it applicable, which is a few weeks ago was speed dating. Because everyone was struggling to have like, those 90 second conversations. But that’s all you do in ABA. It’s *all* you do.

The same participant echoed the dislike for ABA therapy, but also stated that there is a movement in some autism populations expressing a strong dislike for ASD-based agencies.

P6: And like, there’s a few… let’s just say higher functioning, generally girls, that are like, “ABA sucks, Autism Speaks sucks,” and it’s like all this thing and like, “let’s radicalize.”

Another participant referenced a dislike for specific skills training with autism populations. She disagreed with training autistic people to give eye contact and noted she often speaks against this type of learning goal on her students’ individualized program plans.

P7: There’s certain things that they’ll put in and I’m just like, “don’t put that in as a goal.” Like, eye contact is one that is – I hate. I’m like… most people also see eye contact with paying attention, and I’m like, “word it as having their body oriented towards you. Like, don’t force eye contact.” Because it’s not that people with autism can’t do eye contact it’s that we don’t use it appropriately.

*Improved Awareness can lead to Shame.* The last theme in this category refers to the idea that improved understanding and self-awareness can lead to shame regarding one’s current
symptom presentation or past behaviour. While this theme was only prevalent for a few participants, their exemplars included powerful examples of how gaining additional self-awareness can be detrimental as it allows you to re-examine previous experiences from a different perspective. The quote supporting this theme in the Theme Table demonstrated how a participant was not aware he was previously bullied but now understands that some of his earlier interactions with peers constituted bullying. This participant indicated that they would rather not have this additional knowledge when they stated, ‘ignorance is bliss.’

Another participant reported similar experiences and related how this knowledge is detrimental now because it interferes with their ability to engage in social interactions.

P6: And then at 13 when you sort of have awareness, sort of not. It’s like this whole other thing where I’m like, ugh… what have I done? Like there’s a lot of things that I still remember and then, they’ve actually become negative flash backs. When I go to do social things now.

I: Yeah, so like, negative experiences from before kind of -
P6: Yeah, that I didn’t recognize as negative until now. Like people making fun of me or taking advantage, they’re laughing at me not with me, but I wasn’t recognizing that.

Desires. This theme refers to needs or desires that autistic individuals may have. This Level 2 theme consists of eight Level 3 subthemes: specialized research; access to supports and resources; earlier diagnosis; accurate representation of diversity; perspectives on language and labelling; easier access to assessment; better clinical training and knowledge; and to be treated equally, but with understanding and respect.

Specialized Research. This subtheme represents a desire to have research investigate different aspects of ASD. Participants in this theme wanted more research focused on the following topics: autistic people with and without intellectual disability, the diversity of the spectrum, gender presentation in autism, gender differences, diet and gastrointestinal issues, and heritability. In the example below, a participant related their desire for better research and
understanding regarding both gender presentation in autism and gender difference between autistic males and females.

P4: I’m transgender, so I was assigned female at birth, and then I transitioned to male, and um… one thing that my doctor said when I went in for my diagnosis was, um… one in three transgender people are autistic⁶, and I – I was blown away by that statistic, because um… I – I had never like, encountered that statistic, or I had never like, encountered the connection between the two. Um… and the other thing he – he noted was that because um… in female children um… autism is so – it’s much less commonly diagnosed and it’s much less understood, because it’s manifest differently and there’s a lot of masking that occurs with female children.

Access to Supports and Resources. Participants also desire better access to appropriate supports and resources that fit each individual’s needs. They identified difficulty accessing supports (e.g., due to finances, professionals not understanding or specializing in ASD, and/or specific locations lacking services), especially for adults. Participants also related that available services did not always meet their specific needs. The exemplar in the Theme Table indicates both concerns translate into a desire for better access to appropriate supports. Another participant echoed these sentiments and related that it is very hard to find adult services in her current city but hoped that her upcoming move will provide better access to resources.

P7: We’re moving from [CITY] to [PROVINCE]. Hopefully by the end of this year, so I’m hoping that will also give some better access for adult services. It’s really hard to get adult services for autism.

Another participant relayed that it is difficult to access labels in the first place, but noted that it is also challenging to access supports because support access requires one to be able to advocate for oneself. The participant thought this was especially difficult for autistic people.

I: So labels equal access, but a downside to that is it’s difficult to access the labels.
P6: Yes, and sometimes the support. Or waitlists. Waitlists, and more waitlists, and more waitlists.

⁶ While the participant reported one in three transgendered people are autistic. Current research indicates that of 6–26% of transgender populations meet diagnostic criteria for ASD (Thrower, 2020).
I: When you said you need a lot of self-advocacy to be able to access these things, in your opinion, is that something that a lot of people on the spectrum are good at... is self-advocacy?
P6: Nope. I’ve – it’s a imitated and acquired learned skill.

Earlier Diagnosis. This Level 3 theme signifies a desire to be diagnosed with autism earlier in life. Below a participant indicates how this desire was steadfast, and they were able to say with conviction that they wished they received their diagnosis at an earlier age.

I: If you had a choice, would you have found out earlier?
P3: Oh yeah. Absolutely.

Another participant communicated their desire to receive their diagnosis earlier. This participant felt that an earlier diagnosis would have led to enrollment in a treatment program, which also signifies a potential negative outcome of not having an ASD diagnosis such as falling through the cracks since this participant missed out on intervention services early in life because they did not have a diagnosis.

P2: Um… I wish I could think of more things, but um… I honestly wish that I was diagnosed a lot early than I was, because maybe – maybe – my parents would have been more proactive with getting me into some kind of... I don’t know, program to help me figure things out, because I mean, if I had learned a lot of the skills that I had – have now, back when I was younger and more impressionable, it would have made a large difference I think.

Another participant echoed similar concerns and stated that getting diagnosed earlier in life would have eliminated or reduced some of the challenges they previously experienced.

I: Yeah, so you were diagnosed at 19, which is well outside of childhood, right? If you had control over that would you have changed that?
P4: Um… I – I might have liked to have been diagnosed like – like in my early teens. Just because I feel like that would have saved me a lot – a lot of challenges and a lot of difficulty.

Accurate Representation of Diversity. Participants also indicated a desire for ASD to be represented accurately as a spectrum condition. Participants wanted this accurate description to occur not only in the media, but in autism spokespeople as well. In one example, a participant
referenced a television show whose main character is an autistic person with savant syndrome. The participant referenced how this is problematic because it causes the general population to believe that all autistic individuals are savants. Later in the interview, the participant also stated a desire for representation of successful autistic people to be more widespread and prolific.

P4: Ah man… I think that’s – that’s about it. It’s just generally I wish it was better understood. Because there’s so many misconceptions about like – like I don’t know if you know that show The Good Doctor?
I: *Oh! Yes – I do.*

P4: A very young man who’s like autistic and he’s like prodigy autistic…
I: *Yeah, like savant.*

P4: Yeah, savant autism. It – it – it’s such a weird – because I – I know that those people exist, I’ve met a lot of them, and it’s very cool to see. But it’s – it’s weird because it sort of places these expectations on you for the – like oh, “what’s the thing that you’re good at?” “Well, nothing in particular //”.

P4: I just think that… um… visibility of people who like… autistic people who – who have succeeded, and different kinds of autistic people. I think – I think like, if there were more public figures, like Greta Thunberg, who’s – who’s brilliant and a great activist. I think if we had more visibility of people who have autism and have succeeded, then I think that would be really helpful, because that would just be a way of showing people that like, it’s not the end of the world.

A different participant also had concerns about the lack of media representation across the autism spectrum. She was concerned that the media only portrays one end of the spectrum and that there are seldom portrayals of autistic females.

P5: Um… also like, a lot of TV shows and things that are coming out these days I’m not sure are helping it. Because it is so different for everyone. They’re taking very classic symptoms and I’ve watched those because I think it’s funny what they think of most people. Um… it would be nice to see a TV show with a girl that’s autistic.

**Perspectives on Language and Labelling.** Participants expressed various preferences regarding language and labelling used to describe ASD. Some expressed desires towards person-first or identity first language, while others expressed desires regarding their specific diagnostic
label (e.g., ASD vs. Asperger’s vs. autism). In the first example, a participant noted a desire to move from the current ASD description to an autism spectrum condition description.

P3: In the UK they’re actually working to change the definition to autism spectrum condition, which I think speaks a lot better to what it is because it’s not a disorder, um… I mean… disorder/order, that is a bit of a – again, taken in a clinical sense I don’t really have a problem with that, but you do have to take it in the context of “order” means this kind of order, not any kind of order, because technically autism is an order, it’s just a different kind of order.

Another participant echoed similar concerns and said that to be conceptualized as a disorder is not only inaccurate, but harmful.

I: As a person who has been given a few of these labels, do you find any of this labelling helpful?

P8: I find it more harmful than helpful. Um… uh… yeah, the idea that I’m a disorder is – is simply wrong. I mean, um… uh… we don’t have to look back very far to see when gay people were considered a disorder. And now it’s obviously very wrong to think of it that way. It’s just normal variation.

Lastly, an exemplar from a different participant demonstrated a desire for Asperger’s and the Asperger terminology to still be in effect.

P7: Um… I think Asperger’s should still be…

I: A thing?

P7: A thing. Yup. Definitely. Because I get – like, I get the similarities, I get the whole point of a spectrum, but I’m like… it’s – they’re really different. They’re really, really different.

Easier Access to Assessment. Some participants also expressed a desire for ASD assessment to be more easily accessible. Participants explained that it was hard to access assessments because it was difficult to find specialists who understood what autism looked like in adult populations, especially for females. Additionally, participants reported that the assessments were costly and time consuming. Below, a participant explained these concerns but also noted that the expense of the assessment is even more problematic for autistic populations because autistic people are often underemployed.
And for adults it’s really bad, because um… adults – and particularly – particularly girls and particularly your high-functionings, who don’t get a diagnosis as a kid. Um… like, when you can do it through a school – much easier. When you have to do it as an adult – like, to get my diagnosis, was I think – between having to commute, because I had to come to [NAME OF CITY] to go to a specialist um… and then go through with a clinical psychologist a whole battery and interview of like, two days of testing straight. Um… which is exhausting on me, but it’s like… that was probably close to $5,000. To get a diagnosis. And it’s like, we know that people who are autistic, whether they’re diagnosed or not //, but people who have these traits are more likely to be unemployed. And so, like that – so there are so many barriers to accessing diagnoses once you’re an adult. That it’s like… it’s really damaging not having it. Because then it sort of feeds in. It’s like, well you don’t have the diagnosis so you probably are going to be unemployed, because people are overwhelming and like, people skills are… huge. My husband and I were talking about how like, if you have two people and they have the same qualifications, the person with the higher people skills – even if the person who has better people skills is not as educated, they’re probably going to get the job over someone who is more educated, but can’t… doesn’t have the people skills to be able to like, cooperate and get along, and do the things that they need to do socially.

Better Clinical Training and Knowledge. Many participants expressed a desire for health professionals to have a better understanding of ASD. This desire applied to different professionals (e.g., doctors), as well as psychologists. Participants reported that health professionals did not have a good understanding of what autism looks like or how to appropriately treat it. Female participants also reported that there was a misunderstanding of what autism looks like in female populations, which made some professionals unqualified to accurately diagnose them. In the first exemplar a female participant reiterated the above concerns.

OK. Anything else that you want to share, um… chat about, before the interview is over?

Mm… we just need more people that know about girls in Calgary. Because… yeah, that was like, a struggle to try to go through it and find like, oh my god… there’s like no one in Canada that seems to be able to, like, understand what I’m talking about, kind of thing. And even just having psychologists understand it. So that there’s more psychologists that can help with the after process on helping you go through stuff, instead of like, not just the diagnosis side of it. Um… because a
lot of them it also seems like, “oh I don’t fully view - ” or like – their knowledge base is very male oriented.

Another female participant related similar concerns, but also noted that health professionals did not have a good understanding of how to treat non-ASD concerns, such as anxiety, in autistic people.

P7: Um… and a lot of people, I’ve even – people like doctors, psychiatrists – don’t understand it. Don’t know how to treat it. Don’t know how to diagnose it. Um… and it’s really frustrating. Like, for me, it’s – because the anxiety is the biggest – probably – that’s probably the biggest hindrance for me. There’s a lot of, um… there’s not a lot of like, medication that is research-based for autism. But at the same time, there’s not a lot of recognition that anxiety is a huge issue, particularly in girls.

To be Treated Equally, but with Understanding and Respect. This subtheme represents a desire for others to treat autistic people the same as non-autistic people while still understanding and respecting autistic differences. The first exemplar which was previously shared in the theme of diagnosis can lead to excuses highlights this dual sentiment. The participant wants others to understand that his autism and symptoms are not a choice and to respect his difficulties; nevertheless, he also wants to be held accountable for his actions.

I: Okay. Anything else that you think is important about understanding autism, the label?

P1: People need to understand that it’s not something that you choose. That is a big one. Some people like to say, they like, ‘oh you have that so you hide behind it as a shield.’ Like, well sometimes yes, and sometimes no, and sometimes I use it as a crutch to help me in situations that otherwise I would fall through on, but – just like anything else in life – it’s another tool to help explain and interact with the world around us. So it’s up for us to use, because it is us.

I: Yeah, so you’re not using your ASD diagnosis as an excuse for things, right?

P1: Yeah.

I: It just helps explain things?

