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The loss of Asperger Syndrome: An exploration of its effects on self-identity

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The loss of Asperger Syndrome: An exploration of its effects on self-identity

by

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A THESIS

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Abstract

In the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (*DSM-5*), Asperger Syndrome (AS) has been eliminated and integrated into a new Autism Spectrum Disorder (ASD) diagnostic framework. The loss of AS has social implications for people who self-identify and derive personal meaning from their diagnosis. The current study explored the opinions of adults with AS regarding the identity terms related to the changing classification of ASD. A qualitative approach was adopted whereby 12 participants each completed a semi-structured interview that was transcribed and analyzed via Thematic Analysis. The data revealed six themes: 1) Derived Meaning, 2) Knowledge and Understanding, 3) Perceptions and labels, 4) Social Identity, 5) Opinions and Reactions to ASD, and 6) Barriers to Funding and Service Provision. Overall, the results from the current study have practical utility for the AS community, families, and professionals, and will form the basis of future research.

Keywords: Asperger Syndrome, ASD, DSM-5, Thematic Analysis

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Abbreviations	Definitions
AD	Autistic Disorder
AHS	Alberta Health Services
AISH	Assured Income for the Severely Handicapped
APA	American Psychiatric Association
APP	American Psychiatric Publishing
AS	Asperger Syndrome
ASD	Autism Spectrum Disorder
CDC	Centre for Disease Control and Prevention
CDD	Childhood Disintegrative Disorder
DSM	Diagnostic Statistical Manual of Mental Disorders
FSIQ-4	Full Scale Intelligence Quotient, Fourth Edition
GT	Grounded Theory
HFA	High Functioning Autism
ICD	International Centre for Diseases
IPA	Interpretive Phenomenology Analysis
IQ	Intellectual Quotient
IST	Identity Status Theory
LFA	Low Functioning Autism
NT	Neuro-typicals
NIMH	National Institute of Mental Health
NINDS	National Institute of Neurological Disorders
PDD	Pervasive Developmental Disorder
PDD-NOS	Pervasive Developmental Disorder – Not Otherwise Specified
PRI	Perceptual Reasoning Index
RD	Rett Disorder
RRB	Restrictive, Repetitive, Behaviours
SIT	Social Identity Disorder
TA	Thematic Analysis
VCI	Verbal Comprehension Index
WASI	Wechsler Abbreviated Scale of Intelligence
WISC	Wechsler Intelligence Scale for Children

Chapter One: Introduction and Overview

Clinical labels are generally used to explain maladaptive patterns of behaviour and to determine an appropriate course of action to treat an underlying condition (Madsen & Leech, 2007). However, clinical labels can also be used to define a person by his or her condition. When a person is given a diagnosis, the label may result in the individual being reduced to a clinical identity (Lane & Stratford, 1985). Specifically, a clinical identity arises when a person socially categorizes (which refers to the way by which people classify or assign others to a category to better understand and identify groups; Tajfel & Turner, 1979) and self-identifies (which refers to the process of adopting the identity of the group that the person categorizes him or herself as belonging to; Tajfel & Turner, 1979) with their clinical group (Amiot, De la Sablonniere, Terry, & Smith, 2007). Unfortunately, clinical labels are often associated with negative connotations that may result in an increase in stigma, stereotypes, discrimination, and prejudice (Goffman, 1963). Given that people will conform to and draw upon the descriptive language (and/or labels) by which they are described (Hacking, 1993), the perceptions associated with clinical labels can influence how a person self-identifies (Charland, 2004).

Asperger Syndrome (AS) is one diagnosis that was associated with an identity (Giles, 2014; Singh, 2011). Previously considered a Pervasive Developmental Disorder (PDD; a group of autism-related disorders including Autistic Disorder [AD], Childhood Disintegrative Disorder [CDD], and Pervasive Developmental Disorder Not Otherwise Specified [PDD-NOS] characterized by delays in the development of basic functions including socialization and communication; APA, 2000), AS is now integrated into the single Autism Spectrum Disorder (ASD) diagnosis in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (*DSM*-5; APA, 2013a). In general, AS was considered a neurodevelopmental disorder typified

by persistent deficits in social interactions coupled with restrictive and repetitive patterns of behaviours and/or interests (RRB; American Psychiatric Association [APA], 2000). Although AS shared similar diagnostic features with other PDDs, what distinguished AS from the other subtypes was the absence of delayed language and cognitive development (APA, 1994). Given its mild presentation, AS symptoms may remain undetected until adulthood (National Institute of Neurological Disorders and Stroke [NINDS], 2016). Researchers estimate that the prevalence for AS ranged from 1 to 3 in 500 (Fombonne & Tidmarsh, 2003; Mattila et al., 2007) with a predominance in males compared to females.

In general, the emergence of an AS identity and community (Giles, 2013) can be traced back to its introduction in the *DSM-IV* (APA, 1994*)*. In particular, the autistic community (which encompasses AS, AD, and PDD-NOS) is centered on neurodiversity, which is the belief that autism is a variation in human functioning rather than an illness that should be cured (Autism Speaks, 2013). The autism rights movement (which is a submovement of the neurodiversity movement) further supports this message in advocating for the acceptance of autistic behaviours, the respect of the autistic community, and the support of autism social networks to enable people on the autism spectrum to socialize on their own terms (Autism Speaks, 2014). Given the social impact of these groups, the Aspie for Freedom group was inspired to create an Autistic Pride Day (Giles, 2014) that celebrates the neurodiversity of people with ASD. Subsequently, members of the Autistic community began to take pride and self-identify with their clinical label in part because there was a community that also self-identified that way.

The *DSM* went through a process of revision in 2013 whereby an ASD diagnostic framework was adopted and AS (amongst the other PDDs; APA, 2013a) was removed as a

distinct clinical disorder. The taxonomic changes to the structure of ASD have considerable

implications for people who socially identify with their clinical diagnosis. Specifically, what

happens to people who hold a diagnosis that the APA eliminates? Indeed, what happens to the

individuals who have been labeled as having AS who now have a new diagnosis? How will

people diagnosed with AS self-identity when faced with the loss of the diagnosis? Finally, what

will happen to the AS community that prides itself on its label? Given that a large group of

people self-identify with AS, forcing these people to relinquish their long-standing iatrogentic

identity (relating to an illness caused by medical examination or treatment) may be of ethical

concern (Charland, 2004). Thus, an investigation on self-identification and the opinions related

to the identity terms (AS, AD, and ASD) is warranted.

Summary

Overall, the primary objective of this study was to explore the identity-related opinions of

adults with AS on the changing classification of ASD and to shed light on the formation of a

social identity. The findings from the present study will provide researchers, clinicians,

individuals, and families insight into an area that has been largely ignored in the literature.

Furthermore, the results have practical utility for treatment planning, service provisions, and

application in future research.

The current document is organized into five chapters. Following this introduction,

Chapter Two presents a review of pertinent literature including a brief overview the importance

of language and how the removal of a clinical label can affect a community and its population.

A brief history of ASD will follow (whereby AD, PDD-NOS, and AS will be described), leading

to the publication of the *DSM-5* and adoption of the ASD framework. Rationale for the adoption

of the ASD diagnosis and elements of dimensionality (in terms of severity ratings) will be given.

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Finally, an application of the chosen theoretical framework (Social Identity Theory) is presented to educate readers about the importance of an identity, how an identity is formed, and why a clinical population (in particular the AS community) might identify socially with their clinical group. Chapter Three provides a comprehensive description and rationale for the research design, including a justification for the research paradigm, a discussion of the researcher's epistemology, ontology, and axiology, the rationale for the chosen methodology, and a detailed outline of the participants, procedures, and data analysis employed in the current study. The findings will be presented in Chapter Four, with particular focus on the primary and secondary themes. Lastly, Chapter Five offers an interpretation of the results and provides an evaluation of the current study's limitations and implications, and concludes with final reflections.

Chapter Two: Literature Review

Chapter Two provides an overview of language use and labels as they relate to identity formation. The implications associated with the application and removal of clinical labels will be explored followed by a brief history of Autism Spectrum Disorder (ASD) leading to the release of the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (*DSM-5*; American Psychiatric Association [APA], 2013a). Limitations of the *DSM-IV* (APA, 1994) categorical approach will be presented as justification for the adoption of the *DSM-5's* ASD framework. Finally, the rationale and purpose of the study will be outlined below.

Asperger Syndrome as a Social Construct

Arguably, before the nineteenth century, Asperger Syndrome (AS) did not exist. According to Dean and Lane (2001), AS "is not a disease that lurks about in nature, waiting for a psychiatrist with especially acute powers of observation to discover it hiding everywhere. It is a condition created by a new (functional) understanding of diseases," (p. 81). Given that psychological disorders are classified on the basis of symptomatic observations, diagnostic labels may be considered a social construct created as a by-product of identifiable behaviours (Dean & Lane, 2001; Hacking, 1995). From a linguistic perspective, language is a tool used to name and classify objects, groups, and things, rather than a means for discovery (Stace, 2014). Thus, in some respect, diagnostic labels may be considered the most agreed upon scientific description used by the mental health profession to classify observed behaviour (Dean & Lane, 2001).

The Looping Effect and Dynamic Nominalism

Ian Hacking (1995), a Canadian philosopher of science, studied the classification of people and how the effects of classification can change a classified group. Hacking (1995) argues that psychology is in the business of "making up people," whereby human science (a

broad category ranging from sociology to medicine and psychology) can sometimes "create kinds of people that in a certain sense did not exist before" (p. 2). Thus, the process of classifying groups of people requires "systematic, general and accurate knowledge" (Hacking, 1995; p. 394) of classification for people to quickly draw inferences about a person's characteristics based on their association with a particular group. Moreover, Hacking (2007) insists that made up people become "moving targets" as they "change in reaction to politically, medically, and socially imposed categories and classifications which in turn changes the nature of the category itself," (p. 23-27). Thus, when "people conform or behave in the manner in which they are described," (p. 21) this is known as the "Looping Effect" (Hacking, 1995).

Building on his previous work, Hacking (2007) coined the term "dynamic nominalism," which refers to the process whereby the emergence of a label and those who are labeled manifests simultaneously as the "names interact with the named," (p. 23) and "how names affect people and how people feedback onto their names" (Hacking, 2013). To illustrate this point, Hacking (2013) gave the example of what it means to be autistic, which is a term that developed as a by-product of the characteristics people see as making up a person who has autism. At a lecture given at the University of Leeds, Oakley titled 'The Shaping of Autism,' Hacking (2013) purported:

> "[t]he genre [of autistic narratives] is helping to bring into being an entire mode of discourse, cementing ways in which we have recently begun to talk, and will talk about autism. It is developing a language, or, if you will, a new language game, one that is being created before our eyes and ears. This speech is, in turn, creating or extending a way for very unusual people – namely, autistic ones – to be, to exist, to live."

Thus, labels (category) may be created in response to the narratives people associate with the labeled (those classified) much like autistic narratives have the power to transform what it is to be autistic (Hacking, 2013)

Labeling Theory

One subset of language is labels (Stace, 2014). Specifically, labeling is characterized as an "invention, selection, manipulation of beliefs which defines conduct in a negative way and the selection of people into these categories," (Becker, 1963; p. 88). Rooted in the idea of a social construction of reality, labeling theory is based on the "symbolic interactionism perspective" whereby the meaning that people derive and attribute to the world is generated from everyday social interactions (Becker, 1963; p. 89). According to Becker (1963) "social groups create deviance by making the rules whose infraction constitutes deviance" (p. 4). Thus, the words used in labeling may enable a person to partition people based on what the label describes (and psychiatric labeling is one way that partitioning occurs). Though central to the concept of deviance in crime and behaviour, labeling theory closely aligns with the self-fulfilling prophecy (positive or negative events that may affect a person's behaviour in a manner that would cause those expectations to come true), stereotyping, and social identity (Becker, 1963). When a person is given a label, it may be extremely difficult to shed (Becker, 1963). The individual may be labeled a deviant (behaviour that violates social norms) and subject to increased stigmatization (a powerful negative label; Goffman, 1963) by people in society (Becker, 1963). Additionally, the internalization of a label may inform a person's self-identity (Tajfel & Turner, 1979) and lead the deviant individual to act in ways that fulfills the expectation of the label (Becker, 1963). To educate the readers on the effects of psychiatric labeling, the following section explores the challenges associated with the application and removal of clinical labels.

The Application and Removal of Clinical Labels

The application of clinical labels is generally used to explain maladaptive patterns of behaviour and determine an appropriate course of action to remedy the underlying condition (Madsen & Leech, 2007). For some people, a clinical label can help them make sense of their experiences and put past challenges into perspective (Giles, 2014). Thus, a clinical identity arises when a person embraces his or her diagnosis and internalizes the characteristics associated with the disorder as being a part of the self (Singh, 2011). Unfortunately, the application of clinical labels can also give rise to ethical concerns whereby a person is diagnosed with psychiatric labels that they do not want and are helpless to remove (Charland, 2005; Madsen & Leech, 2007). Furthermore, given society's poor understanding and negative views of people with mental health (Charland, 2004), affected individuals often are treated poorly or labeled in a way that hurts their standing in the community. According to Madsen and Leech (2007), a small percentage of people in North America still consider people with mental illnesses to be dangerous. This negative outlook is further compounded because of the negative connotations that society associates with mental health labels (i.e., people with schizophrenia are thought to be erratic, violent, and aggressive; Mann & Himelin, 2004). Lastly, diagnosing a person with a psychiatric condition may subject the individual to increased stigma, discrimination, and prejudice as the label may become his or her defining feature (Charland, 2005; Madsen & Leech, 2007). Thus, the application of a clinical label can have its drawbacks.

Ethical issues similarly exist for the removal of clinical labels. Changes to medical labels and scientific terminology are not uncommon and psychological disorders are susceptible to outside forces including politics and governing bodies (Ozonoff, 2012). Concerns surrounding identity tend to arise when clinical labels are removed or when clinical terminology have been

significantly changed and/or aspects of its original meaning are lost (Charland, 2004; Singh, 2011). Specifically, the removal of a clinical label may "threaten" the identity of people who derived personal meaning from their diagnosis (Charland, 2004; p. 347). Particularly, the loss of a clinical identity may somehow "invalidate a person's experiences under the label" (Charland, 2004; p. 337) as the meaning of those experiences may be impacted. As such, some individuals may refuse to relinquish their "iatrogenic identity provided by their medical diagnostic labels," (Charland, 2004; p. 335) in the face of an official label change. Charland (2004) refers to this phenomenon as a sort of "madness for identity" (p. 335).

Nevertheless, the APA, which is the professional body scientifically classifying mental disorders in North America, published the *DSM-5* (APA, 2013a) that replaced the previously separate autism-related disorders (Autistic Disorder [AD], AS, and Pervasive Developmental Disorders, Not Otherwise Specified [PDD-NOS]) with the all-encompassing Autism Spectrum Disorder (ASD; APA, 2013a). Although the mental health community considers ASD to be the most agreed upon and scientific description of people with developmental disorders (APA, 2013a), this change in classification resulted in the loss of AS (amongst several other disorders) as a clinical disorder which has important implications for people who derive personal meaning from their diagnosis. Given that clinical labels have a large role in people's identity, the following section provides a brief historical overview of ASD to familiarize readers with the events leading to the removal of AS as a clinical diagnosis. A description of the individual autism subtypes is presented to highlight the similarities and differences between each disorder and to solidify the purpose of this study.

Brief History of ASD and the Classification of Disorders in the DSM

The term Autism has evolved considerably since its introduction as a clinical disorder. Originating from the Greek word "autos" meaning "self" (Haubrich, 2003), Autism was first introduced in 1911 by Eugen Bleuler, a Swiss psychiatrist who described a cluster of symptoms associated with childhood Schizophrenia (Bleuler, 1950). However, it was Dr. Leo Kanner at John Hopkins University who first used the term in a clinical setting to describe 11 children who presented with severe social and communication abnormalities with narrow and restrictive interests (Kanner, 1943). The following year, Hans Asperger, a Viennese pediatrician, identified a similar condition in four children who were socially isolated and who demonstrated repetitive behaviours, a preference for sameness, interests in unusual topics, motor clumsiness, and a propensity towards rote memorization of facts and speech (Asperger, 1991). Unlike those described by Kanner, Asperger's clients had expected level intelligence and were verbally fluent, with peculiar use of language and abnormal prosody (Asperger, 1991).