P1: Yeah, yeah. And I still want to be held accountable as any other member of the public. If I’m being a jackass, I don’t want to say, ‘oh no I have autism I’m exempt.’ No, fuck that person that tries to do that. That’s not being a good human being. You’re just trying to be a jerk. Like just… if you make a mistake, fess up to it, if you’re being a jerk, you really need to do some self-reflection, but like… it just helps to explain things and just makes it easier for us to interact with the
world, because like… they want to call us an individual diagnosed with autism or an autistic person or whatever plethora of words they might use, and it’s just like, at the end of the day we’re still people. We still deserve respect as do other people too.

A second participant echoed similar desires, but noted that people should be more understanding of all diagnoses.

I: Mhm, it does. Yeah. So if you, as a person with an autism label, had control over the way that you are viewed, what would you prefer?
P2: I don’t know, it’s more just… I… wish people would… judge me differently. I mean, it’s – it’s not… like there’s that quote from that new Joker movie, uh… you have uh… mental illness, but everyone expects you to act as if you don’t. I mean, like… if I could change uh… people, that’s what I would like, just… um… it’s not necessarily proper, but their expectations, I guess, I mean… I’m not perfect, nobody is, but I mean… I can blend in fairly well, but… it um… it’s not easy and, I mean, I had to learn how to do it //. Like, it was active thing that I would school for effectively, or had to learn through childhood and um… yeah.

I: So do you wish that people would be more understanding of people with mental health concerns?
P2: Yeah, definitely more understanding, or at least more aware that just because we appear normal or are normal or are doing well, like, we’re working to achieve that, we’re not fixed //.

Lastly, a different participant related that he wants people to treat him with the same empathy that they would want to be treated with.

I: If you as a person with autism had control over the way that you’re viewed, what would you prefer?
P3: That people just view me with the same kind of empathy they want themselves to be viewed as.

Summary

This chapter presented the findings regarding the experience of receiving a late ASD diagnosis. A total of 29 themes across three different levels of categories emerged for the eight participants. Level 1 themes represented two different periods of time, pre-diagnosis and post-diagnosis. Each Level 1 theme consisted of multiple Level 2 themes, some of which also consisted of Level 3 themes. The Level 2 and 3 themes primarily focused on the potential outcomes of having/not having a diagnosis.
CHAPTER 5: DISCUSSION

The purpose of this research was to understand the experience of receiving a late diagnosis for autistic young adults. This chapter will discuss the implications of the findings from the data analysis and relate each theme to available literature. Information gained from member checking will be discussed for each theme to provide supplementary information. The chapter will then conclude with an examination of the study limitations and recommendations for future research and clinical practice.

Discussion of Research Themes

A discussion of each generated research theme and their relation to the current literature is presented below. The member checking (see Table 3) outcomes for each theme are also presented.

Table 3

Member Checking Table

<table>
<thead>
<tr>
<th>Themes</th>
<th>Member Checking Participants Agreement</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Level 1</td>
<td>Level 2</td>
<td>Level 3</td>
</tr>
<tr>
<td>Circumstances leading to diagnosis</td>
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<tr>
<td>N/A</td>
<td>✔️</td>
<td>X</td>
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<tr>
<td>N/A</td>
<td>✔️</td>
<td>✔️</td>
</tr>
<tr>
<td>Hidden diagnosis</td>
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<td>✔️</td>
</tr>
<tr>
<td>N/A</td>
<td></td>
<td>N/A</td>
</tr>
<tr>
<td>N/A</td>
<td></td>
<td>✔️</td>
</tr>
<tr>
<td>Alternative identities</td>
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<td>N/A</td>
</tr>
<tr>
<td>N/A</td>
<td></td>
<td>✔️</td>
</tr>
<tr>
<td>N/A</td>
<td></td>
<td>✔️</td>
</tr>
<tr>
<td>Potential negative outcomes of not having an ASD diagnosis</td>
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<td>✔️</td>
</tr>
<tr>
<td>Falling through the cracks</td>
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<td>N/A</td>
</tr>
<tr>
<td>N/A</td>
<td></td>
<td>✔️</td>
</tr>
<tr>
<td>Negative treatment experiences</td>
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</tr>
<tr>
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<td></td>
<td>N/A</td>
</tr>
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<td>✔️</td>
</tr>
<tr>
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<td>¾</td>
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<td></td>
<td>Blaming self</td>
<td>Relationship difficulties</td>
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<tr>
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<td>N/A</td>
</tr>
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<td><strong>Potential benefits of receiving an ASD diagnosis</strong></td>
<td>Access to supports</td>
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</tr>
<tr>
<td></td>
<td>Confirmation, validation, or explanation</td>
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<tr>
<td></td>
<td>Action-based self-awareness</td>
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<td>ASD is less stigmatizing</td>
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<td>Landing ground or starting point</td>
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<td>Enhanced or improved view of self</td>
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<td></td>
<td>Improved relationships</td>
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<td>Diagnosis can lead to excuses</td>
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<td></td>
<td>Dislike for ASD supports or services</td>
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<td></td>
<td>Improved awareness can lead to shame</td>
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<td></td>
<td>Specialized research</td>
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<td></td>
<td>Access to supports and resources</td>
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<tr>
<td></td>
<td>Earlier diagnosis</td>
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</tr>
<tr>
<td></td>
<td>Accurate representation of diversity</td>
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Table: Perspectives on language and labelling

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<tbody>
<tr>
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<td>N/A</td>
</tr>
<tr>
<td>Better clinical training and knowledge</td>
<td>N/A</td>
<td>✔</td>
<td>✔</td>
</tr>
</tbody>
</table>

Note. This table demonstrates the rate of agreement for member checking. A check mark indicates that the participants agreed with all their exemplar(s) matched the theme and theme definition, while an X indicates that participants disagreed that their exemplar(s) matched the theme and theme definition. N/A indicates that participants did not contribute to this theme and the x/x symbol indicates the number of exemplars out of total exemplars in a specific theme that participants agreed on.

Pre-Diagnosis

Circumstances Leading to Diagnosis

This theme refers to the circumstances that led an individual to seek an ASD diagnosis, and indicates that either the participant or someone in their lives noticed ASD symptom presentation and/or personal difficulties that eventually led to an ASD assessment. This theme demonstrates that these individuals were experiencing differences or difficulties that became noticeable enough to initiate the assessment process. It also indicates that, in some cases, these individuals displayed these differences as youth, long before their assessment was initiated, which means their symptoms were misattributed, overlooked, and/or not addressed. As such, this theme is related to the theme of overlooking or misattributing ASD symptoms, though it differs as the present theme indicates the point at which the differences/difficulties became problematic enough to seek out assessment services. If these differences/difficulties were acted upon earlier, it is possible that an assessment could have been initiated at an earlier date that may have led to earlier diagnosis and intervention. All member checking participants agreed with the content in this section. However, one participant provided clarification regarding the wording of one exemplar.
Bailey (2019) stated that adults often go undiagnosed for several reasons, including absence of a language delay, absence of an intellectual disability, absence of characteristic features (e.g., echolalia, neologisms, preoccupations), adequate functioning in structured environments, co-occurring AD/HD, and/or reluctance to give and/or accept a diagnosis. The present results align with Bailey’s contention that individuals may be reluctant to both give (i.e., clinicians) and receive (i.e., clients) a diagnosis as seen in the present themes hidden diagnosis and settling into diagnosis, respectively. However, once individuals in this study had time to adjust to their diagnosis they not only accepted it but expressed a preference for having the diagnostic label. While Bailey (2019) referred to reasons why adults may remain undiagnosed, the current study recruited those who were diagnosed at 12 or later (with a $M$ of 20), meaning some of the participants in the current study ($N = 3$) were diagnosed before adulthood. However, it seems that some of Bailey’s assertions are supported in the current study as all three of the participants diagnosed as youth also had an AD/HD diagnosis, with no co-occurring intellectual disability or communication disorders. Further, two of three participants diagnosed as youth also had their diagnosis hidden from them which indicates that their caregivers demonstrated a reluctance to communicate their diagnosis. Interestingly, participants seemed to accept their diagnosis if they were referred for assessment by someone else or if they self-initiated the assessment.

**Hidden Diagnosis**

This theme refers to instances in which participants were intentionally uninformed of their diagnosis. Participants who contributed to this theme (i.e., data from their transcript supported the development of the theme) indicated that concealment of an ASD diagnosis had the potential to be harmful as it results in confusion. Participants felt that being informed of their
ASD diagnosis was both beneficial and important. Two member checking participants contributed to this theme and both agreed with the researcher’s interpretation of their data. Participant 4 further elaborated that “I think another reason this is problematic is the deliberate withholding of someone else's medical information. Even though this person is a child, they should be entitled to know about their own medical conditions.” This argument emerges from social justice and access-to-information perspectives, which should at the very least be considered when conducting a risk-benefit analysis about whether to disclose an ASD diagnosis.

The decision to disclose receipt of an ASD diagnosis to the individual diagnosed has been an understudied topic in the autism literature; however, Reed & Osborne (2014), Smith-Demers (2018), and Crane et al. (2021) touched on the topic. Literature pertaining to disclosure of an ASD diagnosis comes from a range of perspectives. While some have found that informing an individual of their ASD diagnosis has a positive impact (Jones et al., 2001) and can enhance understanding and be a source of personal pride (Davidson & Henderson, 2010), others have reported that disclosure of ASD diagnoses can result in negative consequences such as rejection of the diagnosis (Huws & Jones, 2008). Further, parents report hesitancy in sharing their child’s diagnosis with them for fear of stigma (Todd & Shearn, 1997). Indeed, Huws and Jones (2008) reported a disclosure delay wherein individuals found out about their ASD diagnosis years after it being provided, resulting in ASD having an “absent presence” in their lives (p. 102). All participants who contributed to this theme made similar comments, with each concluding that a diagnosis should not be hidden from someone.

**Alternative Identities**

This theme refers to the development of alternative identities that help explain ASD symptom presentation. In some cases, participants in the present study adopted an ASD identity
despite not having an official diagnosis; while other participants reported describing themselves as a “weird”, “odd”, or “quirky”. Punshon et al. (2009) and Lewis (2016) touched on this experience when participants in their study communicated experiences that revolved around feeling different from others. In the theme titled, “I always knew I was different”, Lewis reported that some participants developed a negative self-image because they believed that something was wrong with them (i.e., “I always assumed something was wrong with me”; p. 348) because they did not fully understand their differences, which aligns with the theme of blaming self and is further discussed below. However, Lewis noted that negative self-image was not present for all participants as some viewed their uniqueness in a positive light, with some even feeling superior to those without autism. This finding is akin to some of the participants in the present research who interpreted their differences positively. By doing this, participants were able to externalize their symptom presentations rather than internalizing them, which seemed to be beneficial. Two member checking participants contributed to this theme and agreed with the researcher’s interpretation of their data.

Potential Negative Outcomes of not having an ASD Diagnosis

This category refers to any potential negative outcomes that arise from not being assigned an ASD diagnosis. Interestingly, no counterpart to this theme (i.e., potential benefits of not having an ASD diagnosis) was present, as participants did not communicate any benefits related to not having an ASD diagnosis; they only communicated negative outcomes.

Falling Through the Cracks. This theme describes participants who conveyed missing out on supports and services due to not having an ASD diagnosis. This theme also highlights the importance of diagnosis because it demonstrates that access to support services is often contingent on diagnostic labels. Further, while much of the literature confirms that having a
diagnosis can lead to increased access to accommodations, supports, and services (see access to supports below), the current literature does not effectively highlight the converse experience that a lack of a diagnosis can impede service provision. However, Hodge (2005) indicated that there is very little that service providers can do to address a child’s difficulties until an official diagnosis is provided. In fact, some professionals reported feeling pressured to provide diagnoses so clients could gain access to treatment and intervention services (Hodge, 2005; Shattuck & Grosse, 2007). Focusing on the lack of supports available to undiagnosed individuals is important because it highlights the barriers that autistic individuals can encounter if they do not have an official diagnosis. Participants in this research confirmed this as they indicated that their diagnosis allowed access to services when they previously had none. During member checking, one participant offered multiple exemplars that contributed to this theme and agreed with each of the researcher’s interpretations.

**Negative Treatment Experiences.** This theme refers to a dislike for treatment services prior to accessing an ASD diagnosis. Some participants reported that the services provided pre-diagnosis were ineffective and/or misaligned. Punshon et al. (2009) noted similar findings when they discussed pre-diagnosis service experiences among the participants in their study. While a small minority of participants in Punshon et al.’s study noted initiating services that rapidly led to acquiring a diagnosis of ASD, the majority reported having been misdiagnosed which led to ineffective interventions and in some cases to a general mistrust in support services. This consequential mistrust is noteworthy as it suggests that being misdiagnosed and receiving ineffective services may potentially prevent individuals from accessing assessment and/or intervention services in the future. If autistic individuals do not trust that professionals can appropriately identify their needs and provide them with interventions aligned with their
differences/difficulties, their willingness to engage in services will potentially be reduced, resulting in them going without care. During member checking, none of the member checking participants contributed to this theme.

**Overlooking or Misattributing ASD Symptoms.** This theme refers to a failure to consider that a symptom presentation was attributable to ASD. This is problematic because it indicates that symptoms were present but that no one queried ASD or that ASD was queried and not diagnosed. For participants in this study, overlooking/misattributing symptoms not only resulted in frustration, but mistrust of service providers. Aggarwal and Angus (2015) reached similar conclusions and stated that the primary reason for a missed diagnosis was that ASD symptoms are often overlooked by the school system and/or primary care physicians, despite concerns being brought forth by caregivers. This is alarming as it demonstrates that those tasked with initiating ASD referrals may overlook signs and symptoms indicating that ASD may be present. As such, Aggarwal and Angus concluded that ASD can often go undiagnosed and that professionals should be trained to look for potentially missed ASD when adolescents seek treatment for other psychiatric concerns. The presence of this theme suggests that a wide variety of people (e.g., physicians, teachers, parents, mental health professionals) would benefit from being better educated on what ASD looks like in different contexts so that these symptoms can be identified and appropriate referrals made. Further, special attention should be given to recognizing ASD when intellectual disability and/or language impairment are not present, as both Bailey (2019) and Adreon and Durocher (2007) have indicated that ASD diagnoses are more often missed/overlooked in these populations. One member checking participant contributed exemplars to this theme and agreed with the researcher’s interpretation.
**Lack of Understanding and Confusion.** This theme refers to a lack of understanding or confusion that stems from autistic individuals not having an ASD diagnosis to explain their difficulties/differences. Participants in the present study indicated that this confusion was personally troubling as they knew something was different about them but lacked the terminology to externalize this difficulty. All member checking participants had exemplars in this theme and agreed with the researcher’s interpretation of their exemplars. In one case, a participant provided a grammatical edit regarding a statement she made. However, Participant 4 provided additional commentary regarding their exemplars. In one case he stated: “Had I never received a diagnosis, I would simply continue to be confused, and I would never fully comprehend why I felt so different from others.” In another example he clarified that not only is not having a label confusing but it can cause others to “self-label, which could be detrimental, especially if the label is self-deprecating (e.g. ‘freak’).” This outcome also connects this theme to another theme in the present study, *blaming self.*

This theme also relates to a theme found in Schembri (2017) titled, late diagnosis, in which a participant shared that receiving a diagnosis later in life was detrimental because for many years he was unable to name his difficulties. An illustrative quote from the participant was:

> It sucks, it absolutely sucks. Like, every day of your life knowing that there was something wrong, or growing up and not being able to have a name to it, but knowing that something was wrong, and never being able to name what was wrong with you. It was awful (p. 101).

Further, participants in Haertl et al.’s (2013) investigation communicated similar concerns when stating that they knew they were different from others and often felt out of place prior to being
given an ASD diagnosis. Participants in this investigation reported feeling relieved by their diagnosis as it helped provide an explanation for their differences.

**Blaming Self.** This theme refers to instances in which autistic individuals reported thinking that they were to blame for their differences/difficulties. This theme is related to the previous theme, but attributes additional feelings of blame to oneself for shortcomings or difficulties rather than (or as well as) confusion regarding a lack of ASD diagnosis. Two member checking participants contributed to this theme and agreed with the researcher’s interpretation of their exemplars. Participant 4 further elaborated that: “Pre-diagnosis, I tended to feel shame and blame myself for not understanding social norms.” This individual also “believed that if I could simply ‘get over’ things and stop being childish, I could ‘fix’ my difficulties.” This participant’s commentary demonstrates how participants internalized their symptom presentation without having a diagnosis to explain their concerns.

Lewis (2016) identified similar findings under a theme titled, feeling different from others. While their theme is also aligned with the above theme, *lack of understanding or confusion*, Lewis further elaborated that many participants in their study had a negative self-image prior to receiving their diagnosis, stemming from the fact that they thought something was wrong with themselves. Punshon et al. (2009) also reported similar findings whereby participants reported negative life experiences and harmful identity formation prior to receiving their diagnosis which informed the development of specific beliefs related to their ASD presentation. For example, Punshon et al. reported that negative peer group experiences stemming from an undiagnosed Asperger syndrome presentation often led to bullying and feelings of being different from others. Participants in Punshon et al.’s study seemed to believe what others said about them and internalized these beliefs into a form of self-blame. Participants reported that this
internalization led to the formation of mental health difficulties such as anxiety, depression, and self-harm, with one participant in Punshon et al.’s study claiming that had they known about their Asperger’s diagnosis they wouldn’t have blamed themselves for their difficulties.

**Relationship Difficulties.** This theme refers to difficulties establishing and maintaining relationships prior to receiving an ASD diagnosis. Member checking indicated that all participants agreed with the researcher’s interpretation of each exemplar, with one participant also providing additional feedback that further supported this theme. Participant 4 stated that “pre-diagnosis, I would often behave in a way that was socially inappropriate for a particular stage in a relationship and not understand why, nor make a conscious effort to reduce that behaviour (since I didn't know that it was unacceptable).” This participant also clarified that “a diagnosis would have helped me justify my difficulties forming relationships and would have allowed me to make a conscious effort to address them.” It seems apparent that participants in this investigation struggled with relationships prior to their diagnosis because they were unaware of where their difficulties were stemming from, but that the diagnosis helped them understand their difficulties and what they could do to overcome them.

This theme is highly aligned with Schembri’s (2017) themes of personal relationships and working relationships. In these themes, the author found that participants had difficulty making and maintaining relationships in multiple instances. They struggled with establishing meaningful and lasting personal relationships (i.e., friendships and romantic relationships) as well as working relationships (e.g., interacting with professors and/or administrators). Further, multiple research articles have identified that autistic individuals experience social isolation and or bullying prior to their diagnosis (see Hickey et al., 2018; Lewis, 2016; Punshon et al., 2009). Hickey et al. (2018) noted that participants in their investigation were aware of their differences
and made attempts to reduce these differences to fit in with their peer group. This suggests that participants may have been having relationship difficulties and attempted to mask or camouflage those difficulties by attempting to reduce their differences. This aligns with literature pertaining to camouflaging where individuals with ASD will engage in masking and compensatory strategies to fit in socially (Hull et al. 2017).

This theme is also aligned with Butler and Gillis’ (2011) article where the authors found that Aspies are stigmatized due to their unexplained behaviours rather than because of their diagnostic label. It seems apparent that when individuals do not have a diagnostic label to explain their differences, people in Western societies are more likely to stigmatize these individuals because they interpret their behaviour as a personal choice rather than a result of ASD. This assumption then lends itself to relationship difficulties. However, once a label is attached to these behaviours, others can better understand the differences which may then increase understanding and decrease relational difficulties.

**Post-Diagnosis**

**Settling into Diagnosis**

This theme refers to the time it takes to adjust after receiving an ASD diagnosis. Participants indicated that it took them time to adjust to and make sense of their ASD diagnosis. This information is useful because it suggests it may be beneficial for clinicians making diagnoses to offer follow-up appointments or otherwise offer support after a diagnosis has been given. This might allow the client time to process diagnostic information, and reflect on and come back with follow-up questions, while also allowing the clinician to discuss appropriate resources for clients. Lewis (2016) reported similar findings in a theme titled ‘riding an emotional rollercoaster’. Lewis found that some participants required both time and personal
reflection before accepting an ASD diagnosis, especially if the diagnosis was unexpected. Lewis also identified a theme of striving for acceptance in which participants described a period where they needed to re-evaluate how they viewed themselves to accept themselves fully. In terms of member checking, two of the member checking participants contributed to this theme and agreed that the researcher’s interpretation of their exemplars was accurate.

**Potential Benefits of Receiving an ASD Diagnosis**

This category of themes refers to the potential benefits associated with receipt of an ASD diagnosis. This category is important because it highlights that participants find utility in receiving a diagnosis.

**Access to Supports.** This theme refers to a person’s ability to access supports and/or services once they receive an ASD diagnosis. All three of the member checking participants contributed to this theme and agreed with researcher’s interpretation of their exemplars. Participant 4 also further elaborated that “without a diagnosis I would have continued to struggle with sensory difficulties during exams, and my grades would have most likely suffered as a result.” This elaboration suggests that had the participant not received an ASD diagnosis they would not have fully understood their sensory difficulties and/or not have qualified for exam accommodations, which would have resulted in lower grades.

This theme is strongly supported in the current literature both across the field of mental health and then more narrowly in relation to autism research. Many counselling psychologists acknowledge that having a diagnostic label often equates to increased access to clinical services (Domene & Bedi, 2013; Eriksen & Kress, 2005; 2006; MacCulloch, 2010; Sinacore-Guinn, 1995; Strong, 2012). In some cases, a diagnosis helps ensure that the cost of services is covered whereas in other cases a diagnosis provides access to services that would otherwise be
unavailable. In the autism literature, parents have reported that an ASD diagnosis allows access to specialized services such as early intervention therapies (Abbott et al., 2012; Hodge, 2005; Shattuck & Grosse, 2007). ASD diagnoses have also benefited autistic adults by providing access to accommodations in post-secondary settings (Schembri, 2017). Further, Bailey (2019) and Haertl et al. (2013) stated that once an ASD diagnoses is received, the services provided are more aligned with the autistic person’s needs.

**Confirmation, Validation, or Explanation.** This theme refers to how an ASD diagnosis can confirm, validate, or explain why an individual is the way they are. This theme can be seen as the beneficial counterpart to the themes lack of understanding and confusion and blaming self. Receiving an ASD diagnosis seemed to reduce feelings of confusion and self-blame because the diagnosis helped validate and externalize each individual’s symptoms. This allowed them to overcome a lack of understanding and confusion about themselves and stopped them from blaming themselves as many did pre-diagnosis. All member checking participants agreed with the researcher’s interpretation of the exemplars in this theme. Participant 4 provided additional information and stated that “having an understanding of ASD symptoms gives me a frame of reference to assess my "unusual" behaviours.” Further, they noted “labels are helpful tools that allow us to understand ourselves, as well as find community with others.” This participant also stated that the ASD label helped them feel less alone regarding their behaviours, which suggests that the label provides a sense of understanding and community.

Current literature supports this finding as exemplified by Mogensen and Mason (2015) whose participants found that the receipt of a diagnosis was liberating. One participant in Mogenson and Mason’s investigation stated that the ASD label allowed him to “re-frame his problems and incorporate them into an acceptable sense of self” (p. 259). Hickey (2018) also
found similar results in their theme, externalising autism. Hickey found that participants were able to consider ASD as an entity separate from themselves once they received their diagnosis, which provided an explanation for their difficulties. Further, Schembri (2017) found that a diagnosis provided autistic individuals with an explanation for their experiences, behaviours, and differences that allowed them to externalize their concerns and view them as separate from their sense of self. Schembri (2018) also reached similar conclusions in an unpublished case study of an AD/HD adult that suggests that diagnostic labelling may provide confirmation and allow externalization across different diagnoses.

**ASD is Less Stigmatizing Than Other Diagnoses.** This theme indicated that while ASD may be viewed by some as a stigmatizing disorder, it is perceived by some participants as being less stigmatizing than some other disorders. This is important since ASD symptoms can often be overlooked or misidentified as other disorders that are potentially more stigmatizing (as seen in the theme of overlooking or misattributing ASD symptoms). For example, one of the current participants received an ODD diagnosis prior to their autism diagnosis, which could have affected the way caregivers (e.g., parents, teachers, or clinicians) interacted with this individual. The participant in this situation felt that individuals in his life would have been more forgiving of ASD-related behaviours had they known he had ASD, instead of viewing his behaviours as a manifestation of ODD. Additionally, one of the participants was diagnosed with anorexia because she had eating difficulties. However, the participant communicated that these difficulties appeared to be related to sensory differences (a part of our current understanding of ASD) rather than a primary eating disorder. Two member checking participants contributed to this theme and agreed with the researcher’s interpretation.
Reavley and Jorn (2011) reported stigmatizing attitudes across several different disorders and concluded that stigma towards specific disorders is unique and multifaceted, which supports the contention that stigma varies according to disorder. However, Reavley and Jorn did not include ASD in the list of disorders they investigated. Yet, additional literature supports the claim that ASD is a stigmatizing disorder (e.g., Kinnear et al., 2016; MacLeod et al., 2013; Mogenson & Mason, 2005; Obeid et al., 2015), though information discerning if ASD is more stigmatizing than other disorders is relatively scant. Butler and Gillis (2011), who investigated stigma scores for those with and without a diagnostic label, felt that a potential explanation for their research results was that “individuals do not hold as many stigmatizing views towards individuals with AD\(^7\) as they do towards individuals with other mental illnesses” (p. 745). Lastly, in one of the only research studies that compares autism stigma ratings against other mental disorders, Feldman and Crandall (2007) concluded that ASD was the fifth least stigmatized disorder out of the 40 that they compared. Disorders such as AD/HD, depression, insomnia, and psychosis were among those with higher social distancing scores than ASD. While social phobia, posttraumatic stress disorder, female sexual arousal disorder, and narcolepsy were rated as having lower social distance ratings than ASD (Feldman & Crandall, 2007). Regardless, these findings should not detract from the fact that some of the participants in the current study believe ASD to be less stigmatizing than other diagnoses, which may be protective against self-stigma.

**Landing Ground or Starting Point.** This theme refers to a starting point from which a participant can begin to understand themselves and/or their differences once an ASD diagnosis is received. This theme acts as an intermediary between the themes of *confirmation, validation, or*  

\(^7\) The abbreviation of AD is used by the authors in this investigation to describe Asperger’s Disorder, which was their population of investigation.
explanation and action-based self-awareness in that the former explains difference and the later self-awareness you can act upon. Landing ground or starting point offers you a foundation from which to understand your ASD symptoms. For participants in this study, having a landing ground was an essential component of understanding themselves. MacLeod et al.’s (2013) investigation supports this theme as participants in their study identified benefits of receiving an ASD diagnosis that included: (1) a sense of connection with other autistic people, (2) a gain in personal insight/understanding, and (3) gains in their ability to incorporate ASD as an important part of their identity. Mogenson and Mason’s (2015) findings also support the current theme. The authors found that receipt of an ASD diagnosis facilitated control for their participants, meaning that the diagnosis provided participants with valuable information about themselves that they could use as starting point for solutions. Additionally, Bailey (2019) noted that an ASD diagnosis allows for the provision of ASD-related information to caregivers that in turn allows caregivers to research ASD and gain an understanding of the disorder, thus giving them a landing ground or starting point. One member checking participant had an exemplar in this theme and agreed with the researcher’s interpretation.