DSM and DSM-II. Between the 1950s and 1960s, Autism became widely regarded as a form of childhood Schizophrenia (Bregman, 2005). Initial accounts of Autism were classified as 'Schizophrenic Reaction, Childhood-Type' in the initial Diagnostic and Statistical Manual of Mental Disorders (*DSM*; APA, 1952). The disorder was later modified to 'Schizophrenia, Childhood-Type' in the *DSM-II* (APA, 1968). By the start of 1970s, medical professionals began to understand Autism as a biological disorder of brain development (Ozonoff, 2012) rather than a form of Schizophrenia.

DSM-III. In 1980, the *DSM-III* (APA, 1980) was published and 'Infantile Autism' was recognized as a neurologically-based disorder. Unfortunately, the *DSM-III's* definition of Infantile proved to be overly 'monothetic' (i.e., every criterion had to be present) and so the

revised version of the manual (*DSM-III-R;* APA, 1987) introduced Autistic Disorder (AD). The new definition was 'polythetic' (i.e., needing to meet a minimum number of criteria out of a total list of symptoms). It included a triad of core features (social impairments, language delays, and restrictive, repetitive, behaviours [RRB]) and a checklist of diagnostic criteria (APA, 1987). This polythetic approach gave clinicians greater diagnostic flexibility. Additionally, the use of categorical diagnoses is, and continues to be, useful in guiding clinicians in the diagnosis of clinical disorders.

DSM-IV. In 1994, a new classification system, Pervasive Developmental Disorders (PDD), was introduced in the *DSM-IV* (APA, 1994). PDD referred to a group of five disorders (AD, AS, Rett Disorder (RD), Childhood Disintegrative Disorder (CDD), and PDD-NOS) characterized by varying degrees of qualitative impairments in the domains of communication, reciprocal social interaction, and RRB (APA, 1994). Symptoms of PDD present in childhood often persisted well into adulthood (Fitzgerald & Corvin, 2001; Mayes, Calhoun, Mayes, & Molitoris, 2012; McPartland & Klin, 2006; NINDS, 2016). Moreover, PDD was reported to occur in all racial, ethnic, and socioeconomic groups - affecting more males than females (CDC, 2013). The following section offers a brief description of the *DSM-IV's* AD, PDD-NOS, and AS to acquaint the readers with the core features and impairments of each disorder.

Autistic Disorder (AD). AD (see Table 1) as defined by the *DSM-IV* (APA, 1994) was a neurodevelopmental disorder characterized by the marked presence of a triad of core impairments: 1) social interactions, 2) verbal and non-verbal communications, and 3) restrictive repetitive and stereotypic patterns of behaviours and/or interests. Symptoms were required to appear before three years of age (APA, 1994) and persist across multiple contexts. Of note, 50 percent of people with AD had some degree of cognitive impairment (APA, 1994; Haq & Le

Couter, 2004). According to the Centers for Disease Control and Prevention (CDC, 2013), the prevalence rate of ASD is estimated to be 1 in 68 American children. However, this figure is inclusive of all children with PDD and does not reflect the prevalence of AD specifically.

Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS). In contrast, PDD-NOS was considered the "catch-all" diagnosis (American Psychiatric Publishing [APP], 2013; para. 2) or "subthreshold autism" (Autism Speaks, 2014). Also a neurodevelopmental disorder, individuals who exhibited severe and pervasive impairments in the area of reciprocal social interactions, verbal or nonverbal communication skills, and/or marked with the presence of RRB but who failed to meet diagnostic criteria for a specific PDD and/or the presentation was considered sub-threshold often received a PDD-NOS diagnosis (APA, 1994). PDD-NOS can occur in conjunction with a wide spectrum of intellectual abilities (Autism Speak, 2014). Overall, Fombonne (2009) estimated the prevalence rate of PDD-NOS to be 37.1/10,000.

Asperger Syndrome (AS). Also a pervasive neurodevelopmental disorder, AS shared similar primary and secondary impairments with AD. Primary impairments are characteristics that are typically associated with the disorder including: 1) severe and sustained impairments in social interactions and 2) the development of restrictive and repetitive patterns of behaviours, interests, and activities (APA, 1994; see Table 2 in the appendices). In contrast, secondary impairments are characteristics not considered to be defining features such as poor executive functioning, theory of mind, and attention issues (Wing et al., 2011). As such, these impairments may result in persons with AS to experience social rejection, isolation, and peer victimization (Cappadocia, Weiss, & Pepler, 2012). AS was generally considered to be on the high functioning end of the autism spectrum (Autism Speaks, 2014). Particularly, people with AS did not have significant delays or difficulties in language or cognitive development (APA, 1994). As such,

many people with AS were misdiagnosed as a child or did not receive a diagnosis until later in age (Autism Speaks, 2014). Unfortunately, the prevalence of AS was difficult to ascertain due to differences in diagnostic criteria, screening tools, methodologies, and time periods (NINDS, 2016). However, a conservative estimate for the prevalence of AS ranged from 1 to 3 in 500 (Fombonne & Tidmarsh, 2003; Mattilla et al., 2007). According to Attwood (2017), AS is found predominately in males compared to females.

DSM-5. In 2013, the APA published the *DSM-5* (superseding the *DSM-IV-TR*) containing the standards for the classification of mental disorders used in North America by mental health professionals (APA, 2013a). One major difference from the *DSM-IV* includes changes to the taxonomic structure of PDD (APA, 2013b). Specifically, the *DSM-5* adopted a new classification system for the diagnosis of ASD (APA, 2013a). The following section provides a detailed conceptualization of ASD and its diagnostic framework.

Classification of ASD. PDD has been traditionally viewed as a categorical diagnosis. With the categorical or dichotomous approach, "clinicians are required to determine whether a disorder is present or absent" based on a set of diagnostic criteria (APA, 2013b; para. 1) focusing on behaviour rather than function. However, the research on the nosology (the study of the classification of diseases) of PDD supported an ASD framework rather than the *DSM-IV's* characterization of distinct PDDs (APA, 2013a). While all disorders in the *DSM-5* remain in specific categories, scientist believe ASD (which has no clear boundaries) is better suited for a dimensional approach that classifies disorders based on quantification of attributes rather than the assignment of categories (APA, 2013b). As such, the APA incorporated elements of dimensionality (in the form of metrics of severity for select diagnoses) into the current categorical approach to classifying ASD (APA, 2013b). This new approach is believed to "allow

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clinicians more latitude to assess the severity of a condition" and account for variability in phenotypic expression (APA, 2013b; para. 1).

In the *DSM-5*, ASD is conceptualized as a single inclusive category that subsumes the former individual *DSM-IV* diagnoses (AD, AS, CDD, RD, and PDD-NOS; APA, 2013a). In general, ASD is considered a "more accurate, medically, and scientific useful way of diagnosing individuals with autism-related disorders" (APP, 2013a; para. 1). As such, the individual diagnostic subtypes are no longer used. Instead, the spectrum denotes a broad range of symptoms with variable levels of severity (Giles, 2014). People on the high end of the spectrum were previously considered to have High Functioning Autism (HFA), a non-diagnostic clinical term used to describe the 11-34% of individuals with AD who have no apparent intellectual disability or language impairment (Frazier et al., 2010; Gillberg & Ehlers, 1998). Likewise, individuals with AS and PDD-NOS were also considered high functioning because of their mild social-communication and RRB impairments (Volkmar, Lord, Bailey, Schultz, & Klin, 2004). Lastly, AD could be found across the spectrum (Rutter, 2005). The functioning level of these individuals often is commensurate with their degree of cognitive impairment, which ranges from low to moderate severity (Autism Speaks, 2014).

Several changes were made to the diagnostic criteria for ASD (see Table 5 in the appendices). These changes include the unification of the social and communication domains from the previous triad set of impairments to a dyadic set of core impairments (APA, 2013a). Thus, to be diagnosed with ASD, a person must exhibit: 1) impairments in social communication and 2) restrictive and repetitive patterns of behaviours, interests, and/or activities (APA, 2013a). Likewise, the number of symptoms for ASD have been streamlined from the presence of 12 clinical symptoms in the *DSM-IV* to seven in the *DSM-5* (Ozonoff, 2012; Zwaignbaum, 2012).

Overlapping criteria and similar descriptors indicative of ASD behaviours (e.g., limited sharing of interests, reduced back-and –forth conversation, limited social-emotional reciprocity) have been merged while symptoms that were not specific to ASD (e.g., delayed language acquisition) are eliminated. Additionally, with the inclusion of specifiers for the diagnosis of ASD (refer to Table 4 in the appendices), clinicians are expected to describe an individual's symptomatology and the current level of supports required using ratings of severity (Level 1 "Requiring support"; Level 2 "Requiring substantial support"; and Level 3 "Requiring very substantial support; APA, 2013a). The severity ratings for social-communication and social-interaction are distinct from the ratings used for repetitive patterns of behaviour, interests, or activities. Moreover, specifiers can be used to indicate whether an individual has an intellectual or language impairment (e.g., single words only or phrased speech) associated with another neurodevelopmental disorder (attention-deficit/hyperactivity disorder) or catatonia (a disorder characterized by an extreme loss of motor skills or constant hyperactive motor activity), respectively. Lastly, the *DSM-5* recognizes the presence of hyper- or hypo-reactivity to sensory input for the diagnosis of ASD (APA, 2013a), unlike the *DSM-IV*. Examples may include sensitivity to certain aspects of the environment such as aversive reactions to sounds, textures, smells, lights, and temperatures.

  Characteristics. As outlined in the *DSM-5* (APA, 2013a), core deficits of ASD must persist across multiple contexts either currently or historically, present in early childhood, hinder an individual's everyday functioning, and cannot be better explained by another clinical disorder (APA, 2013a). Challenges in social-communication may include verbal and nonverbal social skills ranging from a complete lack of language to delayed language acquisition, poor language comprehension, echoed speech, or stilted and/or overly literal language (APA, 2013a). When speech is acquired, reciprocal social communication including pragmatic use of language may be

impaired (APA, 2013a). Additionally, individuals with ASD may present with a marked

impairment in nonverbal communicative behaviours used in social interactions (APA, 2013a).

This impairment may manifest as an absence or atypical eye contact, body orientation, and facial

expression and/or speech intonation (APA, 2013a). Individuals with ASD also exhibit deficits in

social emotional reciprocity including difficulties in initiating social interactions, a lack of

imitation skills, no sharing of emotions or interests, and difficulties in joining and/or sustaining a

conversation (APA, 2013a). As such, people with ASD often have difficulty developing,

maintaining, and understanding relationships (APA, 2013a). The presentation of RRBs also

varies broadly and manifests differently depending on the individual's age, functioning level,

severity level, and degree of intervention and supports (APA, 2013a). Stereotyped or repetitive

motor stereotypies (i.e., hand flapping, rocking, spinning, and finger flapping) and repetitive

speech (i.e., echolalia) is more common of lower functioning individuals with ASD (APA,

2013a) whereas RRBs may manifest as an excessive adherence to routines and restricted patterns

of behaviours and interest (i.e., lining up toys, ridged thinking, and strict adherence to rules) in

higher functioning individuals (APA, 2013a). Finally, individuals with ASD may also have

highly restricted and fixated interests that are atypical in intensity or focus (e.g., fixation with

buttons, an exuberant knowledge of birds, or strong attachment to a toothbrush; APA, 2013a).

 Prevalence of ASD. According to the Centers for Disease Control (CDC), ASD is not

limited by race, ethnicity, or socioeconomic status (CDC, 2013) and there is an

overrepresentation of males diagnosed with ASD compared to than females (4.5 times more

common in boys [1 in 42] than amongst girls [1 in 189]; CDC, 2013). A recent study suggests

that ASD may be one of the fastest growing developmental disabilities (Autism Speaks, 2014;

CDC, 2012). In particular, the prevalence rate for ASD is estimated to be 1 in 68 (or 14.7 per

1,000 eight-year-olds; CDC, 2014) in the United States. This figure is roughly 30% higher than previously reported in 2012, with 1 in 88 children identified as having ASD (CDC, 2013). To date, no adult epidemiological study on ASD has been conducted in Canada (Public Health Agency of Canada, 2012). Though the cause for the increase in prevalence is unclear, changes in diagnostic practices and greater awareness for the disorder are likely contributing factors (Fombonne, 2003; Rutter, 2005). To understand the reasoning behind the adoption of the ASD framework, the following section details several challenges with the *DSM-IV's* categorical approach.

Rationale behind the Change in Classification of PDD

In general, changes to the diagnostic criteria and terminology of ASD were implemented to address a number of limitations with the *DSM-IV's* approach to classifying PDD. First, the categorical approach has been criticized for the inclusion of a diagnostic threshold while recognizing subthreshold forms of conditions (Volkmar, Reichow, & McPartland, 2012). Second, given that misdiagnoses and/or comorbidities occur at high rates in clinical populations (Ozonoff, 2012), the categorical approach may actually inflate the rates of comorbidity (Bauman, 2010; Ozonoff, 20120. In particular, the use of individual autism subtypes in the *DSM-IV* gives a false impression that diagnostic subdivisions are commonplace (Caron & Rutter, 1991) when incorporation of a dimensionality to classifying PDD may better account for the varying degree of symptoms. Third, the strict categorical approach does not address the developmental changes that can occur with ASD (Volkmar et al., 2012). A longitudinal study following 300 children from two to 21 years of age found that the clinical presentation of ASD at a young age manifested differently later in life in about 20 percent of their participants (Guthrie, Swineford, Nottke, & Wetherby, 2013). Thus, adoption of dimensionality in the form of symptom severity

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may better account for the developmental changes as symptoms levels changes with age and time. Fourth, the categorical approach has been criticized for its difficulty in "attending to the enduring tension between the narrow versus broader definitions" (Volkmar et al., 2012, p. 232). The latter has important implication for research while the former has implications for service planning. With regards to definitions, researchers require concrete descriptions to objectively measure a particular phenomenon (Volkmar et al., 2012). Thus, a broad definition would not lend itself well to research, as the results may be too broad to have any concrete meaning. Alternatively, the narrow categorical approach may constrict a clinician's ability to obtain a breadth of clinical information about a client that could be beneficial to the design of a treatment plan (APA, 2013b; Kite, Tyson & Gullifer, 2013). Therefore, a broad diagnostic definition that includes "the use of specifiers, subtypes, severity ratings, and cross-cutting symptom assessments is believed to better help clinicians capture gradients of a disorder" (Regier, Kuhl & Kupfer, 2013; p. 94) and may be better suited for service provision. In general, the adoption of the ASD framework was guided by the service industry (Spillers, Sensui, & Linton, 2014). Under the *DSM-IV*, people who exhibited symptoms related to social communication dysfunction and RRB could be diagnosed with AD, AS, CDD, RD, or PDD-NOS (APA, 2000). Unfortunately, the diagnostic criteria for these disorders were applied inconsistently across clinicians, practices, and treatment centers (APA, 2013b; para. 4), resulting in high rates of disagreement amongst clinicians. Though clinicians generally agreed on the presence of clinically significantly diagnostic features, they often disagreed on the assignment of a formal diagnosis partially due to the presence of sub-threshold symptomatology (i.e., differences in the individual's behavioural severity, language skills, and intelligence; Buxbaum & Baron-Cohen, 2013; Wilson et al., 2013; Worley & Matson, 2012). Thus, the inclusion of dimensionality to the

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classification of ASD is intended to increase the accuracy of diagnosis.

Similarly, the commonalities between AS and AD further complicated the process of a differential diagnosis (Autism Speaks, 2014). Specifically, AS and AD share similar diagnostic symptoms including marked impairments in reciprocal interactions enacted in non-verbal behaviours (i.e., eye-to-eye gaze and facial expressions) to regulate social communication (APA, 1994). Likewise, individuals with either disorder lack the presence of social-emotional reciprocity (i.e., preference for solitary activities) and a spontaneous sharing of interest or achievements with others (APA, 1994). People diagnosed with AS and AD also exhibit extreme adherence to rules and routines, often favoring one activity or topic more than others. This lack of flexibility can make transitions and changes extremely difficult and distressing for individuals affected by either disorders (APA, 1994). In contrast, there are two significant diagnostic distinctions between AS and AD. First, by definition, an individual with AS could not have clinically significant delays in speech acquisition (e.g., single words are used by age two; communicative phrases are used by age three). Second, those with AS could not demonstrate a clinically significant delay in cognitive development, age appropriate self-help skills, adaptive behaviours, or curiosity about the environment (APA, 1994). In fact, individuals with AS typically possessed average to above average IQ - often in the superior range (APA, 1994). As such, most individuals with AS achieved their early developmental milestones and academic targets within the expected range, whereas those with AD did not.

Despite limitations of the *DSM-IV's* approach to diagnosing PDD, researchers would agree that the traditional categorical model of classification should not be entirely abandoned as its original purpose is still well served (Brown & Barlow, 2002) and is currently used in the *DSM-5*. Overall, the fundamental goals of the *DSM-5* are to increase the accuracy of diagnosing

psychological disorders, reduce the potential for discrepancy between clinicians (by providing more clearly defined criteria for ASD; APA, 2013a; Coury, 2013; Grant & Nozyce, 2013; Insel, 2013), and support the access of treatments and services for people with mental health challenges (APA, 2013a). Unfortunately, the reclassification of the autism subtypes may have engendered some unintended effects. Particularly, there is a group of people from that strongly self-identified and understood that they are AS as a result of their diagnosis under the *DSM-IV* (Giles, 2014; Singh, 2011). But with the adoption of the ASD framework, AS is no longer recognized as an official diagnosis (APA, 2013a). In some sense, the AS status was lost and reclassified under a broader diagnosis (APA, 2013b) that may have significant implications for individuals whose identity is comprised in part by their diagnosis and label. To demonstrate how and why a person with a psychiatric disorder might identify with their clinical label, it is important that readers understand the influence a social group can have on a person's self-identity.

Identity

Identity is the driving force that shapes how a person acts, behaves, believes, and perceives the world around them (Fearon, 1999). Hence, identity provides a global understanding about one's self. Derived from the works of Erik Erikson in 1968, the concept of an identity (see Figure 1 in the appendices) has generated a complex and prolific field of research and theory. Although identity as a term is used in everyday discourse, the challenge with identity research is the field of consensus and broad definition (Hornsey, 2008). Specifically, the ability to provide a short and adequate statement summary that captures the range and scope of its meaning is difficult. Fearon (1999) analyzed the current usage of the word identity in ordinary language and social science discourse, and defined identity as

"either a) a social category, defined by membership rules and (alleged) characteristic

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attributes or expected behaviours, or b) socially distinguished features that a person takes

special pride in or views as unchangeable but socially consequential (or (a) and (b) at

once)." (p. 1).

This definition was chosen for its relevancy to the current research topic. In the fifth stage of the

Psychosocial Development Theory (Identity vs. Role Confusion; Erikson, 1968), identity refers

to the way that people perceive themselves in relation to their world. It is during this stage that

people search for a sense of self and personal identity. When a person successfully navigates

through this stage, he or she will develop a sense of self and an individual identity that can then

be shared with others (Erikson, 1968). However, to achieve this goal, the person must find a

balance between their unique individual self and being accepted within the group (Erikson 1968).

Only when "past experiences are forged with anticipations of the future" (O'Connor, Schaefer, &

Braverman, 2015; p. 335) whereby "the person one comes to be" and "the person society expects

one to become" (O'Connor et al., 2015; p. 335) merge as one, does the person emerge with a

sense of self. Unfortunately, failure to establish a sense of identity within society may lead to

role confusion (also known as an identity crisis) resulting in the individual feeling uncertain

about themselves or their place in society (Erikson, 1968). A lack of a shared identity has been

associated with the development of poor social relationships (Rousseau & Van der Veen, 2005).

Given that identity is inherently social, in that others are involved in its construction

(Tafjel & Turner, 1979), Social Identity Theory (SIT; the chosen as the theoretical framework)

was selected for its ability to account for the social influence of the AS community on the

identity of its members. A more in depth discussion of the topic is presented in the clinical

identity and Autistic Culture and Aspie Community section (refer to p. 27-28). In general, the

formation of an identity is believed to be situated in two senses: 1) personal (individual) and 2)

social (group; Fearon, 1999).

Personal identity. Personal identity is defined as "the set of characteristics, attributes, beliefs, desires, or principles of action," (Fearon, 1999; p. 11) that causes an individual to "categorize the self as a unique entity distinct from other individuals" (Stets & Burke, 2000; p. 228). These characteristics are a) unchanged, b) used to orient a person's behaviours and actions, and c) a feature that a person may take special pride in (Fearon, 1999). Although personal identity can be linked to a specific social identity (thus engendering a unique way of expressing membership amongst a particular group), it can also represent an overarching view of the self (Hornsey, 2008; Stets & Burke, 2000; Tajfel & Turner, 1979). Personal identity tends to be primary in nature (Simon, 1997). Thus, in social situations, a person will act in accordance with his or her own self-interest (Hogg & Reid, 2006) rather than those of the group - particularly if the values of the in-group conflicts with the individual's personal beliefs.

Social identity. Second, derived from the works of Tajfel and Turner (1979) SIT refers to a person's perceived membership within a social group. When acting in groups, "people will define themselves in terms of their group membership and seek to have their group valued positively relative to other groups" (Tajfel & Turner, 1979). In general, researchers believe that a person's sense of pride (in group membership) and self-esteem is strongly embedded within social groups (a collective group of individuals whom uniformly hold a mutual social identity of themselves as members of a social category; Hornsey, 2008; Stets & Burke, 2000). Specifically, social groups can help an individual to develop a sense of belonging in the world (Hornsey, 2008; Stets & Burke, 2000; Tajfel & Turner, 1979). Hence, the central focus of SIT is how a person's self-identity is positively or negatively influenced by their group membership and the perceived status of those groups (Tajfel &Turner, 1979). According to Stets and Burke (2000),

an identity is tied to a set of meaning that a person attributes to him or herself. The meaning

becomes known to the person through his or her interactions with other in which people will

respond to the individual as if they had these sets of meaning (Hacking, 1995; Stet & Burke,

2000). To understand how social identities first develop and become integrated into the self, it is

important to determine how they are organized. Three important mental processes are involved

in the formation of a social identity: 1) social categorization, 2) social identification, and 3)

social comparison (Tajfel & Turner, 1979).

   Social categorization. The first stage, social categorization refers to the "accentuation of

the perceived similarities between the self and the other in-group members, and the attenuation

of the perceived differences between the self and the out-group members" (Stets & Burke, 2000;

p. 225). In other words, members of the 'in-group' are considered to be similar to the self, and

people in the 'outer-group' are categorized as being different from the self (Hogg & Reid, 2006;

Stets & Burke, 2000). According to Hacking (1995), "once you invent a category, people will

inherently sort themselves into it, behave according to the description, and thus contrive new

ways of being," (p. 21). By assigning people into social categories, people may uncover things

about themselves (Hogg & Reid, 2006; Hornsey, 2008; Stets & Burke, 2000; Tajfel & Turner,

1979) based on how they organize the world around them. Similarly, social categorization

allows people to easily retrieve information about a particular individual based on their

association with a group (Hogg & Reid, 2006; Hornsey, 2008). Unfortunately, this quick

inference can give rise to judgments and negative stereotypes as the differences between groups

and similarities between people in the same group may be exaggerated (Tajfel, 1979). How

people derive their identity or sense of self is largely based on the social categories to which they

belong (Stet & Burke, 2000). Specifically, categorization depends upon "a named and classified

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world" (Stets & Burke, 2000, p. 225) whereby the name invokes meaning in the form of expectations regarding one's behaviour.

Social identification. The second stage, social identification, refers to the acts of identifying with a social group (Hogg & Reid, 2006; Hornsey, 2008; Stets & Burke, 2000; Tajfel & Turner, 1979). Specifically, social identification may influence a person to uniformly evaluate the in-group more positively than the out-group (Hornsey, 2008; Stets & Burke, 2000) and adopt the attitudes, beliefs, actions, values, reactions, and behaviours consistent with the in-group (known as depersonalization; Turner, Hogg, Oakes, Reicher, & Wetherell, 1987). Thus, "in-group identification often leads to greater commitment and less desire to leave the group even when the group's status is relatively low" (Stets & Burke, 2000; p. 226). Relatedly, the connections that people form with members of the in-group will reinforce and strengthen a person's social identity (Hornsey, 2008). As this emotional attachment (Stets & Burke, 2000) increases, the person's self-esteem becomes bounded to their group membership (Tajfel & Turner, 1979). Thus, the connotations that people associate with labels, coupled by the way in which groups are described, may affect a person's self-esteem (Hacking, 1995; Hornsey, 2008). Taken from the works of Thomas Scheff (1974), "labels are an integral organizing factor in the lives of the individuals who are labeled as they search for validation and acceptance by bonding with others of their own kind" (Charland, 2004, p. 342).

Social Comparison. The final stage, social comparison, refers to the process whereby the application of the attenuated affects can engender group-enhancing outcomes for the self (Stets & Burke, 2000). Simply put, a person's self-esteem increases when the in-group is evaluated more positively by comparison to the out-group. Furthermore, because people are motivated to evaluate themselves positively, they tend to "evaluate the groups that they belong to more

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positively and discriminate against those they perceived to pose as a threat to their social identity" (Howard, 2000; p. 369). As such, the in-group will seek negative attributes of the out-group to enhance their own self-image (Stets & Burke, 2000). Known as downward social comparison, this means of self-evaluation occurs when a person compares himself or herself against another individual or group that is deemed inferior to the self (Hornsey, 2008). Alternatively, upward social comparison occurs when a person socially compares him or herself against others who are seen as being superior to the self, which may lower the person's self-regard (Hornsey, 2008). Group membership with a devalued social group can have negative implications for a person's self-esteem (Goffman, 1963; Tajfel & Turner, 1979). So when a group's social identity is "threatened" (Charland, 2004; p. 327), opposing groups are forced to compete with one another to maintain or restore the in-group's image (Stets & Burke, 2000). Thus, the act of social comparison can give rise to prejudice, discrimination, and stigmatization (Tajfel & Turner, 1979) by creating a "them" versus "us" mentality.

Identity Salience. Given that people can belong to several social groups (Stets & Burke, 2000), the self is considered to be multi-faceted (Tajfel & Turner, 1979) and comprising of a multitude of social identities. When multiple identities are integrated into the self, it organizes itself in a way that the different structures become simultaneously important to the person's overall sense of self (Augoustinos, Walker, & Donaghue, 2014). According to Stryker and Serpe (1982), social identities are cognitively organized based on Identity Salience, which is conceptualized as:

"one of the ways, and theoretically most important way that the identities making up the self can be organized. Identities, that is, are conceived as being organized into a salience hierarchy. This hierarchical organization of identities is defined by the

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probabilities of each of the various identities within it being brought into play in a given

situation. Alternatively, it is defined by the probabilities each of the identities have of

being invoked across a variety of situations. The location of an identity in this hierarchy

is, by definition, its salience" (p. 206).

An identity high in the hierarchy would have high salience as it has greater relevance to the

individual (Stryker & Serpe, 1982). Likewise, researchers suggest a strong, positive correlation

between commitment and salience (Stets & Burke, 2000). Thus, whether a social identity or

personal identity is activated depends on the context and the individual's level of commitment to

his or her chosen identity (Stets & Burke, 2000). Strong identification with a group does not

necessarily correlate with out-group hostility (Grant & Brown, 1995). Only under conditions of

intergroup threat and competition are in-group identification and out-group discrimination

correlated (Grant & Brown, 1995). Nevertheless, at the group level, identification refers to the

person's level of commitment to the group (Stets & Burke, 2000). "A strong identification will

enhance the accessibility of that self-categorization, even when the consequences of embracing

this identity is negative or threatening," ("Personal and Social Identity," n.d.; para. 2).

Meanwhile, commitment at the personal level may be reflective of the 'motivational primacy,'

whereby personal identity is considered "more basic than social identity" ("Personal and Social

Identity," n.d.; para. 4). Thus, when an individual's personal identity is threatened, the person

may switch from their personal identity to their social identity, but not vice versa ("Personal and

Social Identity," n.d.). Moreover, based on the principle of Functional Antagonism, when a

chosen identity becomes salient (regardless of which identity is activated), it will inhibit all other

competing identities (Stets & Burke, 2000). Subsequently, a person is unable to hold multiple

identities simultaneously ("Personal and Social Identity," n.d.; para. 1). In contrast, Yakushko,

Davidson, and Williams (2009) claim that "aspects of identity do no exist in separate. Rather, these features are inherently intertwined" (p. 180). Specifically, clinically oriented research and writings about identity practice that continue to examine these constructs as separate entities, creates a "false sense of compartmentalization" (p. 180). Thus, Yakushko et al. (2009) argue for a shift in research that places a greater emphasis on issues of multiple identities than currently exists. Although salience is perceived as an automatic process (that can change quickly with comparative context), it may be overridden by conscious awareness and strategic processes (Stryker & Serpe, 1982).

Other Identity Theory. There are other possible theories that could be applied to the present study. One such is Identity Status Theory (IST). As an extension of Erikson's (1968) identity crisis, James Marcia (1980) proposed four Identity Statuses of Psychological Identity Development involved in the development of one's identity – Identity Diffusion, Identity Forclosure, Identity Moratorium, and Identity Achievement. Specifically, IST is based upon the degree to which a person has explored and committed to an identity. First, Identity diffusion is the status in which the adolescent has undergone little meaningful exploration and was not committed to any particular identity. Second, Identity Foreclosure is the status in which the adolescent has yet to formulate or explore his or her own identity, instead conferring to the identity of others. Third, Identity Moratorium is the status in which the adolescent has explored various commitments but has yet to make a commitment to any choice – hence in an identity crisis. Finally, Identity Achievement is the status to which the adolescent has explored possible identities and arrived at a commitment. Given that people with AS are given an iatrogenic identity (which limits the opportunity to explore other identities), IST was deemed unsuitable for

the current study. The following section discusses the role that clinical identity and labels play in one's social identity.

Clinical Identity

Identity can take many forms. For example, a medical label may be used to define a person by his or her condition, which may result in the individual being reduced to a clinical entity (Lane & Stratford, 1985). In some sense, a clinical diagnosis can be liberating as it can provide answers to years of confusion about one's own behaviours (Charland, 2004). Specifically, when the characteristics of the person fit with the presenting symptoms of the disorder, the individual may internalize and identify with the diagnosis (Singh, 2011). Thus, the formation of a clinical identity occurs when a person self-categorizes and accepts the characteristics associated with the disorder as being part of the self (Charland, 2004).

Returning to the discussion about labels, language plays an important role in how people socially construct meaning (Ochs, 1993). Specifically, language can reflect peoples' understanding of themselves and how they want to be, and are regarded by others. Thus, the labels that people use to describe themselves (or by which others use to describe them) and the connotations people associate with those terms will influence how people socially construct their self-identity (Ochs, 1993). Unfortunately, people with a psychological disorder often are subjects of increasingly negative stigma and discrimination that can accompany clinical labels (Goffman, 1963). Likewise, social groups often are at the receiving end of certain attitudes as society categorizes people into their respective groups based on their shared label (e.g., diagnosis) and/or traits (Hacking, 1995; Hornsey, 2008). Thus, the implications embedded in labels is of great importance as there was a group of people who came to self-identify with AS in part because there was a community that also self-identified that way.