**Action-Based Self-Awareness.** This theme represents an increase in self-awareness after receiving an ASD diagnosis. Not only did participants report an increased sense of self-awareness, but they reportedly were able to translate this awareness into action (e.g., gaining awareness regarding sensory concerns and then using ear coverings in loud areas). The member checking participants had multiple exemplars in this theme, and all agreed with the researcher’s interpretations. One participant expanded on the sub-theme by stating: “My diagnosis has helped me be more conscious of the way that I react to situations, and I'm more readily able to differentiate my symptoms from other traits.” The same participant also noted that “having a
label has significantly improved my ability to analyze my own behaviour.” Participants were able to enact changes that were beneficial to their day-to-day functioning once they understood they had autism.

This theme is aligned with Lewis’ (2016) theme, strategizing towards a better life, in that participants in that study reported using “tools” to improve their lives (p. 350). Mogenson and Mason’s (2015) research further supports the current theme as some of their participants reported using their diagnosis to “negotiate living lives of difference” (p. 265) by “gaining control in their lives” (p. 266). This theme demonstrates that obtaining a diagnosis can help autistic individuals become familiar with common concerns that others with ASD experience and offer potential solutions to those concerns. It is postulated that autistic individuals may be able to extrapolate from those concerns components that apply to them and identify what is beneficial for them individually. ASD is a spectrum disorder with varying symptoms and severity levels, so it is extreme important for autistic individuals to understand their specific concerns and what might be beneficial for them since a one-size-fits-all approach is unlikely to work.

**Enhanced or Improved View of Self.** This theme references an improvement in self-perspective related to receiving an ASD diagnosis. This theme contrasts the opposing theme of blaming self, as participants who conveyed this notion reported being able to externalize their concerns as separate from the self once they understood their diagnosis rather than blaming themselves for their faults/difficulties. Again, all member checking participants had exemplars in this theme and agreed with the researcher’s interpretations. Participant 4 elaborated by stating: “Having a thoughtful understanding of myself, as well as a sense of community with other autistic people, has improved my self-image and mental well-being.” This participant also shared that, “I think social norms play a huge role in this change for me. I always had this preconceived
notion that deviating from social norms had negative implications on one's character, but my diagnosis has afforded me some forgiveness to myself in these situations.”

This theme relates to the literature on self-stigma and mental illness, as illustrated by Corrigan and Watson (2002) who stated that self-stigma can form when individuals internalize society’s stigmatizing ideas regarding mental health. Nonetheless, these authors stated that some people become energized by and react to injustice, whereas others are indifferent, resulting in a self-stigma paradox. The authors concluded that people who perceive negative stigmatization towards mental health as legitimate are likely to develop low self-esteem and engage in self-stigma. However, the authors contended an individuals’ self-esteem can remain intact if they perceive negative stigmatization as illegitimate. Further, individuals with low group identification (i.e., do not perceive themselves as part of the diagnosed group) seem indifferent to self-stigma, whereas those with in high group identification engage in righteous anger that pushes back against stigma (Corrigan & Watson, 2002). This contention seemed to resonate with findings from the current investigation as some participants resisted or pushed back against stigmatizing ideas (e.g., Participant 8 noted that “the idea that I’m a disorder is – is simply wrong”) and engaged in ASD advocacy and volunteer efforts while also reporting an improved view of self.

**Improved Relationships.** This theme refers to an improvement in relationships once an ASD diagnosis is received. This theme can be viewed as the counterpart to the theme *relationship difficulties* that emerged prior to diagnosis. Participants reported that their relationships benefitted in two ways after they received their diagnosis: (1) they were able to develop an increased understanding of social interactions and work on enhancing related skills (e.g., using appropriate eye contact) and (2) others understood them better. All three member
checking participants contributed multiple exemplars to this theme. Agreement was found for nine of the ten exemplars, while participant four added the following elaboration: “receiving an ASD diagnosis allowed me to be more thoughtful in navigating relationships, and my ability to maintain good quality relationships has since improved as a result.” This same participant also elaborated that friendships with other autistic people were also beneficial, stating “…having a group of autistic friends is also hugely beneficial to me. I don't need to "perform" nearly as much for them - I can simply interact with them in a way that feels natural to me without judgment.” In the sole instance of disagreement, Participant 4 did not agree with the researcher’s interpretation that one of the exemplars fit into the theme ofPotential Benefits of Receiving an ASD Diagnosis. That individual clarified:

I don't think I was necessarily referring to a positive outcome here. I was more so referring to a difference in how autistic children are socialized versus allistic children. Specifically, I was trying to highlight how a parent's view of their child changes significantly when they're diagnosed, and that affects their parenting style for better or for worse.”

They felt this exemplar fit better in the theme settling into diagnosis because it did not fit into the “positive/negative outcome dichotomy” of the other themes and because “the way a person settles into diagnosis is heavily influenced by the reactions of others in their life.” While the participant disagreed that one of their exemplars fit into this theme, they agreed that their other exemplars did, which still demonstrates strong support for this theme. The researcher did not relocate the exemplar to the theme settling into diagnosis as suggested by the member checking participant for two reasons. First, the theme settling into diagnosis refers to the time it takes the diagnosed individual, and not their family members to settle into their diagnosis (although it is
true it may take their family time to settle as well). Second, the member checking participants also clarified that “I was trying to highlight how a parent's view of their child changes significantly when they’re diagnosed, and that affects their parenting style.” This was interpreted to be positive as a change in parenting style can improve the parent-child relationship.

This theme is also supported in the literature. As noted earlier, Butler and Gillis (2011) found that stigma ratings were higher when people displayed ASD-type symptoms without having a label to explain those differences. Specifically, the authors concluded that “it is the atypical behaviors associated with AD that influence stigmatizing attitudes towards individuals with AD, not the label of the disorder” (p. 745). The authors noted that this finding conflicts with previous research studies and concluded that the “label of Asperger’s Disorder did not significantly impact stigmatization” (p. 745). This may suggest that people are more accepting of differences when they understand those differences, which could then in turn enhance relationships. Hickey (2018) also found that autism support groups, which became accessible to participants after their diagnosis, provided opportunities for belonging, group acceptance, and social comparison. These finding are important because they not only suggest that an ASD diagnosis helps allistic individuals understand autistic people, but also that it helps them connect with the ASD community and form relationships within that community.

**Potential Negative Outcomes of an ASD Diagnosis**

This category refers to the potential negative outcomes associated with the receipt of an ASD diagnosis. While all participants noted that there are consequences to diagnosis, they felt that diagnosis was important and that there were more benefits than harms. The harms identified include: assumptions, stigma, and stereotyping; diagnosis can lead to excuses; improved awareness can lead to shame; and, dislike for ASD services.
**Assumptions, Stigma, and Stereotyping.** This theme references assumptions, stigma, or stereotyping towards autistic people. It was contributed to multiple times by all participants and seemed to be the largest concern regarding receipt of an ASD diagnosis. Participants reported a wide variety of experiences indicating that stigma towards autistic people can manifest variably. All member checking participants agreed with the researcher’s interpretations of their exemplars for this theme. Participant 4 provided many helpful elaborations on his responses and stated that “…others' negative perceptions is definitely the biggest hurdle faced by autistic people.” This participant reflected that his concerns regarding stigma were so great that he was unwilling to share his diagnosis with his parents, stating: “I've never told my parents about my diagnosis precisely because of this stigma. They’re very heavily ingrained in these kinds of views, and I can't foresee any positive results from telling them about it.” This participant also stated:

“I don't feel personally harmed by my diagnosis, since I don't believe autism is bad; therefore, I don't connect with the notion that being labelled as autistic is harmful.

However, I'm still well aware of the personal biases that others have against autism.”

This elaboration highlighted a common theme for participants where they acknowledged that while public stigma was problematic, it did not make the diagnosis harmful to them. This highlights a concern for external stigma, even when self-stigma is not present. This theme is supported in the wider literature regarding diagnoses in general (see Ben-Zeev et al., 2010; Corrigan et al., 2004; Corrigan & Watson, 2002) and within the ASD literature (see Kinnear et al., 2016; MacLeod et al., 2013; Mogenson & Mason, 2005; Obeid et al., 2015).

Ben-Zeev et al. (2010) stated that diagnoses are highly stigmatic and can have disastrous effects on those to whom they are assigned. Milton (2012) agreed with this notion and argued that pathologizing people as abnormal allows for social stigmatization and shunning. This
perspective aligns with the results of the current study as most participants recalled experiencing stigma from other people, or conveyed that stigma from others was the most problematic consequence of receiving an ASD diagnosis and is further aligned with the definition of public stigma (e.g., when a group endorses a stereotype against another group of people; Corrigan et al., 2004; Corrigan & Watson, 2002). However, it should be noted that the present study found less support for other forms of stigma (i.e., self-stigma and label avoidance; Corrigan et al., 2004; Corrigan & Watson, 2002). This may be the case because Corrigan and Watson (2002) have stated that in some instances public-stigma does not translate to self-stigma, especially when the public-stigma is perceived as illegitimate. Corrigan and Watson (2002) elaborated that in some instances self-stigma can be avoided when those assigned a stigmatizing label react against that stigma as a social justice issue. This appears to be the case for some participants who acknowledge that public-stigma is prevalent for those with ASD, but who do not enact that stigma towards themselves. Additionally, the concept of label avoidance is not entirely supported in the current study. In the present study, most participants sought out an ASD diagnosis and therefore were not avoiding the ASD label. In fact, some participants indicated that they would have rather received their diagnosis earlier in life. However, the current study may not represent those who have engaged in label avoidance, as an ASD diagnosis was an eligibility requirement to participate and those who engage in label avoidance are less likely to have sought out a diagnosis or to participate in an ASD research study.

**Diagnosis can Lead to Excuses.** This theme reflects the perspective that ASD diagnoses have the potential to limit autistic people if the diagnostic label is used as an excuse. While most participants stated that they themselves do not use ASD as an excuse, they noted that the potential for this behaviour is a negative consequence of the diagnostic label. Further, some
participants noted that allistic people might think that they use their ASD as an excuse, when in fact they are advocating for their rights and needs or using their diagnosis as an explanation for difference. Two member checking participants had exemplars in this theme and agreed with the researcher’s interpretations. However, participant 5 clarified that she was stating what others might do, not what she does. While the title of this theme can be somewhat controversial and pejorative, the writer chose to use it because it reflected the language that participants used to describe their experiences and the language that was agreed upon during member checking. Further, this theme illustrates the complexities of stigma by highlighting external stigma (when people assume you are using a diagnosis as an excuse), internal stigma (when you think it is bad or shameful to use a diagnosis in such a way), and label avoidance (not wanting to be identified as making excuses or taking advantage of accommodations; Corrigan & Watson, 2002).

**Dislike for ASD Supports or Services.** This theme refers to a dislike for ASD-specific supports, services, or agencies. This is an important consideration as a dislike for services can potentially lead to an avoidance of services. Further, a dislike of services can imply that the services being provided do not align with the goals of the individual receiving them. As such, it is recommended that service providers regularly check in with their clients to ensure that their personal goals are being met. Cascio et al. (2020) recently published an article discussing person-oriented ethics for autism-based research; many of the principles described in their article can and should apply to service provision as well. The article noted that issues of respect, inclusion, and empowerment need to be addressed in autism research and noted the following guidelines:

(1) individualization (e.g., providing individualized support for participants), (2) acknowledgement of lived world (e.g., acknowledging barriers to care that impact research ethics), (3) empowerment in decision making (e.g., creating accessible consent
processes that address specific communication needs), (4) respect for holistic personhood (e.g., addressing sensory and processing needs and strengths), and (5) focus on researcher-participant relationships (e.g., involving autistic people in ways other than research participants, including but not limited to participatory research).

While these guidelines were intended to be applied to the research process, they can also be applied to service provision. By asking for and incorporating autistic viewpoints regarding service provision, we can increase the potential that services will meet the needs of those seeking them and potentially reduce the rates of service drop out and/or avoidance. One member checking participant had exemplars in this theme and agreed with the researcher’s interpretation.

**Improved Awareness can Lead to Shame.** This theme references a longer-term effect of diagnosis. In this case, it was reported that receiving a diagnosis and improving one’s self-awareness can lead to shame when one reflects on past events. Participants in the present investigation noted that they still think about past negative social exchanges, especially when they viewed their actions as the cause of the negativity. This was detrimental to participants who contributed to this theme and was an ongoing cause for concern. This theme demonstrated that more awareness about what is perceived by an individual to be a personal deficit is not always beneficial. This theme is aligned with the theme, life review, in Hickey’s (2018) article where participants reviewed their past considering their diagnosis. For most participants this life review helped them externalize and explain past negative events such as bullying, but for one participant this life review led to feelings of inadequacy when they recalled how they “must’ve been a really bad carer for my parents when they were terminally ill” (Hickey, 2018, p. 14). One member checking participant had exemplars in this theme and agreed with the researcher’s interpretation.
Desires

This level 2 theme refers to desires or needs of autistic individuals. In general, this category is not well supported in available research, indicating that the present literature fails to focus on the wants and needs of autistic individuals, which is why the term desires was chosen, rather than wants/needs. This terminology better captures the longing/yearning that autistic individuals have historically experienced when disvalued as experts in their own lives. However, this is slowly changing and research advisories are being developed to advocate for autism inclusive research (e.g., Cascio et al., 2020; IACC; 2017; Nicolaidis et al., 2019; Pellicano et al., 2018; Tesfaye et al., 2019).

To be Treated Equally, but with Understanding and Respect. This theme represents a desire for others to treat autistic people the same as allistic people, while still understanding and respecting autistic differences. For participants in this study, it was pertinent that people do not make assumptions or engage in stigmatic behaviour, but also be sensitive to any differences that they may have. One of the member checking participants had an exemplar in this theme and stated, “the phrasing in the definition is exactly what I was trying to say, just much more succinctly.” This theme was also supported in Kapp et al.’s (2012) investigation. In this study, participants identified with a “deficit-as-difference” conception of autism where participants self-identified as autistic and celebrated their differences, but still acknowledged their difficulties while advocating for non-curative interventions (p. 7). Those in the current study are in a way asking for a deficit-as-difference conceptualization as they want others to acknowledge and understand their differences while treating them as equal to others.

Specialized Research. This theme represents a desire for specific aspects of ASD to be further researched. While many different ASD-based topics have been researched (i.e., genetics,
perception and cognition, neurobiology, physiology, nosology, neuropsychology, social skills, treatment, diagnosis, comorbidities, behaviours, pharmacology, theory of mind, etiology, and epidemiology; Matson & LoVullo, 2009), this information is not always readily available to autistic individuals. Participant 5 had exemplars in this theme and stated: “If there have been studies on this, I haven't heard about them!”, indicating that there is a desire to have a say in both what is being researched and better access to said research.

**Access to Supports and Resources.** This theme represents a desire for better access to appropriate supports and resources. Participants reported that there are few supports available for adults and that the available services often do not meet their unique needs. Participants were particularly frustrated that the resources available to them were often geared towards those who have an accompanying intellectual disability. This theme was supported by Schembri’s (2017) investigation in which the theme, absence of or mismatch of service provisions, was described. In this theme, autistic students communicated that they lacked accommodations for specific concerns, or the accommodations provided did not meet their specific needs. Gerhardt and Holmes (2005) also reported few available services for adults with ASD. The authors felt that this was problematic as it should not be surprising that those with ASD still have ASD when they grow up, especially when one considers that ASD in a neurodevelopmental disorder. Like other themes in the current study, this theme demonstrates the importance of consulting autistic individuals regarding the types of supports and services they require. When this theme is considered with the additional theme of *dislike for ASD supports and services* and in conjunction with Schembri’s (2017) report of a mismatch of services, it indicates that time, effort, and funds are being directed towards supports and services that autistic individuals do not find useful. Two
member checking participants contributed to this theme and agreed with the researcher’s interpretations.

**Earlier Diagnosis.** This theme represents a desire to be diagnosed with ASD earlier in life. Participants in this study felt that being undiagnosed resulted in many frustrations that may have been ameliorated with an earlier diagnosis. While the average age of an ASD diagnosis is 4.4 years old (CDC, 2014), Bailey (2019) noted that adults are currently being diagnosed more often than children because our ability to detect those who have been missed in childhood has increased. As such, it seems that those who were overlooked in the past are being referred for diagnosis or communicating a desire for earlier diagnosis, suggesting that those diagnosed later in life believe that the benefits of being diagnosed might outweigh the consequences. Individuals diagnosed earlier in life can reap the potential benefits of diagnosis (e.g., earlier intervention), while those without cannot. As such, it is important for clinicians and researchers to consider why so many autistic children and youth are overlooked, and to make efforts to reduce the number of individuals who progress to adulthood undiagnosed. Two member checking participants had exemplars contributing to this theme, with both agreeing with the researcher’s interpretation.

**Accurate Representation of Diversity.** This theme refers to a desire to have ASD better represented as a spectrum condition. Participants felt that having a more accurate portrayal of ASD in the media could reduce harmful stereotypes, as more people would understand that ASD presents in more ways than the dualistic presentation of those with intellectual disability and savant syndrome. All member checking participants contributed to this theme and agreed with the researcher’s interpretations. Participant 4 provided additional clarity and stated: “Having more diverse autistics portrayed in the media would help people understand its nature as a
spectrum.” This participant also added that, “it’s frustrating to see the dichotomous portrayal of autistic people as either savants or intellectually disabled people who struggle constantly. My doctor once told me the adage that ‘if you’ve met one person with autism, you’ve met one person with autism’, and I really connected with it, because I see such a diversity of experiences even in my immediate group of friends.” The essence of this theme is supported in the literature as other research indicates that people do not fully understand the autism spectrum. Adreon & Durocher (2007) note that the spectrum term refers to a range and continuum of symptoms varying from mild to severe. Participants in the current study perceived that the public views ASD as either a disorder characterised by intellectual disability or savant syndrome, and many felt that ASD in female populations is not well represented or understood. Consequently, it is important to disseminate better information on both what the autism spectrum is and how it can present in different people.

**Perspectives on Language and Labelling.** This theme represents a desire for recognition of the different preferences regarding language and labelling. Of all the themes present in the research, this one had the least amount of cohesiveness as each participant had different preferences for how they were labelled. This theme is highly supported in the literature and was discussed in depth in the literature review. Both the current and extant literature indicate diversity of preference regarding language used to describe autistic individuals. Both CASDA (2020) and APA (20202) state that those working with autistic individuals need to be mindful of the language preferences of each individual they are working with. Further, CASDA (2020) noted that references to ASD as a disease or burden should be avoided. This perspective was further supported by a Participant 8 who stated that the idea that he is a disorder is incorrect. He felt that referencing autism as a condition was more accurate and less stigmatizing than the term
disorder. Much of the literature pertaining to the removal of the Asperger’s disorder label also supports the fact that individuals have distinct preferences for language and labelling. Kite et al. (2013) identified concerns about additional negative connotations associated with the terms ‘autism’ and ‘ASD’ that may not be present with the term Asperger’s disorder. Further both Kenny et al. (2015) and Huynh et al. (2020) found that those diagnosed with Asperger’s felt the diagnosis was part of their identity and were worried that removal of this label could result in a loss of personal and community identities. One member checking participant contributed to this theme and agreed with the researcher’s interpretation.

**Easier Access to Assessment.** This theme represents a desire to have easier access to assessment services. Many participants reported that it was difficult and expensive to access these services, especially for adults. This is supported in the literature as Gerhardt and Holmes (2005) noted a lack of services available for adults. Services available seem to focus on intervention, with an emphasis on fostering self-help skills and behavioural interventions (Howlin & Moss, 2012; Howlin et al. 2005). Yet, it has been noted that there is a lack of focus on both developmental and mental health approaches for autistic adults (Nicholas et al., 2017). There is also little mention of a focus on intervention and screening other than Aggarwal and Angus’s (2015) article where they mention that adolescents referred for services for other psychiatric concerns should be screened for ASD. However, Huang et al. (2020) conducted a scoping review on adult ASD assessment and found that barriers to assessment for adults included cost, wait times and gaps between initial consultation and actual diagnosis, difficulty finding an adult ASD specialist, previous negative experiences with mental health professionals, and fear of not being believed by health professions about ASD symptomology. Huang et al. (2020) recommended that research regarding ASD diagnoses in adulthood continue to be
conducted, especially in countries outside of the United Kingdom (UK) as the majority of published adult assessment research has been conducted in the UK. One member checking participant contributed to this theme and agreed with the researcher’s interpretation.

**Better Clinical Training and Knowledge.** This theme represents a desire for professionals to have better clinical training and knowledge regarding ASD. Participants reported that many health professionals (e.g., doctors and psychologists) did not understand ASD, especially in women and/or those without intellectual disability. This was a source of great frustration and often resulted in mistrust of health professionals and the assessment/services they provided. This theme was supported in the current literature as Parsloe and Babrow (2016) found that those with Asperger’s felt that diagnosticians could not be trusted to provide accurate diagnoses. While some participants cited concerns regarding corruption and conspiracy as components of this mistrust (e.g., believing that the subsumption of Asperger’s under ASD was based off a hidden agenda), many reported clinician incompetence as a source of large concern (Parsloe & Babrow, 2016). Two member checking participants contributed to this theme and agreed with the researcher’s interpretation.

**Key Learning: Pre- and Post-diagnosis Comparison**

One of the unique differences of this investigation that separates it from prior literature pertaining to the experience of a late autism diagnosis is its identification of pre- and post-diagnosis timeframes. By asking participants to share their perceptions and experiences both before and after they received their diagnosis, the researcher was able to compare the two different timeframes to gain a better understanding of the meaning attached to those experiences and specifically to the changes in experiences associated with an autism diagnosis. This comparison demonstrated that while participants communicated that there were potential
negative effects of receiving an ASD diagnosis (i.e., assumptions, stigma, and stereotyping; diagnosis can lead to excuses; dislike for ASD supports or services; and improved awareness can lead to shame), they identified more potential benefits of receiving a diagnosis (i.e., access to supports; confirmation, validation, or explanation; ASD is less stigmatizing than other diagnoses; landing ground or starting point; increased self-awareness; enhanced of improved view of self; improved relationships). Additionally, some participants communicated a desire to be diagnosed earlier in their lives. Participants who communicated this desire indicated that an earlier diagnosis would have facilitated earlier access to supports and services, and increased both personal and social understanding. Further supporting the conclusion that the benefits of receiving a diagnosis outweighs the potential consequences is the fact that participants did not communicate any pre-diagnosis benefits to not receiving an ASD diagnosis. Participants in this study only communicated potential negative consequences (i.e., falling through the cracks, negative treatment experiences, overlooking or misattributing ASD symptoms, lack of understanding and confusion, blaming self, and relationship difficulties) and/or neutral perspectives (i.e., circumstances leading to diagnosis, hidden diagnosis, and alternative identities) regarding their pre-diagnosis experiences, suggesting that they did not experience and/or identify benefits to being undiagnosed.

**Theme Interaction**

A consideration in this research is the substantial interaction between themes. Many themes are connected to or act as a counterpart to others. While this initially made the data analysis challenging as it was hard to parse out each individual theme, it resulted in a more comprehensive understanding of how consequences and benefits regarding ASD diagnosis are intertwined. Further, although many themes are connected, the presence of those connections
does not mean that each theme was identified by each participant. We must continue to recognize and understand that ASD is a spectrum disorder and that each individual’s experience of ASD is unique. This thorough and detailed data analysis with a focus on each individual participant’s experience aligns with the philosophical underpinning of idiography that is inherent in IPA research (Smith et al. 2009). Regardless, care was taken to ensure that each unique theme was well formed and substantiated.

**Limitations of the Research**

Though the present research was developed with consideration to ethical practices, accessibility and inclusivity, and qualitative rigour, it was not without limitations. The first pertains to sample size. Although eight participants is considered a small sample size according to most quantitative and some qualitative (e.g., grounded theory, enhanced critical incident) approaches, it is considered a suitable sample according to the IPA standards outlined by Smith et al. (2009). This is because IPA is so meticulous and rigorous in its methods of analysis that it is difficult to maintain the required level of detail when too much data is utilized.

A second limitation is the presence of many individual themes, which has the problematic potential of diluting the importance of each individual theme. The large number of themes is likely due to an interaction of multiple factors (i.e., researching a spectrum disorder, a focus on idiography, and the sample size). As autism is considered a spectrum disorder, it can present in varied ways in those diagnosed which would contribute to different experiences (and therefore themes) being contributed. When this is combined with a focus on idiography (Smith et al., 2009) it results in a detailed analysis that focuses on comparing different experiences for each individual participant. Regardless, each theme should be given the same weight and attention as
the others. Additionally, the participants who engaged in member checking agreed that each of the individual themes were separate entities with distinct definitions.

Another limitation of the investigation regards the direct translation of the results to the broader autism population. As IPA protocol recommends the use of homogeneous samples (Smith et al., 2009), it is difficult to determine the relevance of results to individuals who are not autistic young adults diagnosed later in life. For example, the results may not be relevant to those diagnosed before the age of 12, those over the age of 35 (in general and at time of diagnosis), or those who do not fall into the study’s FSIQ and SRS inclusion criteria. Further, the sample in this research had limited ethnic and cultural diversity. As such, the findings from this sample do not reflect non-Western views of diagnosis and/or diagnostic acceptance [see Freeth et al. (2014) for additional information on this topic]. Lastly, while there was relative gender balance in the data pool, the sample size was not large enough to inform how the results may pertain to solely male, female, and/or gender diverse autistic populations. Caution in interpreting and applying findings to non-Western and gender diverse populations is recommended. Despite this, the category time frames used in the data analysis allowed participants to reflect on their experiences both pre- and post-diagnosis, which increases the translatability of the findings.

Another limitation regards the interpretation of the data by a single researcher. While this is a limitation of all IPA studies, it should be noted that the interpretive feature of IPA is also considered by Smith et al. (2009) to be a benefit of this analysis rather than a hindrance. Despite this, the researcher felt it was her ethical duty to engage in member checking as outlined by Mays and Pope (2000) as autistic individuals are often excluded from providing their first-hand perspectives of what it is like to live with autism. As such, the researcher provided theme titles, definitions, and their own exemplars to each participant to confirm or disconfirm their agreement.
with the researcher’s interpretation of the data they provided. This information was included to provide context regarding the relevance and perceived fit of the researcher’s interpretation.