Autistic culture and Aspie identity. "Beyond the identity associated with the AS diagnosis is the emergence of the identity of AS itself" (Singh, 2011, p. 243). Specifically, the social influence of the AS community has a large impact on the identity of its members (Singh, 2011). Since its introduction in the *DSM-IV,* a prominent cultural and community response developed around the AS label (Brownlow & O'Dell, 2006; Giles, 2014). The emergence of an AS identity in mainstream culture can be linked to three historical movements. First, the societal influence of the neurodiversity movement (a self-advocacy movement) helped to unite the community to stand for the acceptance and understanding of ASD as a variation of human functioning rather than a disability (Autism Speaks, 2014; Giles, 2014; Singh, 2011). Second, the increased use and availability of the Internet supported the development of a social identity and sense of community (Brownlow & O'Dell, 2006). Specifically, with the support of the Internet, members of the community are given a forum to express their views more easily (for those who might otherwise be unable to speak, meet, or form a cohesive self-advocacy movement; Bagatell, 2007; Brownlow & O'Dell, 2006; Giles, 2014) and on a global scale (Bagatell, 2007), thus uniting members across the world. Hence, an online Autistic identity and community was formed as people connected and developed meaningful relationships by giving and receiving social support to one another (Brownlow & O'Dell, 2006). Lastly, the impact of the media and the portrayal of AS in mainstream culture has made AS become more commonplace and accepted by society (Jones & Harwood, 2009). Characteristics indicative of AS have been featured in popular TV shows and movies such as "Big Bang Theory," "Bones," "Community," and "The Accountant." In these popular media portrayals, AS is displayed as a group of highly intellectual individuals who are also positive, contributing members of society. Likewise, AS has been associated with famous intellects such as Albert Einstein, Thomas

Jefferson, Thomas Edison, and Bill Gates, among others. As these images of AS make their way into the media, they get taken up in transformative ways by people who embrace, self-identify, self-diagnose, and associate themselves with AS (Giles, 2014; Hacking, 1993; Singh, 2011). Hence, AS has taken on a positive identity - one that arguably has moved beyond the diagnostic boundaries (Singh, 2011).

The acceptance of a positive AS identity by the AS community is evidenced by their preference for disability first language (e.g., AS person) rather than person first language (e.g., person with AS; Giles, 2014; Singh, 2011). Of note, members typically will refer to themselves as an Aspie (a term used to describe a person with AS; Giles, 2014; Singh, 2011) as the label represents a group of unique people who perhaps view the world a bit differently (Linton, Krcek, Sensui, & Spiller, 2013). Although Autism and AS are not truly a culture, both disorders can influence the ways in which an individual speaks and communicates, dresses, understands their world, and spend their leisure time. Thus, in some sense, Autism and AS function like a culture in that they yield distinctive characteristics and predictable patterns of behaviours (Brownlow & O'Dell, 2006; Giles, 2014). Although, people with AS did not choose their clinical identity (rather a diagnosis imposed by the medical profession), the community took up the label and re-framed in a more positive way (Charland, 2004). Consistent with Marcia's (1980) identity foreclosure, people with AS may have committed to an identity without having explored other options or ideas, which can occur when the person's symptoms closely match that of the clinical diagnosis, leading the individual to self-identify with the term (Stets & Burke, 2000).

Unfortunately, with the reclassification of PDD into the new ASD framework, people who currently hold an AS diagnosis will likely receive a different diagnosis when re-evaluated (Volkmar et al., 2012). This change has the potential to be confusing for parents of children with

a previous AS diagnosis as well as people whom strongly self-identify with their AS diagnosis. Furthermore, given that the new ASD criteria is said to be more thorough compared to the *DSM-IV* (APA, 2013a), one concern is that someone who is high functioning may not meet the strict diagnostic criteria and may have difficulties accessing relevant services. Given that AS culture is built upon the pride and characteristics members associated with the disorder and label (Giles, 2014; Singh, 2011), replacing AS with ASD may "threaten" the loss of an AS community (Singh, 2011, p. 235), particularly for people whose identity is derived in part by their diagnosis.

Present Study

The current study offers a unique insight into the social construction of an identity based on the diagnosis and self-diagnosis of AS. Although researchers have investigated the impact of receiving a clinical label (i.e., stigma, discrimination, negative consequences), considerably less attention has been given to the loss of a psychological disorder (Charland, 2004; Giles, 2014). From a clinical perspective, researchers understand the justification for an ASD framework (APA, 2013a). However, little is known about the opinions of those directly affected by the *DSM-5*. The focus of this study was to explore the impact of the *DSM-5* on the identity of adults with AS regarding the identity related terms associated with the change in classification of ASD. Specifically, what do the participants self-identify as when faced with the loss of a clinical diagnosis? Additionally, the study sought to explore the opinions of adults with AS on the *DSM-5* and the changes in diagnostic terminology describing ASD within it. Although no participants formally lost their diagnosis (in the sense that they were previously given an AS diagnosis and were re-assessed for ASD), they did however, have strong opinions regarding the disenfranchisement of a community that the researcher sought to capture. To the researcher's knowledge, this topic of research that had yet to be explored - which will provide a unique

contribution to the literature. Given that the AS community (by comparison to AD) is a

population that has been largely ignored in the literature (Hurlbutt & Chalmers, 2002), the

current investigation offered members of the AS community an opportunity to share their views

with the scientific community.

Chapter Three: Methods

Chapter three begins with considerations for the chosen ontology, epistemology, and axiology. Information pertaining to the researcher's reflexivity and potential biases will be bracketed and highlighted throughout. Next, justification for the use of a qualitative approach via semi-structured interviews will be presented. A description and rationale for the chosen methodology will follow. Specifically, Thematic Analysis (TA; Braun & Clark, 2006) will be described, compared, and its use rationalized against alternative approaches. Finally, the participants, recruitment efforts, research measures, ethical concerns, procedures and data collection, and data analysis will be outlined.

Ontology and Epistemology

The major dimensions of qualitative research are ontology, epistemology, methodology, and methods (Carter & Little, 2007). Each dimension impacts how research questions are formulated, how the project is conceptualized, and the project's execution. Specifically, ontology and epistemology inform the chosen methodology and method (Bracken, 2007; Carter & Little, 2007).

Ontology. Ontology refers to "the nature of reality and being" (Carter & Little, 2007, p. 1327), and addresses questions regarding the nature of existence and what constitutes reality. Ontology is crucial to research as it enables social science researchers to consider their perceptions of human nature (Bracken, 2007; Carter & Little, 2007). The researcher adopted a positivist ontology ("scientific paradigm"), holding the belief that social reality is constructed by verifiable human interactions whereby individuals actively interpret the meaningfulness of their world (Bracken, 2007). It is through this process that people form their opinions based on their personal experiences. Furthermore, the researcher believes that an identity emerges from shared

social experiences through a reflexive process of self-categorization and/or identification (Stets & Burke, 2000). Therefore, a person's perceived group membership or roles will shape the way in which people think, understand, and become consciously aware of their own constructed selves. Lastly, the self is believed to be an unformed, unfixed concept that is social in origin and constructed through discourse (Watson, 2002).

Epistemology. While ontology embodies the understanding of *what is,* epistemology tries to understand *what it means to know* (Charter & Little, 2007). Epistemology refers to "the study of the nature of knowledge and justification" (Schwandt, 2001; p. 71). It guides the methodological choices and is present in the determination of the research design, methods, and research quality (Bracken, 2007; Carter & Little, 2007). In particular, it informs the participant-researcher relationship, data analysis, and reporting of the findings (Carter & Little, 2007).

Critical realist. A critical realist epistemology was adopted as it was believed to be a valid and reliable approach to eliciting participants' unique opinions (on the loss of a clinical disorder) and for ascribing human meaning to reality (Carter & Little, 2007). Specifically, critical realism contends "the way we perceive facts, particularly in the social realm, depends partly upon our beliefs and expectations," (Bunge, 1993; p. 231). Further, it is believed that critical realism "mirrors the language and procedures that we routinely adopt and the explanations that we create," (Easton, 2010; p. 119).

Social constructionist. The researcher also adopted a social constructionist epistemology, which emphasizes the collaborative nature of learning, social interactions, history, and the importance of cultural and social contexts (Bracken, 2007; Carter & Little, 2007). Specifically, a social constructionist "believes that individuals seek understanding of the world in which they live and work by developing subjective meanings of their experiences," (Creswell,

2013; p. 8). In essence, the language that people gain from their learned experiences and social interactions provides a representation of their demonstrated knowledge and reality (Bracken, 2007). Taken together, from a social constructionist approach, people need the best language that they can gain through their learning and social interactions to use in addressing phenomena and experiences.

Axiology and reflexivity. Axiology concerns the role of the researcher's values in the scientific process (Bracken, 2007; Carter, 2007). Given that the data's meaningfulness is imparted through the interpretations of the researcher, qualitative research requires active reflection on the entire research context (Carter, 2007). Specifically, transparency of any pre-conceived notions, personal beliefs, or interest wherein the interviewer and/or respondent may influence the production and/or identification of codes and themes must be acknowledged to establish research rigor (Carter, 2007). This acknowledgement is known as bracketing (method used to suspend preconceived conceptions thereby allowing the reader to gauge its influence on the subsequent research analysis; Tufford & Newman, 2012). Additionally, upon reviewing the literature prior to the commencement of the current study, the researcher developed an understanding as to the motivation towards the unification of the *DSM-IV* diagnoses and the controversy surrounding the removal of the clinical terms. However, through her experience and interactions with members of the AS community, the researcher perceives AS to be distinct from AD given their clinical and behavioural presentation (Kugler, 1998). Hence, in the formation of the research questions, she sought to explore the views and opinions of members of the AS community whose identity may have been "threatened" (Charland, 2004; p. 347; Singh, 2011; p. 235) as a result of the changes in the *DSM-5*. Further, the researcher did not hold any presumptions about specific types of impacts or opinions that may be reported in the data. To

minimize the effect of potential personal biases and to establish analytical rigor, a second coder was enlisted to analyze the data and question or confirm the researcher's derived codes and themes. The findings, credibility, and justifications of the final themes were also sent to and corroborated by two faculty professors for an additional peer audit.

Research Design

A research design is "the plan that describes how, when, and where data are to be collected and analyzed," (Parahoo, 1997; p. 142). Justification and rationale for the use of qualitative research and semi-structured interviews will be provided below to support its design as an approach to inquiry.

Qualitative research. A qualitative design was adopted for its ability to assist the researcher in exploring and capturing the rich, personal, and unpredictable nature of the participants' experiences, views, and opinions (Carter & Little, 2007; Johnson & Christensen, 2014) on the changing nature of AS. A quantitative approach would have been less appropriate for the current study as it evaluates and measures human behaviour in an objective, pre-formulate, hypothesized, statistical, and mathematical manner (Carter & Little, 2007; Johnson & Christensen, 2014) for which opinions cannot be formally quantifiable. Further, a quantitative approach would not have captured the breath or the depth of the participants' responses adequately as quantitative research is typically based on predefined, controlled variables and statistical relations (Carter & Little, 2007). Similarly, a quantitative approach focuses on generating predictions and testing hypothesized causal relations (Johnson & Christensen, 2014), which misaligns with the exploratory nature of the current research design. It is unknown what impact the change in diagnostic terminology will have on the lives of individuals with AS or their identity. Thus, no specific a priori hypotheses were generated. Rather, a qualitative

approach was better suited for the study as it allowed for greater flexibility and facilitation of participants' opinions via an inductive (data-driven) approach to generate tentative themes that can be deductively tested in subsequent analysis of further data (Braun & Clark, 2006).

Semi-structured interviews. In seeking a method that would enable the researcher to facilitate and explore the richness of participants' opinions in the contexts to which they applied, semi-structured interviews were considered the most appropriate method to achieve this goal (Braun & Clark, 2006). Semi-structured interviews align with Thematic Analysis' (TA) primary focus on analyzing textual data. Further, these interviews provide a rich method for generating information, thus enabling the opportunity for spontaneous dialogue and flexibility (Braun & Clark, 2006). Semi-structured interviews also allow for further investigation and clarity of certain domains that might otherwise not have been sufficiently assessed by a quantitative approach. The open-ended format (considered to be a guide rather than a strict interview protocol) of semi-structured interviews allows for an exploratory discussion wherein the participants could voice their opinions, thoughts, and experiences in a field dominated by impersonal experimental studies (Humphrey & Parkinson, 2006).

Methodology

The following section describes the methodology of choice, which was determined by comparing TA with other similar yet distinct qualitative approaches (Interpretive Phenomenological Analysis [IPA] and Grounded Theory [GT]) that also seek to derive patterns of relevant meaning in the data.

Thematic analysis. TA, as described by Braun and Clark's (2006) analytic procedures, was chosen as the methodology of choice to systematically guide, identify, examine, analyze, and interpret discernible themes based on the patterns of meaning. TA lends itself well to

answering questions related to people's opinions and perceptions, understanding and representation, and relating to the construction of meaning (Braun & Clark, 2006). Moreover, TA was considered appropriate as it aligned closely with the chosen qualitative paradigm, epistemology, and ontology that allowed the researcher to explore and capture the meaningfulness of participant's responses to an inquiry (Braun & Clark, 2006).

TA's epistemology, a semantic approach, was adopted whereby participants' words and the codes and themes derived from them were taken at face value (as opposed to a latent or interpretive approach whereby inferences are made regarding what was meant by the respondents' statement). Further, one of the hallmark features of AS is challenges with social communication. As such, people with AS have a tendency to misinterpret information, particularly idiomatic or literal language (Ozonoff et al., 1991). Thus, a latent approach may have resulted in additional analytical challenges given their social communication impairments. As such, participants' opinions were accepted as truthful for them (Braun & Clark, 2006) and a unidirectional relation between meaning/experiences and language used in expression was assumed (Braun & Clark, 2006). TA was also adopted for its flexibility (Braun & Clark, 2006) in allowing both an inductive (data driven) and deductive (theory driven) approach in identifying, analyzing, checking, and modifying themes and codes consistent with interview content and theory. In other words, the researcher inductively derived preliminary themes (establish clear links, categories, relations and associations between the research questions and findings; Braun & Clark, 2006) which were then deductively (anchor the analytical claims made about the research to the theoretical framework; Braun & Clark, 2006) analyzed through TA's process of constant comparison (whereby newly collected data is compared against previous collected data to evaluate whether the codes hold up).

According to Braun and Clark (2006), TA has a number of advantages including its ease of implementation, "accessibility to researchers with little or no experience with qualitative research" (p. 37), ability to summarize large datasets, and capability to highlight similarities and differences within the data. However, TA is not without its limitations (see Discussion). Although the flexibility of TA as a methodology is deemed an advantage, it can also be a challenge. When a semantic approach is adopted, TA does not unravel the complexities of interpretation and the hermeneutic aspects of uncovering meaning and the on-going process of sense-making (Braun & Clark, 2006). Additionally, consistencies and contradictions across individual transcripts would be difficult to identify as the codes and themes from each interview were amalgamated into one common dataset (Braun & Clark, 2006).

In sum, TA comes out of an interpretive tradition of qualitative research and for contrast two other approaches will be highlighted - Interpretive Phenomenological Analysis (IPA) and Grounded Theory (GT). These are two similar yet unique analyses. However, for the reasons provided below, IPA and GT were not selected as the method of choice for the current study.

Interpretive Phenomenological Analysis. IPA was developed by Jonathan Smith (1996) and adopts a phenomenological epistemology whereby it serves to investigate how individuals "make sense of their experiences" (Pietkiewicz & Smith, 2014; p. 8) by understanding the meaning that they attribute to and/or interpret from the events, objects, and people in their everyday experiences of reality (Braun & Clark, 2006; Larkin, Watts, & Clifton, 2006; Smith, Flowers, & Larkin, 2009). Compared to TA, IPA is better thought of as a methodology (a theoretically informed framework for how to do research) rather than a method (a technique for analyzing data; Smith et al., 2009). Likewise, IPA is used to answer research questions concerning people's experiences and perspectives whereas TA may be used to address

a broad range of research questions (Braun & Clarke, 2006; Larkin et al., 2006). As such, IPA is considered an unsuitable approach for the current study as the study calls for the identification of patterns of meaning across the entire dataset (including opinions) rather than only on people's experiential interpretation of the subject matter (Larkin et al., 2006).