An additional limitation of the research is that contributions to the themes in the pre-diagnosis timeframe relied on retrospective data collection. In some instances, this retrospective data collection referred to a relatively distant time prior to diagnosis (i.e., 16 years) which may have limited participants in their ability to accurately recall what their life was like prior to receiving their diagnosis. However, this was not the case for all participants as some had been diagnosed more recently (i.e., 9 months prior to participation).

Another limitation is COVID-19 that emerged amidst this research. Although all data collection was completed prior to the start of the pandemic, member checking occurred after. Due to delays related to COVID-19, it took longer than expected to disseminate the member checking tables to the participants so they could engage in member checking. The length of time between participation in the study and member checking may have reduced interest in participating in member checking. Additionally, the stress associated with a worldwide pandemic may have reduced participation in member checking as only three participants (37.5% of participants) submitted their member checking forms by the end of the three week deadline.

**Recommendations for Future Research**

It is recommended that future research utilize the first-hand perspectives of autistic individuals. Previous research has demonstrated that autistic adults are dissatisfied when overlooked as experts in their own lives (Gillespie-Lynch et al., 2017; MacLeod et al., 2013; Nicolaidis et al., 2019), yet few studies currently incorporate such approaches (DePape & Lindsay, 2016; Nicolaidis et al., 2019). Studies should also focus on utilizing member checking/respondent validation and participatory action approaches to enhance the involvement
of participants in the research process [see Cascio et al. (2020) for guidelines regarding best practices for research engagement with autistic communities]. Benefits of including these methods go beyond enhancing participant satisfaction by adding to the extant literature, as no one better understands the experience of autism than autistic individuals.

It is also recommended that the specialized research areas mentioned in the desires category be further explored. Participants in this investigation indicated that they wanted more research regarding diversity across the spectrum, the differences between autistic people with and without intellectual disability, and heritability. As such, it is recommended that researchers continue to investigate different aspects of ASD, but that the focus also shift towards accessible ways to disseminate this information. In feedback provided during member checking, one of the participants noted that they had not heard of studies in a specific ASD domain, indicating that research on autistic populations is not easily accessible and/or disseminated to autistic populations. Autistic individuals should be able to access research pertaining to themselves so they can utilize this information to their advantage and make informed decisions about their own lives. Further, participants also indicated a strong desire for additional research regarding what autism looks like in adults without intellectual disability. Female and non-binary participants also advocated for enhanced understanding regarding both gender presentation and gender differences across the spectrum. As such, research efforts should focus on how autism symptomology is different in female populations so that it can be more readily identified in this population. Research efforts should also focus on how gender presents in autistic individuals with a specific focus on transgender and non-binary folks.

The diversity in the theme *assumptions, stigma, and stereotyping* indicates that we need to garner better understanding of stigma and its impact on autism populations. Participants in this
theme indicated that that along with concerns regarding public-stigma from those without ASD, some forms of self-stigma and/or label avoidance (Corrigan & Watson, 2002) may also be inherent (e.g., not wanting to be seen as making excuses or accessing resources). Little research is available on this topic, and it would be helpful to understand how stigma and label avoidance are related to both use of accommodations and other ASD-related service provisions. Further, it is also essential to understand how label avoidance may relate to receiving a late diagnosis. Bailey (2019) reported that reluctance to give or receive an ASD diagnosis can play a role in individuals going undiagnosed; it is essential to understand the role of stigma in late diagnosis.

Participants in this study described consequences to receiving an ASD diagnosis, including stigma, but many also identified more consequences to not receiving a diagnosis. As such we should investigate why people are reluctant to both give and receive ASD diagnoses. However, some participants felt that ASD was less stigmatizing than other disorders, and specifically less stigmatizing than other disorders that were assigned to explain their difficulties (e.g., those who were diagnosed with ODD and anorexia prior to their ASD diagnoses). More research needs to be conducted regarding the impact of stigma for specific disorders so that we can discern if certain labels are more stigmatizing than others. Lastly participants communicated that while stigma is a significant concern, some relationships improved upon getting an ASD diagnosis suggesting that the stigma of an ASD label is not a detriment to all relationships. Additional research should be conducted regarding stigma, ASD disclosure, and relationships in different contexts (e.g., in a romantic relationship vs. a collegial work relationship).

The themes of Overlooking or Misattributing ASD Symptoms and Earlier Diagnosis indicate that we need to develop a better understanding of why certain individuals and their symptom presentations are being overlooked in their early years, and why diagnosis is occurring
later in life. As participants are indicating that they would have rather been diagnosed earlier in life it is important to develop greater understanding of why people are being overlooked. This information could then be translated into clinical practice to support earlier identification and diagnosis of autistic people. Further, different types of caregivers (e.g., teachers, parents, psychologists) ought to be trained to identify ASD symptoms and should be wary of conflating ASD symptoms with different disorders.

**Recommendations for Clinical Practice**

In addition to recommendations for future research, this investigation garnered recommendations for clinical practice that are applicable to professionals who work with autistic populations. Majority of the clinical implications born out of this research investigation are related to the Level 2 theme of potential negative outcomes of not having an ASD diagnosis. Level 3 themes subsumed in the above theme such as falling through the cracks, negative treatment experiences, and overlooking or misattributing ASD symptoms indicate areas in which clinicians might consider further growth. In the above instances individuals fell through the cracks and did not receive appropriate treatment, had their symptoms overlooked/misattributed, and/or received treatment that they felt was detrimental and misinformed. These negative outcomes of being undiagnosed were problematic for the participants in this research and resulted in adverse life experiences that could be potentially avoided if these individuals had received care from clinicians who have a better understanding of what ASD can look like across different presentations. As such, it is recommended that clinicians become more aware of what ASD is and how it presents. For clinicians who are not well versed in assessment and/or neurodevelopmental disorders, it is recommended that clinicians be open and honest about the limits of their competency in this area so they can facilitate an appropriate referral. These
concerns are also related to the theme *better clinical training and knowledge*. Participants reported that they wished mental health professionals had better training and clinical knowledge across multiple different domains related to ASD. As ASD often presents with other mental health concerns it is probable that clients with ASD (both diagnosed and undiagnosed) will seek treatment for other mental health concerns. Clinicians treating these concerns should understand how ASD presents and how it may impact treatment planning.

With the theme *landing ground/starting point*, it is recommended that clinicians working with those who have received an ASD diagnosis can process the diagnosis with the client and provide them with resources that are applicable to their diagnosis. The clinician is often the first point of professional caregiving after the diagnosis so time and care should be spent processing the diagnosis as indicated in the theme *settling into diagnosis*. Another recommendation regards the theme *improved awareness can lead to shame*. This theme highlighted a consequence of improved self-awareness involving the experience of shame regarding current symptom presentation and/or past behaviour. Participants reported that they were acutely aware of how they may have been perceived by others in the past once they developed a better understanding of their concerns. This is an important aspect of self-awareness that should be considered and potentially processed with clients in a therapeutic setting once they receive a diagnosis.

Additionally, a small subset of participants discussed the harms of hiding an autism diagnosis from people who receive one. In the results chapter, a poignant example was presented of a participant whose family hid his diagnosis from him at the suggestion of the diagnosing clinician. The participant communicated that having his diagnosis hidden from him resulted in feelings of anger and resentment towards his family and the diagnosing clinician, that made it more difficult for the participant to accept the diagnosis as he concluded that he would have been
told about it at the outset if the diagnosis had any credence. As such, this information can be used to inform clinician and caregiver decisions to communicate with autistic individuals about their diagnosis. Clinicians can help caregivers process their thoughts and feelings about a diagnosed family member and educate those family members regarding the benefits and consequences of informing the diagnosed individual of their diagnosis. Smith-Demers (2018) investigated diagnosis disclosure and found that the process of sharing a diagnosis with a child was highly complex and required consideration of many unique factors. However, Smith-Demers (2018) found that parents underscored both the benefits and importance of diagnosis disclosure. Brown et al. (2021) provided suggestions for how professionals can support a neurodiversity perspective from the point of diagnosis, which includes partnering with caregivers during disclosure. Partnering with parents can help clinicians identify those who may need more information and support regarding ASD diagnosis disclosure. Further, clinicians can share autobiographical accounts of what it is like to receive an ASD diagnosis with caregivers so that they can glean an understanding of the impact of diagnosis. The research investigation adds much to the current literature regarding the experience of receiving a late autism diagnosis which can be translated into knowledge used for clinical services/care. First, the study highlighted the dual perspectives regarding the benefits and harms of receiving an ASD diagnosis. This information is useful to clinicians, caregivers, and individuals who remain undiagnosed as it can inform the willingness of the above-mentioned parties to seek out an ASD diagnosis actively. As mentioned in the stigma literature by Corrigan and Watson (2002) individuals and/or their caregivers may engage in label avoidance and fail to seek out autism-based assessments due to misconceptions and/or assumptions regarding autism. These results can be used to challenge those misconceptions and/or assumptions and encourage those (and/or their families) experiencing ASD symptoms to
seek out assessments. This is because despite the potential for the harms from diagnosis communicated by autistic participants, the benefits were perceived as greater, with participants wanting earlier diagnoses.

The information gleaned from this research can also serve to inform general views regarding the utility of a diagnosis. In Chapter 2 it was noted that the various disciplines in psychology (e.g., clinical, counselling, school, health, industrial/organizational) hold different views regarding the purpose, role, and impact of clinical diagnosis. These views have traditionally been polarized, with many in the counselling psychology field pushing back against the medical model and its use of diagnostic labeling (e.g., Sinacore-Guinn, 1995; Strong 2012) because of conflicts between the medical model and the underlying philosophical assumptions inherent in the field of counselling psychology. As such, these results can be used to inform the counselling psychology literature regarding views on autism diagnoses, and potentially views regarding other neurodevelopmental diagnoses and/or other diagnoses present in the DSM.

This research may also inform those who work with individuals undergoing ASD assessment. Bailey (2019) noted that there can be a reluctance to both give and accept an ASD diagnosis because of beliefs that an ASD diagnosis is harmful. Despite the misgivings of some practitioners, Bailey clarified that there are benefits to an ASD diagnosis which include: (a) autism-informed treatment plans and interventions; (b) looking for and treating common co-occurring disorders; and (c) providing ASD related information to relevant family members. The current research supported points (a) and (c) above, but also highlighted additional benefits to receiving an ASD diagnosis (e.g., improved relationships, improved self-esteem, and action-based self-awareness). If professionals are more aware of the benefits of receiving an ASD diagnosis, it may reduce their hesitancy to provide such a diagnosis. Further, for individuals who
may qualify for an ASD diagnosis but who may be engaging in label avoidance by not pursuing psychological assessment, findings from this study regarding the benefits and consequences of diagnosis may help them make more informed decisions.

Lastly, the information communicated in the desires (i.e., to be treated equally, but with understanding and respect, specialized research, access to supports and resources, earlier diagnosis, accurate representation of diversity, perspectives on language and labelling, easier access to assessment, and better clinical training and knowledge) portion of the results highlighted areas of want/need for autistic young adults. Of important note was the need for better access to autism assessments for adults and the need for access to appropriate adult resources. Participants consistently noted that it was difficult to obtain an ASD assessment and/or diagnosis because of the costs associated with the assessments and the ability of clinicians to understand what autism looks like in adult populations without intellectual disability accurately, especially for females and non-binary individuals.

**Summary**

The aim of this research was to glean a better understanding of the experience of receiving a late diagnosis for young autistic adults. The findings revealed two Level 1 themes that were constructed off the pre- and post-diagnosis timeframes. These themes were then broken into different Level 2 themes, four of which were then broken down further into several Level 3 themes. In total, 29 diverse themes that highlighted the differences in pre- and post-diagnosis experiences were discovered. Many of the findings were aligned with the current literature, though some were new to the scholarly literature. The specific focus on the difference between the two diagnostic time periods was novel and offered new revelations regarding the perceived benefits and harms of receiving an autism diagnosis later in life. Future research...
should continue to focus on the experience of diagnosis, especially for different groups within the autism spectrum. Additionally, it is advisable that future research elicit the first-hand perspectives of autistic individuals by utilizing not only qualitative or mixed method approaches, but also engaging participatory action approaches. The results highlight dual perspectives regarding the benefits and harms regarding receiving an autism diagnosis. Yet, despite these harms, many participants preferred having an official diagnosis. As such, it is hoped that the findings may inform assessment-based service providers and their willingness to assess for and diagnose ASD and the way they approach sharing this information with autistic clients.
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Appendix A: Recruitment Documents

Third Party Recruitment Script

[NAME OF ORGANIZATION] is assisting the University of Calgary to better understand what it is like to receive a diagnosis of Autism Spectrum Disorder (ASD) which also includes diagnoses of Autism, Asperger’s, or Pervasive Developmental Disorder – Not Otherwise Specified.

To do this, the researchers want to interview and audio-record individuals who received an ASD diagnosis at age 12 or older. Participants must be between 18-35 years old and must have their diagnosis for 6 months. Participants must be able to read and write in English. If you are interested in the study, you may contact Taylor Schembri at taylor.schembri@ucalgary.ca for more details.

You should note that you are in no way obligated to participate in the research. If you decide not to participate in the research, it will in no way affect your relationship with CanLearn.

Participants who are interested in the research project may be entered to win one of two $25 gift cards.

The University of Calgary Conjoint Faculties Research Ethics Board has approved this study (REB18-1302).

Researcher Recruitment Script

Dear (insert name),

You are receiving this email because you previously participated in a research study titled: “Understanding and supporting the needs of post-secondary students with autism spectrum disorder (ASD): A qualitative study of the student perspective.” When you participated in this study you indicated that you would like to be contacted in the future regarding other autism related research opportunities. The student researcher who you previously worked with at the University of Calgary is working to better understand what it is like to receive a diagnosis of Autism Spectrum Disorder (ASD), including Autism, Asperger’s Syndrome/Disorder, and Pervasive Developmental Disorder – Not Otherwise Specified.

The researchers at the University of Calgary are interested in understanding what an autism diagnosis means to those who receive it and how the diagnosis might impact people’s lives. To do this, the researchers want to interview and audio-record individuals who have received an ASD diagnosis by age 12 or older. Participants must be between the ages of 18-35 and must have had their diagnosis for 6 months.

If you are interested in the study, you may contact Taylor Schembri at taylor.schembri@ucalgary.ca for more details.
You should note that you are in no way obligated to participate in the research, and your decision to participate or not participate in the research will in no way affect your relationship with the researcher or the University of Calgary.

Participants interested in participating may be entered to win one of two $25 gift cards. University of Calgary Conjoint Faculties Research Ethics Board has approved this study (REB18-1302).

**Recruitment Advertisement**

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*Do you have Autism Spectrum Disorder? Or Asperger’s Syndrome or PDD-NOS? IF SO, WE WANT TO HEAR FROM YOU!*  

Many people receive an ASD diagnosis outside of early childhood. We are conducting a study to better understand what it is like to receive an ASD diagnosis later in life and what this diagnosis means to you.

If you received an ASD diagnosis at age 12 or older, are between the ages of 18-30, speak English, and have received an ASD diagnosis at least one year ago, you may be eligible to participate!

Participation involves doing some activities, filling out some forms, and an audio-recorder interview about your experience of receiving an ASD diagnosis. The entire process should take 1-2.5 hours. To show our appreciation for your time, you can enter into a $25 gift card draw.

If you would like more information about the study or are interested in participating, please contact Taylor Schembri at taylor.schembri@ucalgary.ca.

This University of Calgary Conjoint Faculties Research Ethics Board has approved this study.
Appendix B: Consent Form

Consent Form

Name of Researcher, Faculty, Department, Telephone & Email:
Taylor Schembri, M.Sc.
Counselling Psychology Doctoral Candidate
Werklund School of Education
Email: taylor.schembri@ucalgary.ca

Supervisor:
Adam McCrimmon, Ph.D., R.Psych, Associate Professor
Werklund School of Education
Alberta Children’s Hospital Research Institute
University of Calgary

Title of Project: The Experience of Late Diagnosis for Young Adults on the Autism Spectrum.
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.

The University of Calgary Conjoint Faculties Research Ethics Board has approved this research study

Purpose of the Study
This study wants to investigate the experiences of late diagnosis for individuals with autism, Asperger’s, and PDD-NOS (referred to as Autism Spectrum Disorder; ASD). We want to know:

1) What was it like to receive an ASD diagnosis?
2) What does your diagnosis mean to you?

What Will I Be Asked To Do?
At the start of the interview process you will be asked to complete some brief tasks (e.g., organizing blocks to match pictures, answering questions, and filling out forms). If you are eligible, you will be asked to complete a form asking general questions about yourself (e.g., age, gender) and your personal health (e.g., psychological/psychiatric diagnoses). You will then be interviewed and asked more detailed questions regarding your experience of receiving an ASD diagnosis. The entire research process should take approximately 1-2.5 hours. After participation in the interview process, and the data from the study has been analyzed, you will be invited to review some of the research data to ensure the researcher has correctly interpreted what you communicated in the interview. If participants choose to assist with member checking they will receive an email that takes examples from their interviews and organizes them into themes with matching definitions. Participants can then communicate by email if they agree with the researcher’s interpretation of their interview. Member checking should take approximately 45 minutes.
Your participation in this research is completely voluntary. You may decline to participate in individual parts of the study or decline to participate altogether. You may also withdraw from the study at any time without penalty. If you wish to withdraw after the interview and/or form completion, you can contact the interviewer and ask for your information to be removed. Data withdrawal is only possible within two weeks from participating in the interview.

**What Type of Personal Information Will Be Collected?**

Should you agree to participate, you will be asked to provide your name, age, age at diagnosis, gender, and psychological/psychiatric diagnoses. If you have access to and feel comfortable sharing your ASD assessment report, a copy of this will be kept by the researcher. No identifying information from this report will be included in the final write up. In addition, you will be interviewed to collect your opinions and perspectives on an ASD diagnosis. If you agree, your interview will be audio recorded. Your specific responses, which will be recorded and transcribed by an independent transcriber, will be kept private by the researcher on password-protected computers where it will be stored for up to 10 years. Any published data from the interviews (e.g., quotes) will not be associated with any personal or identifying information. Access to audio files and transcripts will be restricted to the research team and will be stored for up to ten years on password protected computers.

**Are there Benefits or Risks if I Participate?**

There are no anticipated risks associated with your participation in this research. Any risks encountered in the research are anticipated to be similar to those encountered in everyday life. Although it is perceived as unlikely, there is the potential for emotional vulnerability due to the discussion of personal experiences that will be covered over the course of the interview and brief surveys. You will be provided with a list of university and community supports. Should you experience distress as a consequence of participating in this research, you are free to contact one of the services listed on the resource sheet.

To further ensure your comfort while participating, you are free to answer the questions you wish to answer. You do not have to answer any questions you do not wish to answer. If you become fatigued or upset, you may take a break, ask to resume the study on another date, or request to stop the study altogether. If you choose to stop the study, there will be no consequences.

The benefits to being in this study are that you will contribute to the research literature regarding the current understanding of the experience of diagnosis for individuals with ASD. Knowledge obtained from the study will be shared with post-secondary institutions and agencies that support individuals on the spectrum.

Your participation in this research study is entirely voluntary and will in no way affect your relationship with any of the participating organizations (e.g., the University of Calgary, ASERT Lab, Ability Hub, or other agencies) regardless of your decision to participate in, decline, or withdraw from the study.

Participants in this study will be offered the opportunity to enter in a draw to win one of two available gift-cards valued at $25.00 as a form of compensation for your time and participation in
each portion of the study (interview and reviewing study data). If you choose to withdraw from
the study at any point, you are free to do so without penalty or loss of the ability to enter the
draw to win the gift-card.

What Happens to the Information I Provide?
If you decide to participate, your information will be kept private. Only the research team will
know you participated in the study. To ensure privacy, you will be asked to select an alias or
I.D. number to put on your questionnaires. This same alias or I.D. number will also be used
when transcribing the audio information from the interviews and feedback sessions. All of the
information you give will be kept private in a locked cabinet. Only the research team will have
access to it. Audio recordings will be kept for up to 1 year to ensure transcript accuracy.
Anonymized information (i.e., information with no personal identifiers attached to it) will be
kept for a period of ten years, and may be retained for up to 25 years, at which point it will be
destroyed. Lastly, your individual information will not be shared in any presentation or reports.

If you agree, there are different options for you to consider. You can choose all, some, or none of
them. Please think about the options and choose Yes or No:

I grant permission for researcher to make a copy of my ASD assessment report and use this
information in the study:         Yes: ___ No: ___

I grant permission for researcher to use the information from my forms for the study:     Yes: ___ No: ___

I grant permission for researcher to audio record my interview:                       Yes: ___ No: ___

I grant permission for researcher to use the information from the interview for the study:
                                                                                     Yes: ___ No: ___

I grant permission for the researcher to enter me into the draw for a chance to win a gift-card.
                                                                                     Yes: ___ No: ___

I grant permission for the researcher to use the information from this study in a potential follow-up study:
                                                                                                                                                                                                                         Yes: ___ No: ___

I grant permission for the research team to contact me regarding future ASD research:
                                                                                     Yes: ___ No: ___
I am interested in reviewing the study data after it has been analyzed:  
Yes: ___  No: ___

I grant permission for researcher to use the information from my feedback of the data analysis:
Yes: ___  No: ___

The pseudonym/I.D. number that I choose for the study is:

The researcher may contact me at: Email: - __________________  Phone: - ________

Signatures

Your signature on this form indicates that 1) you understand to your satisfaction the information provided to you about your participation in this research project, and 2) you agree to participate in the research project.

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.

Participant’s Name: (please print) _____________________________________________
Participant’s Signature: ________________________________________  Date: _______

Researcher’s Name: (please print) _____________________________________________
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 McCrnimmon

EDT 531, 2500 University Dr. NW
Werklund School of Education
Calgary, AB, T2N 1N4
(403) 220-5004, awmccrim@ucalgary.ca

If you have any concerns about the way you have been treated as a participant, please contact the Research Ethics Analyst, Research Services Office, University of Calgary at (403) 210-9863; email 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: Demographic Forms

Information Sheet

Contact: Taylor Schembri, M.Sc
Counselling Psychology Doctoral Candidate
Email: taylor.schembri@ucalgary.ca

Completed Informed Consent: □ Yes □ No
Participant ID: ____________________ Date Completed: ________________

Demographics:
Date of Birth: ________________ Age at diagnosis: ________________
Ethnicity: ____________________ Gender: ____________________

Diagnosis (dx):
□ Autism (Spectrum) Disorder
□ Asperger’s Syndrome / Disorder
□ Pervasive Developmental Disorder, not otherwise specified
□ Other __________________________

Who gave dx (name/specialization): ______________________________________

Personal History:
To your knowledge, have you ever been diagnosed with any of the following conditions?
(check all that apply and write the age of diagnosis beside the check mark)

**Intellectual Disorder:**
□ Intellectual Disability □ Global Developmental Delay

**Communication Disorder:**
□ Language (Expressive/Receptive) □ Social Communication □ Speech articulation

**ADHD:**
□ Inattentive □ Hyperactive/Impulsive □ Combined

**Disruptive Disorder:**
□ Oppositional Defiant □ Intermittent Explosive □ Conduct

**Learning Disorder:**
□ Reading □ Written Expression □ Math
Motor / Movement Disorder:
☐ Developmental Coordination  ☐ Stereotypic Movement  ☐ Other

Tic Disorder:
☐ Tourette’s (motor + vocal)  ☐ Vocal  ☐ Motor

Anxiety:
☐ Separation Anxiety  ☐ Social Anxiety  ☐ Phobia
☐ Panic Disorder  ☐ General Anxiety  ☐ Agoraphobia

Obsessive Compulsive:
☐ Obsessive-compulsive Disorder  ☐ Body Dysmorphic Disorder  ☐ Hoarding
☐ Trichotillomania (hair pulling)  ☐ Excoriation (skin picking)

Depression:
☐ Major Depressive Disorder  ☐ Persistent Depressive Disorder
☐ Disruptive Mood Dysregulation Disorder

Bipolar Disorder:
☐ Bipolar I  ☐ Bipolar II  ☐ Cyclothymic

Eating:
☐ Anorexia  ☐ Rumination Disorder  ☐ Pica
☐ Bulimia  ☐ Binge-Eating
☐ Avoidant/Restrictive Food Intake Disorder

Sleep:
☐ Insomnia  ☐ Hypersomnolence  ☐ Parasomnia
☐ Breathing Related  ☐ Other

Gender Dysphoria:
☐ Gender Dysphoria  ☐ Other

Trauma/Stress Related:
☐ Reactive Attachment Disorder  ☐ Adjustment Disorder  ☐ Posttraumatic Stress Disorder
☐ Acute Stress  ☐ Disinhibited Social Engagement Stress Disorder

Addictions:
☐ Alcohol-related  ☐ Drug-related  ☐ Gambling

Reality:
☐ Delusional  ☐ Brief Psychotic
□ Schizoaffective □ Schizophreniform

**Personality:** (Please Specify)

_________________________________________________________________________________________

**Other:** (Please Specify)

_________________________________________________________________________________________

Is there anything else you would like to share about what it is like to receive an autism diagnosis?

_________________________________________________________________________________________

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Is there anything you would like to share about your experience participating in this study?

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______________________________________________________________________________
______________________________________________________________________________

201
Appendix D: Procedure Flow Chart

Stage 1

Prospective Participant Receives and Signs Consent Form to Participate

Meets Inclusion Criteria

Telephone Screening Interview

Does not Meet Inclusion Criteria

Thank prospective participant for their time

Stage 2

Intellectual Testing

Does not Meet Inclusion Criteria

Thank participant for their time

Meets Inclusion Criteria

Demographic Forms and Interview

Enter gift-card draw #1

Stage 3

Member Checking

Enter gift-card draw #2
Appendix E: Telephone Screening Protocol

To begin, the interviewer will go over the details of the research study and ensure that the participant understands all of the information conveyed to them. The researcher will also take the time to explain to all prospective participants that they must meet eligibility requirements to participate in the research and that not everyone will be able to contribute to the interview stage. During this time the researcher will answer any additional questions that the participant may have. The researcher will also take time to discuss items such as audio-recording and confidentiality so the participant is aware of the requirements of the research study before proceeding. Lastly, the researcher will clarify the different stages of the research process and inform the participant that they may or may not be invited to participate in the additional stages of the research process.