Grounded theory. Similarly, GT was also considered as a potential methodology for the current study for its ability to capture data depth and richness, well-defined analytical process, and data supported interpretations (Birks & Mills, 2015; Charmaz, 2006; Glaser & Strauss, 1967). GT was first introduced by Glaser and Strauss (1967) as an inductive qualitative method for making analytic claims grounded in the data and founded upon the basis of generating a plausible theory describing the phenomena. Comparatively, TA and GT are similar in terms of procedures for coding themes from data (Braun & Clark, 2006; p. 8-10). Specifically, TA and GT derive codes and themes based on an inductive and iterative approach from textual data to inform theoretical models (Glaser & Strauss, 1967; Pidgeon & Henwood, 1997). Moreover, both approaches require the parallel collection and analysis of data in a multistep process (Braun & Clark, 2006; Glaser & Strauss, 1967). Although TA and GT share similar defining features, GT was considered unsuitable for the current study because of the potential for methodological errors (by selecting purposive rather theoretical sampling which will result in a lack of conceptual depth; Benoliel, 1996), multiple approaches to GT (Glaser & Strauss, 1967; Hussein, Hirst, Salyers, & Osuji, 2014), and its use in theory development (which was not the purpose of the current study; Birks & Mills, 2015; Charmaz, 2006; Holloway & Todres, 2003).

In sum, TA differs from IPA and GT in that TA "aims to explore themes or patterns *within* qualitative data rather than themes *across* an entire dataset" (Braun & Clark, 2006; p. 8). As such, TA was deemed the most appropriate methodology for answering the research question.

Method

  The following section outlines the steps taken to execute the current study with focus on participants, recruitment efforts, ethical considerations, data collection process, data analysis, and interpretation of the findings.

  Participants and recruitment efforts. The sample was purposively drawn (selected to serve an investigative purpose as opposed to being statistically representative of the population, Carter & Little, 2007) and an idiographic (in depth analysis of a single case examining each individuals' perspective in their unique context; Carter & Little, 2007) method of inquiry was utilized. Participants were recruited from within a major Canadian urban setting through several ASD-related community organizations (see Appendix A for recruitment flyer). Eligible participants were required to be a minimum of 18 years of age, English proficient, and have a previous diagnosis of AS (participants were also required to provide documentation of a formal diagnosis at the intake interview). All interested persons were asked to contact the primary researcher via email or telephone after which they were informed about the objectives, rationale, procedure, and potential risks and benefits associated with their participation. Consenting individuals (see Appendix B for consent form) were invited to partake in a screening evaluation.

  To meet inclusionary criteria, participants were required to demonstrate cognitive and verbal capacity to comprehend, reflect, and express their opinions on the changes in the *DSM-5*. This evaluation occurred through the use of standardized measures of cognitive ability (as indicated by verbal (VCI) and performance intelligence (PRI) ≥ 85 on the Wechsler Abbreviated Scale of Intelligence – Second Edition (WASI-II; Wechsler, 2011). Of the 13 initial participants, one was excluded due to failure to complete the WASI-II. The remaining sample consisted of eight males and four females. See Table 6 for descriptive information about participants. The

final sample size was determined through the process of saturation (the endpoint in which emerging themes are no longer present; Braun & Clarke, 2006). Guest, Bunce, and Johnson (2006) conducted a study to determine the number of interviews needed to reach saturation (the gold standard by which purposive sample size is determined). The results indicated that saturation occurred within the first 12 interviews and basic elements for meta-themes emerged as early as six interviews.

Measures. The following is a brief description of the research measures utilized during the screening and interview process of this study.

General demographic questionnaire. A general demographic questionnaire (see Appendix C) was used to gather information regarding each participant's age, gender, date of diagnosis, name, profession of the individual who provided the diagnosis, comorbidities, and documentation of any cognitive or language impairments.

Wechsler Abbreviated Scale of Intelligence – 2nd Edition (WASI-II). The WASI-II (Wechsler, 2011) is an individually administered standardized measure of cognitive ability. Participants were required to demonstrate verbal and nonverbal (perceptual reasoning) intelligence scores of ≥ 85 to ensure that there were no cognitive and/or verbal impairments consistent with an AS diagnosis. The Verbal Comprehension Index (VCI) is comprised of the Similarities and Vocabulary subtests while the Perceptual Reasoning Index (PRI) includes Block Design and Matrix Reasoning. The sum of the four subtests is used to compute the Full-Scale Intelligence Quotient (FSIQ). The WASI-II was administered according to the standardized procedures outlined in the examiner's manual by a trained examiner. All raw scores were converted to norm-referenced standard scores (M = 100, SD = 15).

The WASI-II was normed on a sample of 2,300 individuals (n = 1,100 children; and n =

1,200 adults) aged 6 to 90 years with stratification based on age, sex, ethnicity (including Caucasians, Africans, Americans, Hispanics, Asians, and other racial groups), educational level, and geographic region. The sample also represented children with special needs (i.e., Attention-Deficit/Hyperactivity Disorder, Learning Disorder, ASD, and various levels of cognitive impairments). Evidence for the reliability of the WASI-II included internal consistency, test-retest reliability and inter-rater reliability. In both the child and adult samples, the internal consistency was high with estimates ranging from .92 to .97 for the FSIQ. The test-retest reliability coefficient ranged from .87 to .96 for the child and adult samples. Across the four subtests, the inter-rater reliability was similarly high with estimates ranging from .94 to .99. Lastly, scores on the WASI-II were highly correlated with the Wechsler Adult Intelligence Scale, Fourth Edition (WAIS-IV; Wechsler, 2008) and Wechsler Intelligence Scale for Children, Fourth Edition (WISC-IV; Wecshler, 2003; estimated scores ranging from .86 to .92 for IQ scores; and scores ranging from .85 to .91 for IQ scores respectively) providing support for the validity of the WASI-II as a strong measure of cognitive functioning.

Interview protocol. In developing the interview protocol (see Appendix D) and questions for the current study, the researcher adopted Jacob and Furgerson's (2012) guidelines for writing interview protocols and conducting interviews. A script was used at the beginning and end of the interview to guide the interview process and present information (i.e., purpose of the study, and the researcher's contact information) to the participants. The questions were developed to stimulate participant discussions by having participants to speak to certain questions related to that topic. The overarching topic was participants' understanding, appreciation, opinions and identity related to the changing diagnostic structure of the disorder. Given that the construction of opinions is based on a person's knowledge, understanding, experiences, and interactions, the

research questions were developed accordingly to inquire into these domains of opinions. Moreover, the questions were developed through consultation with the co-investigators and piloted in a related study to test for rigor. The interview started by asking participants basic background information as a way of building rapport with the interviewees. Subsequent questions were arranged from least difficult or contentious to those that were more controversial. Any questions deemed to be directive or leading were eliminated or modified to reduce presumptions in the current study. Finally, prompts were designed to provide clarity and expand on the respondent's answers. Given the paucity of existing empirical literature in this particular area of interest, the research questions were based loosely around the controversy surrounding the impact of the changes in the *DSM-5*.

The interview protocol consisted of 25 open-ended questions and additional follow-up probes designed to encourage participants to discuss issues relating to their opinions on the changing nature of AS. The interview began with a "warm-up" question that the respondent could answer easily and at some length to establish rapport with the researcher. Questions one to six explored the participants' knowledge of AS, AD, ASD, and the changes in the *DSM-5*. Questions seven to 11 served to investigate the participants' opinions regarding the loss of AS and their reactions to ASD. Questions 12 to 18 surveyed the perceived impact that the change in classification could have on service provision. Questions 19-24 captured the participants' self-identity since the change in terminology was adopted. The final question afforded participants an opportunity to discuss additional topics that they felt might be relevant to the study.

Ethical considerations. Prior to commencing this study, ethics approval was obtained from the Conjoint Faculties Research Ethics Board. Informed consent was obtained from each participant prior to his or her participation. Given the sensitive nature of the study, anonymity of

each participant was protected. Participants were each given the opportunity to clarify any questions prior to their involvement in the study. Further, their participation was completely voluntary and interviewees were free to terminate at any time during the study. All interviews were audio recorded with the consent of the participant. All recordings were transferred to a password-encrypted computer and deleted from the voice recorder upon completion of the interview. Subsequently, all interviews were transcribed for data analysis. Interview transcripts and related documents were stored in a locked cabinet in a locked room to which only the researcher and principal investigator had access. Although it was believed that participants would enjoy the opportunity to voice their opinions on the changing nature of the diagnosis, the researcher anticipated that some participants could experience emotional distress or discomfort given the sensitive nature of the questions. Subsequently, all participants received a handout (see Appendix E) at the end of their session that included a comprehensive list of psychological services and resources available in the city. The handout also referenced an article (Lohr & Tanguay, 2013) discussing the controversy around the change in diagnostic terminology to ensure that all participants left with accurate information about AS and ASD. Lastly, all interviewees received a small honorarium as an appreciation for their time and participation.

  Procedure and data collection. Participants completed a general demographic questionnaire and the WASI-II to establish eligibility to participate. Participants who met these criteria were invited to partake in a semi-structured interview wherein a number of open-ended questions were used to elicit their knowledge, opinions, and self-identification in light of the changes in the *DSM-5*. This approach allowed for the open exploration and facilitation of participant opinions on the changing nature of AS in a non-restrictive manner (i.e., participants were not limited by having to choose amongst a predetermined set of responses; Braun & Clark,

2006). The interviews were audio recorded and conducted by the researcher to ensure

consistency across participants and predominantly guided by the participant's responses. The

interviewer adhered to the interview protocol and presented questions in a natural, conversational

format so as to not unduly influence the respondents' responses. Additionally, notes regarding

potential themes were recorded on the margin of the interview protocol as initial themes and

codes (identified patterns that may be confirmed, revised, or disconfirmed during the later

analysis) emerged from subsequent interviews. Each interview was completed in one session

and ended when the participant felt that they had exhausted the topic (i.e., saturated the

discussion). However, participants were presented with additional probing questions if the topic

of interest was not organically generated through discussion or if greater insight and/or

clarification was sought from the respondent. Probes that served to help answer the research

questions were not standardized but were used to extend and deepen participants' meanings. The

interviewer also engaged in the process of active listening by paraphrasing the interviewees'

responses to seek confirmation of what was said. Participants were free to deviate from the

particular question and divulge as much or as little information about their experiences and

opinions as they desired. The interviews ranged from 25:24 to 64:37 minutes (median = 42:48)

in duration.

All interviews were manually transcribed verbatim for the purposes of analysis following

the completion of each interview. The following transcribing practices were implemented in

accordance with APA formatting. Each transcript had its own document and was titled

accordingly (i.e., AS study – Interview #1). "P" was used for participant and "I" was used for

interviewer. Each statement was typed on a single line with a space between comments. All

utterances including 'yeah,' 'um,' or 'okay,' were omitted. A pause during the interview was

represented with the word [pause] in square brackets. Non-verbal communication was noted using square brackets (i.e., [chuckles]). Sections of the interview that were inaudible were indicated with the word inaudible in square brackets (i.e., [inaudible]). Quotations were used to indicate something the respondent said about another person during the interview. Words emphasized by the respondent were italicized. Word tenses may be altered to align grammatically with the statement made. When the aforementioned occurred, the modified word was enclosed in square brackets (i.e., [was] instead of is). Lastly, third party names were removed for anonymity and replaced with the relationship to the respondent in square brackets (i.e., [friend]). The researcher checked each interview transcription for accuracy and audio recordings were compared to the transcription for anomalies and/or inaccuracies. Further, respondents were given a copy of the transcribed interview for review to minimize the risk of misquoting or words taken out of context. The intent of this step was to validate what was said in the transcripts by addressing perceived inaccuracies, making corrections to language (written versus spoken), and providing additional clarification. Interviewees had one week following receipt of their transcripts to withdraw their participation. Any request beyond this date was declined. Seven out of 12 participants responded to the request. The lack of response by the remaining five participants was due to professional obligations and time constraints. Two types of approval were discerned from the interviewees who returned the transcripts via email; some participants expressed complete approval (e.g., "everything looks okay with me") while others gave approval contingent upon corrections to the original transcript (e.g., "I've reviewed the document using track changes").

Data analysis. While "there is no accepted, standardized approach to carrying out a thematic analysis" (Howitt & Cramer, 2008; p. 334), Braun & Clark's (2006) six-stage

evaluative process is arguably the most systematic account of TA to date. The model of TA was used to guide the data analysis to capture the complexities of meaning and patterns within the transcribed textual data. This process includes: 1) familiarization with the data, 2) generation of initial codes, 3) searching for themes, 4) reviewing themes, 5) defining and naming themes and 6) producing the report. Although outlined in a linear fashion, the researcher is free to move recursively (forwards and backwards; also referred to as constant comparison) between each step during the analysis (Braun & Clark, 2006).

The first step was familiarization with and immersion in the data through reading and re-reading of it. This step enabled the researcher to become familiar with the depth and breadth of the content with repeated readings of the data (interviews). This process was completed prior to coding, as the conceptualization of patterns was shaped with subsequent readings. The act of transcription is typically part of early stages of the analysis. In doing so, the process aided the researcher in developing a more comprehensive understanding and familiarization with the data (Braun & Clark, 2006). All potential codes that pertained to participants' experiences and the knowledge, opinions, stigma, impact, or identity associated with the changing nature of AS were copied and pasted into a separate document for analysis. The remaining data was deemed to be outside the scope (i.e., irrelevant to answering) the research questions (i.e., the impact of the *DSM-5* on people diagnosed with AD).

The second step was to generate initial codes that identify basic features, segments, or elements of the data that could be analyzed meaningfully. A "good code" is one that captures the qualitative richness of a phenomenon (Boyatzis, 1998; p. 1). Specifically, codes represented a single important feature of the data that may be relevant to answering the research question. The process of coding was an integral part in the analysis as the researcher begins to organize the

data into meaningful categories. This process involved an open coding approach whereby each line of the data was closely examined "giving full and equal attention to each item" (Braun & Clark, 2006; p. 86) and codes are generated. For an example of open coding, refer to Table 7. Additionally, extracted data can be coded "in as many different 'themes' as they fit into" (Braun & Clark, 2006; p. 89), suggesting that an extract may be uncoded, coded once, or coded many times, as relevant. Thus, a quote given by the participant (whether that be a few sentences or a thought fragment) could have several points that analytically relate to multiple themes. Significant points, summaries of responses, connections, and interpretations of the data were documented in a spreadsheet, and the text was highlighted to indicate potential themes.

The third step involved a search for overarching themes by combining codes once the data had been successfully coded and analyzed. Unfortunately, there is no hard and fast rule for determining what constitutes a theme. Themes are not necessarily based on the frequency at which a theme occurs. According to Pyett (2003), "counting responses misses the point of qualitative research," (p. 1174) as frequency does not determine value. Thus, "it is not the case that if it was present in 50% of one's data items, it would be a theme" (Braun & Clark, 2006; p. 10). Furthermore, a single quote may be considered a theme for its uniqueness and ability to fully capture the essence of the participants' responses (Braun & Clark, 2006; Pyett, 2003). Thus, whether something is insightful or important for answering the research question is not necessarily determined by whether large numbers of people said it. As such, a researcher's judgment is key in determining which themes are considered crucial. Nevertheless, themes generally represent recurring patterns of response derived from the data that is related to the research question. More specifically, Boyatzis (1998) defined a theme as "a pattern in the information that at a minimum described and organizes the possible observations and at

maximum interprets aspects of the phenomenon" (p. 161). As themes emerged, codes and brief

descriptions of each were noted and grouped accordingly. This step in the analysis involved

moving into a higher level of abstraction, thus making connections from the literature. Factors

such as the richness of the account and how certain themes illuminated other aspects of the

account were considered important in the development of themes.

The fourth step was to review and revise the initial themes. This step consists of two

levels. The first level involved reviewing the extracts data to determine whether the themes form

a coherent pattern. As themes were identified, they were compared and tested against earlier

transcripts (also known as constant comparison) for convergence and divergence and to

determine whether new themes emerged through the process of saturation using an inductive

approach. If the themes did not come together meaningfully, further modification and re-coding

of the data was necessary to add, discard, or refine certain items. The second level considered

the validity of individual themes with regards to the entire dataset - specifically, whether the

thematic map (organization of the themes; see Figure 1) reflected the meaningfulness of the data.

If the map did not portray the themes found in the data, further review and refinement was

necessary. This process ensured that all data was coded and that no information was missed

during the previous coding stages.

Additionally, a second rater familiar with TA and unrelated to the project re-coded the

data for consistency of the derived codes and themes. In alignment with accepted guidelines for

analyzing qualitative data, any examples of textual passages that did not conform to the emergent

themes ('negative cases' or 'divergences') were noted (examples of these are presented at

appropriate points in Chapter 4) and any discrepancies between raters were discussed and a

resolution was agreed upon before proceeding. Finally, the analysis and justifications for the final themes were sent to the researcher's supervisor for further credibility and peer audits.

The fifth step was to appropriately define and name themes. Specifically, this step was used to ensure that the essence, or most relevant meaning, of each theme was captured and that a clear set of themes describing the crux of the data as it pertains to the overarching research question had been developed. Justification for theme names is evidenced by the description and quotes used to illustrate its meaning to the readers.

The final step involved extracting excerpts from the data (i.e., meaningful quotes from the interviews that would contribute to answering the research question) and reporting the findings (which can be read in Chapter Four). Direct quotes from the interview that were deemed poignant and/or most representative of the research findings are provided as support for the derived themes presented in Chapters Four and Five.

Evaluating Qualitative Research and Rigor

Qualitative research is often criticized for being biased, small scaled, anecdotal, and/or lacking rigor. However, when executed properly in a systematic and organized fashion, the interpretation of textual data derived from interviews of observations can be valid, reliable, credible, and rigorous (Malterud, 2001). To ensure that qualitative research rigor was met, the researcher adopted Malterud's (2001) guidelines, considerations, and standards for conducting and reviewing qualitative research. Ten domains of rigorous qualitative research were outlined and guided the quality of the research reported here: aim of study, reflexivity, suitability of method and design, data collection and sampling, theoretical framework, analysis, findings, discussion, presentation of the findings, and importance of references (Malterud, 2001).

Additionally, the effect of the researcher on the study (reflexivity), transferability

(adequate and sufficiently varied sample), and the process of organization and interpretation

during the analysis (systematic approach and theoretical frame of reference) were taken into

consideration as it can affect the validity of the findings (Malterud, 2001). Finally, by adopting

and adhering to these practices, the researcher was confident in the credibility and

trustworthiness of the study and current findings.

Chapter Four: Results

Chapter four discusses the six primary themes and their respective subthemes derived from the researcher's application of Thematic Analysis (TA) to the transcribed interviews. To arrive at these themes, the researcher reviewed the textual data from the interviews using the constant comparison method for patterns and meaning in conjunction with discussion and consultation with the researcher's advisory committee (i.e., co-supervisors and secondary rater). Definitions of the current study's primary themes and subthemes are offered in Table 8. Overall, the textual data as interpreted by the researcher fell into the following distinctive themes:

1. Derived meaning from their experiences with the disorder

2. Knowledge and understanding about AS, AD, ASD, and *DSM-5*

3. Perceptions associated with labels

4. Social identity

5. Opinions regarding the reclassification of PDD and the *DSM-5*

6. Barriers to funding and service provision

Please refer to Figure 2 for a visual map/representation of each theme. Quotations provided below are direct interview excerpts selected for their central issues, importance, and/or interest.

Theme One: Derived Meaning from their Experiences with the Disorder

Theme One captures the participants' experiences with living with AS (both positive and negative). This theme was chosen first for its prominence within the interviewees' responses. Four subthemes were identified from the textual data: 1) Challenges, 2) Personal insight, 3) A different kind of normal, and 4) Involvement in the AS community. Overall, the meaning that participants derived from their diagnosis reflects their personal experiences with the disorder.

1.1 Challenges. This first subtheme refers to the challenges that participants experienced related to the AS diagnosis. Comparatively, symptoms of AS are more difficult to detect than AD due to its mild presentation (Autism Speaks, 2014). As such, many individuals with AS do not undergo a formal assessment/diagnostic process until later in development. Indeed, some participants were told they were "lazy," "did not try hard enough," "different," and/or were "weird" (P2, P6, P7) growing up. The following excerpt offers a concrete example of challenges that participants experienced.

> **P6:** "I think [back] when I was younger, I was being treated a bit more severely because no one really knew what it meant back then. I was considered the weird one, odd, or strange. I think part of that had to do with the fact that while I was different, I could sort of pass as being "normal" and that's why I didn't get diagnosed till my mid 20's because I could hide it pretty well. But still, even with the Asperger term I was treated much differently than say my brother. People would say what is that? [I would answer] "It's a form of Autism." Okay, so what do we do with people that are autistic? I don't think they understood what it was back then. And because of that I did not get the level of freedom and control that I think I deserve. There were times I would be [inaudible] held back from events that were going on. I certainly hope that kids with Asperger in their formal years [now] are being treated more in line with what they need these days then what I got when I was that age."

Unfortunately, not all of the textual data was as meaningful in interpreting themes as other data. As such, information deemed unrelated to answering the research question was not analyzed and was instead represented by three dots and surrounded by ellipses (…) used to indicate that some textual data was left out. The excerpt below presents a parsed version of the statement above

used to illustrate the researcher's decision-making process in excluding certain words/parts of the participant's statement while keeping the essence of the quote intact.

> **P6:** "When I was younger, I was treated severely because no one really knew what it meant back then. (…) [Although] I was considered the weird one, odd, or strange (…) I could sort of pass as being "normal" and that's why I didn't get diagnosed till my mid 20's. (…) But still, even with the Asperger term (…) I did not get the level of freedom and control that I think I deserve."

This practice (using ellipses) was adopted throughout the remainder of this chapter. In general, the challenges that participants experienced growing up with the disorder manifested differently in each individual, including difficulties with "perspective taking," "understanding sarcasm," "thinking abstractly" (P1 and P7) to name a few. However, incidents of bullying and isolation, feeling confused and misunderstood, and being mistreatment were reported across all interviewees. As the participants' understanding of AS increased, they began to attribute many of their challenges as a child to the diagnosis. Participant nine explains.

> **P9:** "As a child I had a hard time making friends and I was bullied, isolated, and teased for being different. I have difficulty understanding what to do in social situations and difficulty interpreting facial cues. (…) But as I grew up and learnt more about the disorder, I slowly came to realize that many of these challenges were characteristics of having Asperger Syndrome."

Moreover, prior to 1994 (when AS was first introduced), participants endured a different set of challenges, including "undetected symptoms," (P1) "misdiagnosis," (P1) and "unfit treatments" (P11) at the hands of professionals whose own understanding of the disorder was limited (Kite et

al., 2013). Because of this limited understanding, the challenges and behaviours of people with AS were often overlooked.

> **P11:** "I was misdiagnosed a lot. Doctors told my parents I had ADHD, sleep disorder, depression, and OCD. (…) Because of that, I was put on different medication and given different treatment options. (…) It wasn't until I was in my late 40's did I get [a proper] diagnosis [Asperger Disorder] which explained everything."

Similarly, the female participants in this study noted the medical community's lack of understanding of AS symptomatology in women. As such, these participants were diagnosed later in life and received ineffective supports growing up as a result.

> **P9:** "Doctors didn't understand what it was. (…) Aspergers wasn't recognized in females until the late 90's. So I kept getting overlooked [when I was younger] because there was nothing to look for."

Although most participants are cognizant of their social impairments, they lack the understanding regarding how to reach some sense of normalcy. Despite their desire to develop and maintain friendships, participants reportedly felt isolated from their peers. In particular, participants would study the interactions of other people because they "didn't know what to do," and "don't know what to say" (P1 and P5) in social situations. Participant six explains:

> **P6: "**Looking back now, my Asperger was probably the reason that I had trouble fitting in. (…) When I was younger my parents put me in a social skills class to learn to make friends. (…) But I still find eye contact very distracting, I have a hard time interpreting facial expressions and information, I have very peculiar interests that others might find different, and I find crowds too overwhelming."

In general, living with AS proved to be challenging. On a daily basis, persons with AS must cope with the social demands of society (i.e., being misunderstood, overlooked by professionals, and dealing with the public's perceptions) in addition to the fundamental impairments of the disorder (i.e., difficulties with social communication, trouble grasping the bigger picture, sensory integration issues, and RRBs). However, as detailed in the next section, AS can also bring about personal insight about life.

1.2 Personal insight. In contrast to subtheme 1.1, the second subtheme highlights the participants' understanding of the causes of their social challenges and behaviour. Despite the challenges growing up, participants generally believe that the positive attributes associated with AS far outweigh the negative experiences. As participant two describes, the diagnosis helped to legitimized participants' challenges and their eccentricities.

> **P2:** "For me, the diagnosis provided proof that I wasn't crazy. That there was a reason why I couldn't understand what to do or how to act in certain situations."

Likewise, the introduction of AS led many participants, including participant two, to significant discoveries, insight, and knowledge about themselves and the community.

> **P2:** "I felt that the purpose of having gained a diagnosis of Asperger syndrome is because [it] opens the door for new self-discover [and] a light bulb goes on and then it forever changes your life."

Furthermore, the diagnosis helped participants frame their social issues in such a way that they better understood their challenges and past behaviors. Thus, by making sense of their past through the lens of their diagnosis, participants were able to retroactively develop an understanding of previous life events (including why they were treated differently or why they had certain difficulties) so that they could move forward in life.

P12: "[Having a diagnosis] helped explain a lot. It's made it easier to understand myself.

I [am able to] understand the challenges, *why* I have challenges, [and] what things I can

do to deal with those challenges. (…) [With this] understanding, I can work towards

moving on and achieving success despite it or because of it."

The diagnosis also gave participants a label to research and gain a better understanding of the

disorder and the available treatments and services in the community.

P1: "When I did get diagnosed with Asperger (…) I could do a lot more research and

figure more out about me, why I am different, and what I can do about it."

Likewise, the diagnosis proved to be useful in helping participants explain and educate the public

about the challenges associated with AS.

P12: "I was always considered the odd one growing up. (…) But with the diagnosis, it

legitimized by behaviours and gave me a label that I could use to help my friends and

family understand why I act the way that I do."

Despite the challenges associated with AS, participants had positive impressions of the disorder.

In particular, the diagnosis aided in the participants' understanding of their disorder and helped

them to educate others about the diagnosis. The following section illustrates how the diagnosis

shifted the way that participants perceived their diagnosis of AS.

1.3 A different kind of normal. This subtheme reflects the participants' understanding

of their differences as a variation of normal within the context of the AS community.

Specifically, the diagnosis reportedly enabled the participants to connect and meet others in the

AS community who face similar challenges. As such, it created a sense of belonging and

comfort whereby these individuals felt accepted for being different – a different kind of normal.

P9: "For me, it was the understanding that there was a profile that I fit into but it also

meant that there was nothing wrong with me (…) I [also] recognize that I am definitely

different. But when I started meeting other people on the spectrum and see how similar

we were, I had a paradigm shift. I was no longer a weirdo; I was part of a minority that

was normal to itself. (…) I was no longer the freak. I am a different kind of normal!"

Likewise, participants acknowledged their neurological differences that led them to perceive the

world differently. Consistent with the advocacy of the neurodiversity group, participants three

and 10 understand their AS differences as unique gifts that should be celebrated rather than an

illness or disability that needs to be cured.

P3: "I'm not looking for a cure. (…) I just think a little differently. That doesn't make it

any less right or wrong. Being different makes me unique from others and I'm proud of

the gifts that I have."

P10: "The way I see neurodiversity is that it is an alternative way of being. Another way

of wiring the brain and I wouldn't change any of it."

Taken together, the participants' understanding of AS as a variation of normalcy helped to

cultivate a positive image of AS within the community. A related aspect of this topic is

discussed in the following subtheme.

1.4 Involvement with the AS community. The fourth subtheme reflects the

participants' membership and involvement in the AS community as they came to understand

ASD. Specifically, participants attributed much of their understanding, attitudes, knowledge,

and acceptance of the diagnosis to their involvement in the community. The following quotes

offer concrete examples of how the participants' involvement and interaction with others in the

community led to their understanding of themselves.

P9: "I'm involved in several [Autism and Asperger organizations] throughout the city and when I run into another Aspie, I know immediately how to treat them. I know how to interact with them. I know how to greet them. I know what behaviours to expect. And I know that they're going to expect the same of me. They [too] are going to recognize the same things in me. And so I feel drawn to these people because we are all alike. We all belong to the same group if you will."

The following quote illustrates how a participant's statement can be coded for multiple themes. Known as boundary object (Star & Griesemer, 1989), this statement was selected for its central importance as it speaks to both Theme One and Theme Five. Specifically, boundary object refers to information that is used in different ways by different communities (Star & Griesemer, 1989). The quote below highlights how participant 12's experience within the AS community influenced her social identity.

P12: "My identity as an Aspie stems from my understanding of Asperger as a community and what it represents. I began to truly embrace my diagnosis when I became involved in the community. For me, the community is a hub for social support, interaction, help, and understanding. Subconsciously, I think I accepted my new identity in part because there was a community that identified that way. A community that I finally felt that I belonged."

Participants who are actively involved in the ASD community (either online or in real life) reported greater understanding of the similarities and differences between AS and AD (discussed in greater detail in Theme Two), and the controversy surrounding the classification of ASD, than those less involved. The following participant demonstrates how his understanding and involvement in the community may be correlated.

60

P5: "I would say I'm fairly active in the community and because of this, I am more informed about the ongoings of the DSM than most Aspies. (…) I make it a point to research and learn more about Aspergers versus say other people who might not be as involved in the quote on quote Aspie community."

In contrast, participant three purported not to know much about the disorder, which supports the previous claim. Specifically, this individual self-reported as someone who was not active in the AS community.

P3: "Personally, I'm not involved with any organization or online community. I mean, I used to be but not in recent years. (…) I pretty much just walk around to the tune of my own tone deaf drum oblivious to the things [changes in the DSM-5] around me."

In general, the meaning that people ascribe to labels may mirror their learned experiences, social interactions, and reality. Thus, when a person accommodates this new information into their sense of self, they may internalize the diagnosis and self-identify with the community (Charland, 2004).

Theme Two: Knowledge and Understanding about AS, AD, ASD, and *DSM-5*

Theme Two encapsulates the participants' demonstrated knowledge and understanding of AS, AD, ASD, and the *DSM-5*. In particular, this theme articulates how the participants' understanding of the diagnostic subtypes led them to socially categorize themselves into their respective groups. Subthemes include the participants' understanding of AS, their perceived understanding of the shared similarities and differences between AS and AD, and the participants' knowledge of the changes regarding the clinical terminology and classification of ASD. Overall, the participants' level of understanding varied widely across the subthemes.

2.1 Understanding of AS. This first subtheme refers to the participants'

understanding of the diagnostic characteristics associated with AS. When asked to define the disorder, participants' responses varied greatly. In general, participants understood AS to be a "high functioning form of autism" (P1, P5, P7), inferring that a spectrum may be a more accurate reflection of PDD.

> **P1:** "There is too much overlap [btw Aspergers and High Functioning Autism] (…) to really say it is *completely* separate. (…) But also, there is enough differences that I don't think [the individuals disorder] should be completely eliminated. That's why I like the idea of a spectrum because it reflects the best of both worlds."

Likewise, participants were able to identify a broad range of primary (i.e., core AS features) and secondary (i.e., sensory sensitivities, average to above average IQ, and poor executive functioning skills) characteristics consistent with AS.

> **P9:** "Asperger syndrome is a neurological series of constellation symptoms that affects cognition, [and] cognitive interpretation of the world. They affect experiences through sensory sensitivities [that] are frequently viewed as impairments (…) Aspergers is mostly considered to be more of a social disorder. And a lot of that is simply due to non-understanding and non-acceptance."

> **P11:** "The way I understand it, [Aspergers] is a limitation in social thinking which results in an impairment to the emotional development. By definition a person with Asperger Syndrome is average to above average intelligence because if they had a mental retardation diagnosis they would be autistic. (...) So generally a smart person who is socially awkward. [They may have a] wide range of behaviours and ideas. All obsessive areas of knowledge, extreme details in some things, and complete neglect for others."