1) Have you been diagnosed with ASD (or any previously used autism diagnostic terminology)?
   
   **YES** = move to question two  
   **NO** = thank the prospective participant for their time

2) How old were you when you were diagnosed with ASD?
   
   $\geq 12$ = move to question three  
   $< 12$ = thank the prospective participant for their time

3) How old are you currently?
   
   $\geq 18$ = move to question four  
   $< 18$ = thank the prospective participant for their time

4) Does the participant seem to understand the information conveyed to them and demonstrate ability to participate in the interview?
   
   **YES** = begin interview questions  
   **NO** = thank the prospective participant for their time
Appendix F: Interview Protocol

Please note: this is a semi-structured script and not all questions will be asked of participants

-When did you receive an ASD diagnosis?
  -What diagnosis did you receive?
-Who initiated the referral for assessment for diagnosis?
  -Why did you/they initiate this referral?

Self-Concept
-In what way did your ASD diagnosis change the way you view yourself?
  -In what way has your sense of self changed since receiving a diagnosis?
-In what way has your life changed since receiving the diagnosis?
-How did you understand yourself before the diagnosis?
  -How did you make sense of your Autism symptoms and experiences before receiving a diagnosis?
  -How did you understand yourself before the diagnosis?
-In what way has the diagnosis benefited you?
  -How so?
-In what ways has the diagnosis harmed or restricted you?
  -How so?

Meaning making
The field of psychology has created labels to help us understand and name conditions for people that might be different from others (e.g., autism, Aspergers, PDD-NOS).
-As a person who has been given one of these labels, in what ways is this labelling helpful?
-In what ways is this labelling harmful?
-What do you think about the autism label?
  -Do you think being labelled as having autism is helpful/hindering?
-If you as a person with autism had control over the way you are viewed, what would you prefer?
-If we lived in a world where we didn’t use any labels, and you consider all the aspects of having autism, in what ways does the autism label bring meaning to your life?
-In what ways do you identify with your autism label or other labels?

Community
-How has your connection with other people changed since receiving a diagnosis?
-As a result of your diagnosis, have you been given access to services that you did not previously have access to?
  -What services have you been given access to?

End
-In what ways can receiving an ASD diagnosis hinder people?
-In what ways can withholding an ASD diagnosis hinder people?
-Do you have anything else you would like to share with me that you think is important for me to know? (about receiving an ASD diagnosis) (about the use of labels)?
### Appendix G Example of the Member Checking Template

<table>
<thead>
<tr>
<th>Theme: NAME OF THEME</th>
</tr>
</thead>
<tbody>
<tr>
<td>Subtheme: NAME OF SUBTHEME</td>
</tr>
<tr>
<td>Definition: DEFINITION FOR THAT THEME</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Exemplar:</th>
<th>Do you agree with the theme and example of the theme?</th>
<th>Why/why not?</th>
<th>Any other comments?</th>
</tr>
</thead>
<tbody>
<tr>
<td>(In each row below and example from your interview is provided to confirm the above listed themes and definitions)</td>
<td>(Please check the yes or no box for each example)</td>
<td>(Please type your reasons for agreeing on not agreeing with the exemplar, responses may be in point form)</td>
<td>(Please share any other comments you may have)</td>
</tr>
<tr>
<td>Exemplar 1</td>
<td>□ YES</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ NO</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Exemplar 2</td>
<td>□ YES</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ NO</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Exemplar 3</td>
<td>□ YES</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ NO</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## Appendix H Participant Themes

### Participant 1

<table>
<thead>
<tr>
<th>Pre-Diagnosis</th>
<th>Post-Diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Circumstances Leading to Diagnosis</strong></td>
<td><strong>Potential Benefits of Receiving an ASD Diagnosis</strong></td>
</tr>
<tr>
<td></td>
<td>• Access to Supports</td>
</tr>
<tr>
<td></td>
<td>• Confirmation, Validation, or Explanation</td>
</tr>
<tr>
<td>Alternative Identities</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Landing Ground or Starting Point</td>
</tr>
<tr>
<td></td>
<td>• Improved Relationships</td>
</tr>
<tr>
<td><strong>Potential Negative Outcomes of Not Having an ASD Diagnosis</strong></td>
<td><strong>Potential Negative Outcomes of an ASD Diagnosis</strong></td>
</tr>
<tr>
<td>• Falling Through the Cracks</td>
<td>• Assumptions, Stigma, and Stereotyping</td>
</tr>
<tr>
<td>• Negative Treatment Experiences</td>
<td>• Diagnosis can Lead to Excuses</td>
</tr>
<tr>
<td>• Overlooking or Misattributing ASD Symptoms</td>
<td>• Dislike for ASD Supports or Services</td>
</tr>
<tr>
<td>• Lack of Understanding and Confusion</td>
<td><strong>Desires</strong></td>
</tr>
<tr>
<td>• Eluding Self</td>
<td>• To be Treated Equally, but with Understanding and Respect</td>
</tr>
<tr>
<td><strong>Legend</strong></td>
<td>• Specialized Research</td>
</tr>
<tr>
<td>Italic text = Level 1 theme</td>
<td>• Earlier Diagnosis</td>
</tr>
<tr>
<td>Bold text = Level 2 theme</td>
<td>• Perspectives on Language and Labelling</td>
</tr>
<tr>
<td>Standard text = Level 3 theme</td>
<td></td>
</tr>
</tbody>
</table>

### Participant 2

<table>
<thead>
<tr>
<th>Pre-Diagnosis</th>
<th>Post-Diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Circumstances Leading to Diagnosis</strong></td>
<td><strong>Settling into Diagnosis</strong></td>
</tr>
<tr>
<td></td>
<td><strong>Potential Benefits of Receiving an ASD Diagnosis</strong></td>
</tr>
<tr>
<td></td>
<td>• Access to Supports</td>
</tr>
<tr>
<td></td>
<td>• Confirmation, Validation, or Explanation</td>
</tr>
<tr>
<td></td>
<td>• Landing Ground or Starting Point</td>
</tr>
<tr>
<td></td>
<td>• Action-Based Self-Awareness</td>
</tr>
<tr>
<td></td>
<td>• Enhanced or Improved View of Self</td>
</tr>
<tr>
<td></td>
<td>• Improved Relationships</td>
</tr>
<tr>
<td><strong>Potential Negative Outcomes of Not Having an ASD Diagnosis</strong></td>
<td><strong>Potential Negative Outcomes of an ASD Diagnosis</strong></td>
</tr>
<tr>
<td>• Falling Through the Cracks</td>
<td>• Assumptions, Stigma, and Stereotyping</td>
</tr>
<tr>
<td>• Lack of Understanding and Confusion</td>
<td>• Diagnosis can Lead to Excuses</td>
</tr>
<tr>
<td>• Eluding Self</td>
<td>• Improved Awareness can Lead to Shame</td>
</tr>
<tr>
<td><strong>Legend</strong></td>
<td><strong>Desires</strong></td>
</tr>
<tr>
<td>Italic text = Level 1 theme</td>
<td>• To be Treated Equally, but with Understanding and Respect</td>
</tr>
<tr>
<td>Bold text = Level 2 theme</td>
<td>• Access to Supports and Resources</td>
</tr>
<tr>
<td>Standard text = Level 3 theme</td>
<td>• Earlier Diagnosis</td>
</tr>
</tbody>
</table>
Participant 3

**Pre-Diagnosis**

| Circumstances Leading to Diagnosis | Hidden Diagnosis |

**Potential Negative Outcomes of Not Having an ASD Diagnosis**
- Lack of Understanding and Confusion

---

**Post-Diagnosis**

| Settling into Diagnosis | Potential Benefits of Receiving an ASD Diagnosis |

- Access to Supports
- Confirmation, Validation, or Explanation
- Landing Ground or Starting Point
- Action Based Self-Awareness
- Enhanced or Improved View of Self
- Improved Relationships

---

**Desires**
- To be Treated Equally, but with Understanding and Respect
- Specialized Research
- Earlier Diagnosis
- Perspectives on Language and Labelling

---

Legend:
- Italic text = Level 1 theme
- Bold text = Level 2 theme
- Standard text = Level 3 theme

Participant 4

**Pre-Diagnosis**

| Circumstances Leading to Diagnosis | Hidden Diagnosis |

**Potential Negative Outcomes of Not Having an ASD Diagnosis**
- Lack of Understanding and Confusion
- Blaming Self
- Relationship Difficulties

---

**Post-Diagnosis**

| Potential Benefits of Receiving an ASD Diagnosis |

- Access to Supports
- Confirmation, Validation, or Explanation
- Action Based Self-Awareness
- Enhanced or Improved View of Self
- Improved Relationships

---

**Desires**
- To be Treated Equally, but with Understanding and Respect
- Specialized Research
- Earlier Diagnosis
- Accurate Representation of Diversity

---

Legend:
- Italic text = Level 1 theme
- Bold text = Level 2 theme
- Standard text = Level 3 theme
Participant 5

<table>
<thead>
<tr>
<th>Pre-Diagnosis</th>
<th>Post-Diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Circumstances Leading to Diagnosis</td>
<td>Potential Benefits of Receiving an ASD Diagnosis</td>
</tr>
<tr>
<td>Alternative Identities</td>
<td>Potential Negative Outcomes of Not Having an ASD Diagnosis</td>
</tr>
<tr>
<td>Potential Negative Outcomes of Not Having an ASD Diagnosis</td>
<td>Desires</td>
</tr>
<tr>
<td>• Overlooking or Misattributing ASD Symptoms</td>
<td>• Access to Supports and Resources</td>
</tr>
<tr>
<td>• Lack of Understanding and Confusion</td>
<td>• Earlier Diagnosis</td>
</tr>
<tr>
<td>• Blaming Self</td>
<td>• Accurate Representation of Diversity</td>
</tr>
<tr>
<td>• Relationship Difficulties</td>
<td>• Perspectives on Language and Labelling</td>
</tr>
<tr>
<td></td>
<td>• Easier Access to Assessment</td>
</tr>
<tr>
<td></td>
<td>• Better Clinical Training and Knowledge</td>
</tr>
</tbody>
</table>

Legend:
- Italic text = Level 1 theme
- Bold text = Level 2 theme
- Standard text = Level 3 theme

---

Participant 6

<table>
<thead>
<tr>
<th>Pre-Diagnosis</th>
<th>Post-Diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Circumstances Leading to Diagnosis</td>
<td>Potential Benefits of Receiving an ASD Diagnosis</td>
</tr>
<tr>
<td>Hidden Diagnosis</td>
<td>Potential Negative Outcomes of an ASD Diagnosis</td>
</tr>
<tr>
<td>Alternative Identities</td>
<td>Desires</td>
</tr>
<tr>
<td>Potential Negative Outcomes of Not Having an ASD Diagnosis</td>
<td>• Access to Supports</td>
</tr>
<tr>
<td>• Hitting Through the Cracks</td>
<td>• Confirmation, Validation, or Explanation</td>
</tr>
<tr>
<td>• Lack of Understanding and Confusion</td>
<td>• ASD is Less Stigmatizing than Other Diagnoses</td>
</tr>
<tr>
<td>• Relationship Difficulties</td>
<td>• Action Based Self-Awareness</td>
</tr>
<tr>
<td></td>
<td>• Enhanced or Improved View of Self</td>
</tr>
<tr>
<td></td>
<td>• Improved Relationships</td>
</tr>
</tbody>
</table>

Legend:
- Italic text = Level 1 theme
- Bold text = Level 2 theme
- Standard text = Level 3 theme
Participant 7

Pre-Diagnosis

Circumstances Leading to Diagnosis

Alternative Identities

Potential Negative Outcomes of Not Having an ASD Diagnosis
- Falling Through the Cracks
- Negative Treatment Experiences
- Overlooking or Misattributing ASD Symptoms
- Lack of Understanding and Confusion
- Blaming Self
- Relationship Difficulties

Legend
- Italic text = Level 1 theme
- Bold text = Level 2 theme
- Standard text = Level 3 theme

Post-Diagnosis

Potential Benefits of Receiving an ASD Diagnosis
- Access to Supports
- Confirmation, Validation, or Explanation
- Action Based Self-Awareness
- Enhanced or Improved View of Self
- Improved Relationships

Potential Negative Outcomes of an ASD Diagnosis
- Assumptions, Stigma, and Stereotyping
- Dislike for ASD Supports or Services

Desires
- Access to Supports and Resources
- Perspectives on Language and Labelling
- Easier Access to Assessment
- Better Clinical Training and Knowledge

Participant 8

Pre-Diagnosis

Circumstances Leading to Diagnosis

Potential Negative Outcomes of Not Having an ASD Diagnosis
- Falling Through the Cracks
- Overlooking or Misattributing ASD Symptoms
- Lack of Understanding and Confusion
- Blaming Self
- Relationship Difficulties

Legend
- Italic text = Level 1 theme
- Bold text = Level 2 theme
- Standard text = Level 3 theme

Post-Diagnosis

Potential Benefits of Receiving an ASD Diagnosis
- Access to Supports
- Confirmation, Validation, or Explanation
- Action Based Self-Awareness
- Enhanced or Improved View of Self
- Improved Relationships

Potential Negative Outcomes of an ASD Diagnosis
- Assumptions, Stigma, and Stereotyping
- Dislike for ASD Supports or Services

Desires
- Specialised Research
- Earlier Diagnosis
- Perspectives on Language and Labelling
- Easier Access to Assessment
- Better Clinical Training and Knowledge