However, some participants misidentified characteristic unrelated to the disorder (i.e., dyspraxia and language impairment were considered diagnostic criteria whereas RRB were not) as being part of the diagnosis. This misconception, exemplified by participants three and four, is indicative of the poor understanding that many people with AS have of the disorder.

> **P3:** "[Aspergers] means to be clumsy socially. To be challenged in work situations. Whether dyspraxia is part of Autism, well it does seem to be part of the literature. So yes, it is!"

> **P4:** "People with AS have trouble with language. Also with ASD, people have to have repetitive patterns of behaviours whereas that was not a criteria before with AS."

Likewise, the participants' perspective of the public's understanding of the disorder was no better. Specifically, they believe the public obtains much of their knowledge about ASD from the media, which they consider an inaccurate portrayal of AS.

> **P2:** "I just felt that in my personal experience with other people, that is except for the autism community, [the public] still has very little understanding of what Aspergers is."

> **P7:** "When society thinks of Autism or Asperger, they see rain man, an autistic savant. And both you and I know that isn't the case."

Given that people usually behave and conform to the manner in which they are described (Hacking, 1993), the public's misconception of the disorder may affect how people with AS are perceived and treated by society. The following section presents the participants' overall demonstrated understanding of AD and knowledge of the disorder's associated characteristics.

   2.2 Understanding of AD. This subtheme reflects the participants' understanding and knowledge of AD. Participants defined AD as a neurological disorder characterized by impairments in the domain of social interaction, language, and RRB. Additionally, participants

recognized that AD can be found across the spectrum with symptoms ranging from low to high

functioning autism.

> **P1:** "Autism too is a neurological disorder with social difficulties. People with low
>
> functioning Autism often have difficulty with speech. Their speech may be delayed
>
> speech, limited or they may never develop speech at all. Also, people with autism tend to
>
> rock, flap their arms, spin, or line up objects. Their behaviour is similar to someone with
>
> OCD."

In general, participants understand AD to be a more debilitating disorder compared to AS due to

the lower functioning and severity level of those affected.

> **P2:** "Autism is on the lower end of the spectrum compared to AS in terms of
>
> independence and functionality."

With the participants' understanding of AS and AD in mind, the following section highlights the

participant's comparison of the two disorders.

2.3 Understanding of the shared similarities and differences between AS and AD.

The third subtheme captures the participants' understanding and knowledge of the perceived

similarities and differences between the AS and AD. As depicted by participants three and five,

challenges within the social and RRB domains are a commonality between the two disorders.

> **P3:** "What we [Aspergers and High Functioning Autism] have in common is that we both
>
> have trouble reading facial expressions, interpreting information, and picking up on
>
> social cues. We also have oddities like routines, specific interests, and are rigid in our
>
> thinking. The difference between us and them is the severity of our challenges."

Alternatively, participants consider the differences in the acquisition and development of

language and cognitive functioning as the fundamental distinction between the two disorders.

Participant 12 explains:

>   **P12:** "[Aspergers and Autism] have similar if not the same set of traits and mannerisms [that] show throughout the spectrum. I think one of the main distinctions between the two, the lower versus higher functioning members of the community, is their IQ level, language differences, and lower or higher capacity for independence."

Thus, how participants socially categorize themselves into the respective groups depends on whether participants view the similarities and differences between AS and AD as being distinctively large or fundamentally small (Stets & Burke, 2000). Consistent with the researcher's critical realist epistemology, how people perceive facts is seen as dependent on their beliefs and expectations. Thus, participants who believe that the social difference between the two disorders are insurmountably large will understand AS and AD as distinctive entities.

>   **P1:** "Autism and Aspergers is just as similar as you and I are, and that's say a lot [because] we could not be more different. I see myself as an Aspie because we share common characteristics. The same can't be said of Autism."

In contrast, participants who believe that AS and AD are a manifestation of the same underlying condition perceived the differences between the two disorders as being insignificant.

>   **P5:** "I don't really understand why there was a distinction to begin with. (…) It's the same conditions with more or less of the same features."

Taken together, the participants' understanding of the shared similarities and differences between AS and AD was reported as determining how they reacted to the change in classification of ASD (discussed in greater length in Theme Five).

>   **2.4 Understanding of ASD.** The fourth subtheme reflects the participants' scientific understanding of ASD and knowledge of the events pertaining to the reclassification of PDD.

Comparing the participants' understanding of AS and AD to their knowledge and understanding of ASD, their knowledge of ASD was significantly poorer. The participants' understanding of ASD can be classified into three distinct categories: (1) little to no knowledge of ASD, (2) some awareness but lack concrete understanding about ASD, and (3) well informed about ASD and the reclassification.

Although proposed changes to classification of ASD were made public over a decade ago, a small subset of participants acknowledged having no knowledge of ASD prior to their involvement in the study. Participants five and eight had this to say:

P5: "I don't think [people] are aware. I don't know about the other people you've talked to but from people that I've talked to [they are not aware of the changes in the DSM-5]. More importantly people weren't clearly explained the scientific evidence behind [the changes in diagnostic categorization]."

P8: "Most people haven't really mentioned Aspergers as a separate thing. They aren't aware that it's been removed. (…) It's usually assumed that [Aspergers] was a different level of autism. I [personally] didn't realize there was much of a change until recently. I only heard about the changes to the DSM a few days before the interview."

Conversely, of those aware of the changes in the *DSM-5*, their understanding of ASD and that diagnostic framework was poor. The following quote depicts how one participant's understanding of ASD is reflected in his own understanding of AS.

P1: "[The DSM-5] bundled Asperger Syndrome and Autism Syndrome Disorder along with PDD-NOS and a few other ones. It changed some of the diagnosing criteria most notably in the repetitive acts [because] Aspergers did not require it originally and now with it being an Autism, it requires repetitive acts to qualify."

While participants generally understood ASD as a spectrum that encompasses the former PDDs, they were less aware of the scientific reasoning behind the adoption of the ASD framework and the diagnostic changes.

> **P1:** "I know *what* happened. (…) I read articles and they explain that Autism, Aspergers, Rett Disorder, and PDD have been merged into one. (…) But there is less emphasis on *why* it happened."

Lastly, there is a small group of participants who are well informed of the changes to the classification of ASD, having followed the proposed changes online when they were first posted online for public commenting. The statements below reflect the participants' understanding of the *DSM-5* and the newly adopted changes to the ASD framework.

> **P5:** "[I learnt about the DSM-5] from various websites; officially from the DSM-5 site and from the commentaries on different blogs. (…) The change [was used to] eradicate Asperger syndrome and allow for a dimensional assessment using a 1-3 scale (…) that explains how a person's functioning level is affected on the spectrum."

> **P11:** "I obtained this information from the DSM-5 and from other people that have been talking about the change. Having looked at the criteria, I know that the social communication symptoms have been combined with the verbal and nonverbal categories. (…) They've also removed the imaginative criteria. So, although it's still there as a supportive feature, it's not there as a diagnostic feature. They've also put [in] the hypo and hyper-sensitivity to sensory stimuli and they've added to the list of diagnostic features for their restrictive repetitive behaviours."

Overall, the extent of the variability in participants' understanding of AS, AD, and ASD suggests that more awareness is needed to educate the ASD community. Theme Three presents the

findings on the perceptions associated with labels.

Theme Three: Perceptions Associated with Labels

The focus of Theme Three pertains to the perceptions that society associates with the AS, AD, and ASD terms and how participants coped with these connotations associated with the respective terms. The distinctiveness of Theme Three pertains to how it captures the way in which language use can be used to represent the different views people hold of certain terms and the way by which language can shape a person's self-identity. The participants' interpretation of how society views these disorders is presented in the subthemes below.

3.1 Public's perception. In general, participants believe that the public holds certain pre-conceived notions about an individual when they heard the term AS, AD or ASD. Specifically, given AS' prominence in the media and Internet, participants believe that the public holds a positive image of AS. Thus, by association, some participants think that this positive image subsequently makes them "cool" (P2).

> **P1:** "I think when people think of Aspergers, they think Albert Einstein, Sheldon Cooper, Abed, or Mr. Spock who are considered super geniuses. (…) So AS is seen in a positive light."
>
> **P8:** "Aspergers is like the latest thing in the media. Before it was werewolves, or zombies, but now having characters with Aspergers is considered cool. (…) So that makes me cool too cuz I have Aspergers."

Furthermore, some participants believe that society perceives AD and ASD as a lower functioning, non-verbal, severely impaired, debilitating disorder as compared to AS.

> **P4:** "Everyone knows or has heard stories about someone with autism. They are that person who is weird, a bit off, different, socially awkward, often by himself. (…) And

when people see someone on the street that is acting a bit strange, you immediately jump

to the conclusion that they have autism, like it's a bad thing."

Given society's perceptions of the individual diagnostic labels, the connotations associated with

these labels can have significant implications on how a person perceives him or herself.

    3.2 Stigma. An analysis of the textual data revealed that the topic of stigma elicited the

greatest discontent amongst participants. In general, stigma tended to surface when AS was

associated with AD or ASD. The reason may be that the public generally associates less stigma

to the AS label compared to AD or ASD despite diagnostic commonalities between the disorders

(Giles, 2014). As such, participants are concerned that the public may equate ASD with AD,

thus failing to recognize the broad differences across the spectrum.

    P3: "There is this prejudice between the two groups. While it's not [the] autistic people

    that have the issue (…) because they are already diagnosed with autism. It's the

    Aspergers people who have the stigma [because] they believe they are separate and it

    seems to be a pervasive thought through the whole community. They are afraid people

    will think they're autistic."

    P11: "People see Aspergers as someone who is high functioning whereas people see

    autism as low functioning. So, there is more stigma associated with Autism compared to

    Aspergers. That's not to say that there isn't stigma with Asperger, cuz there is. Just

    less."

Moreover, participants fear that being grouped under ASD may result in their being

discriminated against due to negative associations such as "stigma," "prejudice," and

"discrimination" (P2, P3, and P6) attached to the AD label, prompting participant eight to

comment:

P8: "To say that I'm autistic, well I'm sorry but that's not me. I don't rock, I can speak, I can do things independently for myself. I take offense when people say that we are all the same. Because we're not!"

As such, some participants, including participant one, believe that people who exhibit characteristics of AS may choose not to seek a formal diagnosis because the negative outcome is too great. Specifically, the diagnosis was said to do more harm than good. In TA, individual extracts of data may be categorized according to more than one theme in part because codes may address different yet relevant interpretations (Braun & Clark, 2006). Thus, the following excerpt was coded for Theme Six and Theme Three, which speaks to the participants' concern regarding the failure to meet diagnostic criteria for ASD (thus the denial of services) and the stigma surrounding the diagnosis.

P1: "I think that for people who have high functioning autism, they won't want to get a diagnosis because they won't really benefit. They probably won't qualify for services because they are high functioning. So, whether they have a diagnosis or not won't change much. […] If anything, a diagnosis [ASD] might make things worse for them. Before they could get by being the weird, quirky one. But with a diagnosis, they might be discriminated against for having ASD."

Instead, some participants strongly advocated for retaining the *DSM-IV* subtypes (AS, AD, Childhood Disintegrated Disorder [CDD], Pervasive Developmental Disorder – Not Otherwise Specified [PDD-NOS]) as the terms denote a distinction between AS and AD.

P6: "Having [the] different terms for different parts of the spectrum is good cuz it helps keep that separation and reduces the stigma then if we were grouped under this general ASD category."

However, one participant preferred the ASD term as it removes the perceived elitism associated with AS (i.e., a milder and more gifted disorder than AD). Rather, he believes that ASD fosters a sense of equality with everyone classified under the autism spectrum. He stated that,

> **P5: "**Some people think that because they have Asperger, that they are better than the rest of us. I personally don't care for it [Aspergers]. (…) If anything, I prefer the ASD label cuz it makes us all equal and less judgmental of others."

Participants were also concerned that members of the ASD community will internalize the public's stigma of ASD, which may lead people diagnosed with AS to buy into society's misconceptions about the disorder (i.e., low functioning, disabled, and non-verbal).

> **P3:** "The world already thinks of ASD as low functioning individuals and my fear is that people on the spectrum might actually start believing in this stuff which can affect their beliefs, attitudes, and behaviours."

Finally, participants feared that the stigma around the ASD label could potentially impact their family and friends. Known as courtesy stigma, this occurs when the people closest to the stigmatized individual (i.e., families and friends) experience discrimination because of their affiliation with the person (Goffman, 1963). Given that participants know first-hand what it is like to be stigmatized for something beyond their control, they worry that their loved ones will also be affected by the change in terminology.

> **P10:** "The ASD label has a direct effect on me but what about my family and friends? (…) Did these experts consider what might happen to them?
>
> **P11:** "My son who is three, is neurotypical (…) I don't want him to grow up and get made fun of at school for having a dad who has Aspergers.

Taken together, participants' apprehension about ASD stems from the perceived stigma that society associates with the word autism (public stigma). In particular, participants noted an increase in stigma in the education and the work setting.

      3.3 Stigma in the different settings. In general, participants experienced the greatest stigma when in the workforce and in educational contexts. Much of the stigma stemmed from the connotations that people associated with the different labels (e.g., AS, AD, and ASD). With regards to the education system, participants feared that the change in diagnostic labels would alter the way that teachers and school administrators (whether consciously or unconsciously) perceive students with ASD.

      P9: "Students with Asperger are considered bright, smart students with above average intelligence. In contrast, others might consider a student with ASD to be cognitively challenged with a learning disorder. So, the stigma that teachers and administrators hold of a student, I would imagine could affect the way that they are treated in schools."

Specifically, teachers may hold preconceived notions about a student based on their presenting diagnosis (Parsons & Kasari, 2013). Thus, teachers' biases may cloud and change the way that students are taught in the classroom (Parsons & Kasari, 2013).

      P4: "Related to your question before, changing the label from AS to ASD may cause some teachers to treat students differently. (…) The teacher [might] not challenge or push the student to reach his or her potential because the teacher believes that that person to be incapable because due to his or her disability."

Similarly, participants worried that students with ASD may be discriminated against and/or bullied in school because of the stigma associated with ASD.

      P11: "Children with AS already get bullied at school because of their social challenges.

And changing the label to ASD only makes it worst because the label implies dysfunction

whereas AS did not."

As such, these compounding issues may have aversive effects on a student's academic

achievements and success in the classroom (Kelley & Joseph, 2000).

Additionally, employment research suggests that people with AS struggle to obtain

and/or maintain jobs due to the hallmark features of the disorder (i.e., social and RRB

impairments; Autism Speaks, 2014). Given the change in classification, participants fear that

employers may only see the diagnosis and not the person. As such, participants believe that

employers may not hire someone with ASD because of the negative connotations surrounding

the more encompassing ASD label. As such, the qualifications of a high functioning individual

could be overlooked, thus further hindering the person's prospects of getting a job.

> **P1:** "People with Aspergers have a unique skillset that can lend itself in the work force
>
> (…) but the reality is, people with AS have difficulty landing the job because of our
>
> social challenges (…) Also when employers think Aspergers, they think Rainman, the
>
> autistic savant. Whereas ASD implies disability and no one is going to want to hire
>
> someone that is disabled."

The following subtheme provides insight into the strategies participants use to combat stigma.

3.4 Describing AS symptoms as a protective factor. Despite the positive attributes

(i.e., unique, and intelligent disorder) associated with AS, there is the potential for stigma as AS

is a psychological disorder. Thus, in everyday life when the topic of AS arises, participants

reportedly will describe their AS symptoms (as opposed to using the label) as a means of

protecting themselves from possible stigma.

> **P8:** "Most of the time I only describe symptoms to my potential employers so they know

the difficulties that I may face at work. (…) I don't need to give them another reason to think I'm different."

In this manner, participant nine indicated that she often uses rehearsed scripts to describe the type of person she is, including her challenges, to new people that she encounters. This is a strategy given by her therapist that allows her to avoid having to disclose her AS diagnosis and avoid the judgments of others.

> **P9:** For those situations at work, I've learned to use the "I am a kind of person that (blank)" scripts (…) to describe an aspect that I have frequently found to be problematic with in the past and the accommodations for the behaviour. It has worked immensely well and it has saved me so many problems at work. Many people know my symptoms and it allows me to avoid the 'A word [Aspergers]' so I am able to avoid that stigma."

Taken together, the stigma and connotations associated with a label may affect whether a person self-identifies and conforms to their social group (Hacking, 1993; Tajfel & Turner, 1979). The aforementioned will be discussed in the next section.

Theme Four: Social Identity

Identity was chosen as Theme Four for its central importance in explaining the impact that the changes in the *DSM-5* may have on those who identify by, and derive personal meaning from, their diagnosis. This theme distinguished the labels and identity terms that participants identified with given the removal of AS and its replacement with ASD. Overall, participant responses were consistent. Topics included self-esteem, social comparison, and the effects of *DSM-5* on the identity of the AS community. Specifically, four subthemes were derived: 1) Maintain an AS Identity, 2) An incorporated ASD identity, 3) A label does not define me, and 4) Identity of the AS community.

4.1 Maintaining an AS identity. This first subtheme refers to the strong conviction by some participants to maintain their AS identity. In general, participants described how they came to identify with AS. For many, the diagnosis seems to "fit." Supporting Theme One, subtheme two (Personal Insight), the diagnosis was "the missing piece of the puzzle" (P1) that helped participants to understand and explain a lot of the challenges that they endured growing up. As participants began internalizing and identifying with their diagnosis, AS became a label that was used to *"describe me"* (P9). The following quote exemplifies this subtheme.

> **P7:** "I don't remember a time before I was diagnosed. I don't view Asperger as disorder so much as a word that describes *a part of me* and who I am. It was the missing piece to the puzzle."

Moreover, understanding the social differences between AS and AD (Theme Two) led some participants to self-categorize and identify as an Aspie. In particular, some individuals believe that their symptoms closely align with those of AS and socially categorized themselves as such.

> **P2:** "Unlike Autism (…) all my quirks and personality traits just seemed to fit with Aspergers. So naturally I consider myself an Aspie and identify that way."

Given that a person's identity may be comprised in part by his or her diagnosis (Charland, 2004), the loss of AS as a clinical diagnosis may engender a sense of confusion, as participant one described of his "identity crisis" (Erikson, 1968).

> **P1:** "Well I strongly oppose [the DSM-5] and I know most other people [with AS] do too (…) as the diagnosis has become a significant part of our identity. (…) If I'm no longer an Aspie and I'm not an NT [Neurotypical], then who am I?"

Moreover, some participants believe that the loss of AS somehow invalidates who they are under the diagnosis, as people's understanding of themselves is constructed from the subjective

meanings of their experiences.

> **P8:** "I'm a bit leery to remove [the AS terminology] and maybe that's because I've
> always thought of myself as an Aspergers more than autism. That's the way that I've
> always been treated and what I've been told I had. (…) I've always identified as
> Aspergers first and autism second. (…) So, it feels like I'm being stripped of who I am."

Participants' preference for disability first language (i.e., I am an Aspie) rather than person first
language (i.e., a person with AS) provides further evidence of their commitment to the AS label.

> **P4:** "You researchers think you are being sensitive by using person first language but we
> actually prefer disability first language. I *am* an Aspergian, not a person *with* Asperger!
> (…) If you truly wanted to be respectful of the Autistic community, you would address us
> as an Aspie."

The statement below offers another example of how a participant's statement could be coded for
multiple themes. Participant nine begins by expressing her adamancy to "vigorously cling onto
her AS diagnosis" (which coincides with Theme Five – Opinions and Reactions to the *DSM-5*).
She then goes on to describe what her life was like prior to receiving the AS diagnosis (Theme
One – Subtheme 1.1; Challenging Experience). Specifically, she recalled having "suffered for
many years," not knowing the underlying reason or cause of her difficulties in life. However,
she was able to understand "why" and make sense of some of her challenges upon receiving her
AS diagnosis (Theme One – Subtheme 1.2; Positive Experience). Furthermore, the participant
stated that the diagnosis has opened the doors to a number of resources and services (see Theme
Six) that she could access through the community. Lastly, the participant relayed the meaning
that the diagnosis held for her as it allowed her to connect and identify with others in the
community (Theme Four – Identity).

P9: "I am vigorously clinging to the [AS diagnosis]. You cannot take my diagnosis from me. (…) I suffered for many years not knowing what was wrong with me and to finally have those words. Those words were the answer! Here is *what's* wrong. Here is *why* it's wrong and *why* it's causing problems. It opened to doors to resources about what you can do about it to change all of that. Those words were magic for me. They changed my life. Having people to identify with now, it's more than just a diagnosis it is an identity! I will not let go of that diagnosis! No! (…) Asperger is who I am. This is me!"

Lastly, as participants observed their own children/sibling(s) navigate the diagnostic process to obtain their own ASD diagnosis, they began to recognize characteristics of AS within themselves. This realization helped to further reinforce the participants' AS identity.

P11: "When my son was getting tested for AS, I was going down the checklist going "Yup, I have that, I have that, no I don't have that," and it really opened by eyes. (…) While I was told all my life that I had AS, in that moment, it really became apparent."

In light of changes to clinical terminology, participants indicated the fit of the diagnosis, shared similarities with the disorder, self-categorization, validation, language preference, and recognition as some to the reasons for choosing to maintain their AS identity.

4.2 An Incorporated ASD identity. This subtheme was unique as it captures the manner by which participants incorporated ASD into their current identity. Though some participants acknowledged that ASD is a better representation of PDD, only one participant surrendered his AS identity in favour of an ASD one. Rather, other participants chose to incorporate ASD into their current AS identify, often using both terms interchangeably.

P8: "I identify first as Aspie, but I also recognize myself as autistic. I have no problem with that and using both terms."

Moreover, some participants questioned why they had to identify with one disorder over the other. Their thought was that given that AS is represented under the autism umbrella, these participants felt that they should be allowed to identify with both terms as they see fit.

> **P5:** "Why do I have to choose one over the other? […] Why can't I identify with both [Aspergers and Autism Spectrum Disorder]?"

Additionally, some participants found it easier (depending on the situation) to explain AS within the context of the ASD framework given the complexity of PDD. Participants one and 12 describe:

> **P1:** *"I do say that I'm on the Autism Spectrum whereas I didn't before. (…) But now I say I have Asperger which is *on* the Autism Spectrum. So, I've changed [the way] that describe myself."*

> **P12:** "I've always thought of myself as an Aspie. But I guess now it will take a little more explaining to other. Yeah an Aspie is someone with Asperger which is a form of autism (…) but on the higher end of the spectrum."

Although some participants support the adoption of an ASD framework, many are unwilling to abandon their long-standing social identity of an individual with AS for the greater part of their lives. Hence, the embrace of an incorporated ASD identity.

> **4.3 An alternate identity.** This third subtheme denotes a small group of participants who did not identify with either the AS or ASD label. Specifically, these participants feel that AS does not represent who they are, choosing instead to identify with another social group or by another personal identity.

> **P3:** "I was taught not to let [the term/label] define you, you define it! (…) I am my own person who just happens to have Asperger traits. (…) I don't really think of myself an

Aspie. (…) Rather, I see myself as a unique person with eccentricities."

P4: "Although on paper it says that I have Aspergers, but I really don't identify with

Aspergers or Autism (…). My symptoms are so mild that I forgot about it until my own

son was diagnosed with PDD."

While most participants have other comorbid diagnoses and/or complex conditions affecting

their AS, only a few individuals strongly self-identified with their other disorders more, or not at

all. As one participant states:

P5: "I've been diagnosed with [diagnosis #1], [diagnosis #2], [diagnosis #3] and

[diagnosis #4] amongst other things. (…) So, if you were to ask me which one I identify

with more, I couldn't tell you. To be honest, I don't identify with any of them (…). They

are simply things that I have; thing that doctors use to describe my conditions, but it

doesn't make up the person that I am."

Lastly, in light of the changes to the classification of ASD, one participant spoke about his

identity confusion. Specifically, this individual questioned his placement in society as he no

longer considered himself an Aspie, did not identify with ASD, or see himself as an "NT"

(neurotypical; a term used in the autism community to describe people who are typically

developing) either.

P6: "Well if I'm no longer an Aspie, and I certainly don't consider myself an ASD, then

what does that make me? Neurotypical? [scoffs] I don't think so. (…) So where does that

leave me?"

Overall, the findings illustrated by this subtheme revealed that some participants adopted an

alternate identity as AS did not represent who they are as a person or because the individual self-

identified with another social group.

4.4 Identity of the AS community. The last subtheme refers to the participants'
opinions regarding the classification of ASD and its effects on the AS community. With few
exceptions, participants generally believe that the AS community will continue to flourish
despite the changes in the *DSM-5*. In particular, participants consider the AS community to be
robust, speculating that the community would sustain itself as a by-product of social media and
word-of-mouth.

> **P11:** They can change the labels as often as they want but people will continue to identify
> with Aspergers. (…). Everybody will still know [what it is] in the Autism community
> and people will likely continue to use the different descriptors in every day
> conversations."

However, not all participants shared this view. One individual believes that the changes in the
DSM-5 will somehow mean a loss for the AS community. With clinicians using the *DSM-5* to
diagnose patients with ASD, he predicts that the AS population will diminish over time.

> **P2:** " [I think] moving forward there will be less people in the Asperger community
> because doctors will no longer be give out the Aspergers diagnosis (…) And people that
> were diagnosed as an Aspie will be diagnosed with ASD instead if they are forced to get
> a re-evaluation. (…) So, the community is bound to collapse. "

Regardless, most participants declared, "it may be too soon" to determine the effects the *DSM-5*
on the AS community and that more time was needed to assess its impact.

> **P9:** "I don't know how things are in the US, but in Canada I haven't seen too much
> change. (…) But with any government policy, it takes time for changes to occur. We'll
> have to wait and see I suppose."

The formation of a person's identity may be based on their personal experiences, knowledge and

understanding, and social interactions (Hornsey, 2000). In light of the changes to the classification of ASD, these factors lead participants to adopt one of three identities: AS, incorporated ASD, or alternative identity. The following section provides insight into the participants' opinions of the *DSM-5* and the new classification of ASD.

Theme Five: Opinions Regarding the Reclassification of PDD and ASD

Theme Five captured the participants' opinions regarding the classification of ASD and change in diagnostic terminology. In general, participants' views widely differed across three subthemes: 1) Reject the removal of AS as a clinical disorder, 2) Support the changes in the *DSM-5*, 3) and Neutral/mixed feelings about ASD.

5.1 Reject the changes to the *DSM-5* and retain AS. This subtheme encompasses the opinions of participants who reject the removal of AS as a clinical disorder and the related changes in the *DSM-5*. In particular, these participants contend that the AS community has enough problems with social marginalization - even without the recent change to the diagnostic terminology and criteria of PDD. Further, participants concluded that the removal of AS is a "huge disservice" to the community (P2) as it signifies the "end of an era" (P1). The following quotes refer to the loss of AS and the adoption of the ASD framework.

P2: "I'll say very few people welcome the changes because they felt that Asperger is two separate things, similar but different you know. A lot of people have strong opinions that Asperger should be like a separate diagnosis because it's almost like Autism, high functioning autism, as in Asperger Syndrome (mumble). They're like cousins but they are not exactly the same. So, people shouldn't incorporate and combine those two together."

P5: "I'd say 80% oppose it or 90% [people with AS oppose the changes in the DSM-5].

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So, there is [that] 10% that thought (…) it was time to change. (…) A change that was

going to happen sooner or later. Although I think the uproar was probably an initial

emotion reaction. If those people were asked again 3 years later they may not have the

same reaction."

This next quote further illustrates the disapproval of the *DSM-5* and support for the retention of

AS. Specifically, participant six was adamant that the collapse of the individual subtypes in

favour of a single ASD umbrella would oversimplify the complexity of the disorders, and others

regarded ASD as "a catch all," (P1) and too much of "a grab bag" (P2) to have any real meaning.

> **P6:** "I don't like it [the DSM-5]. I think it's trying to over simplify things that shouldn't
>
> be simplified. Collapsing categories together that don't really and shouldn't really be
>
> grouped together so uniformly."

Some participants resented the scientific community because the AS community was not

consulted when the changes to the classification of the disorder were first proposed.

Specifically, participants believed that the AS community ought to be the highest authority on all

matters concerning AS.

> **P5:** "They should have come to us and asked us about our thoughts before changing
>
> everything. (…) We're the ones who live with the disorder so we should have a say in
>
> what happens!"

Although the majority of participants are displeased with the APA's decision to re-classify PDD,

others are more accepting of the new changes.

> **5.2 Support the changes in the *DSM-5*.** The second subtheme, Support for the Changes

in the *DSM-5*, highlights the opinions of participants who support the adoption of the ASD

framework. These participants argue that the *DSM-IV's* approach to classifying PDD creates a

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"false separation" (P3) and that the spectrum does away with outdated research.

> P4: "Before you had childhood schizophrenia, Autistic Disorder, Autism, Rett,
> Childhood Disintegrative Disorder, and PDD. But that was all based on old research.
> New studies show that these disorders are all related and that the division that once was,
> no longer applies."

Moreover, some participants claim that the diagnostic criteria for AS were too lax and that they prefer the more stringent requirements in the *DSM-5*, thus showing their support for ASD.

> P2: "The criteria [for AS] is way too low. You only need to (…) have obsessive interest,
> and social difficulties in order to be named Asperger syndrome and I feel that it's not
> enough. The experts should have set up higher standard levels like defining 3 or 4
> different [criteria] to call it Asperger syndrome. That's why change is good."

Others support the ASD framework because of its flexibility and inclusion of symptoms severity in comparison to the *DSM-IV*.

> P11: "I guess the upside of the spectrum is that the dimensional approach is more flexible
> compared to the categorical approach especially as people get older and their symptoms
> manifest differently or their severity levels change with time. Although technically the
> DSM-5 still abides by the categorical approach."

Other interviewees favor the new ASD terminology because it eliminates confusion and uncertainty regarding the proper labels to use (given the overlapping PDD symptomatology).

> P7: "[Having the ASD label] is easier in away because it removes my internal worry that
> someone is going to correct me or accuse me of using the wrong term or whatever it is
> now."

Additionally, this group of participants believes that the benefits of a spectrum outweigh the

advantages of the individual descriptors (i.e., AS, AD, and PDD-NOS), thus supporting the unification of the disorders.

> **P11: "**I think pragmatically changing to ASD was the right thing to do. Logically it just chang[es] the label from pervasive developmental disorder to autism spectrum disorder and then not breaking it down further into exact behavioural subtypes which may come in the future if they decide over time if it is specific. (…) So change of label. Meh!"

Lastly, a group of participants support the ASD framework because it fosters a sense of unity, belonging, inclusion, and community amongst those on the spectrum. One participant said it best:

> **P2**: "I felt that it [the new ASD framework] was more inclusive now. Like for example, the meet up groups that I attend, I think now with the new Autism Spectrum, there is more of a chance to meet other people with different disorders like Autism and PDD and Rett then before because it was just for people with Aspergers."

While most participants firmly held to their beliefs (whether that be in favour or against the changes in the *DSM-5*), some took a more neutral stance on the topic.

> **5.3 Mixed/neutral feelings about ASD.** The third subtheme pertains to a few

individuals who indicated mixed/neutral feelings about the *DSM-5*. Complex feelings of uncertainty combined with a sense of understanding yet unwillingness to relinquish their AS identities was a commonly reported topic. Although most participants acknowledged the importance and contributions of both the AS and ASD terms, a number of interviewees advocated for the co-existence of both labels. The following quotes provide concrete examples to exemplify participants' mixed/neutral views about ASD.

> **P6:** "The ASD framework I have no issues with. The terms I don't have a problem with.

I've always understood it to be a part of a bigger thing. The only thing I've really take issue is taking away the sub-classifications and subdivisions within the big spectrum. I think both terms [AS and ASD] should be recognized."

P7: "I think we should have both [AS and ASD]. I think both terms should exist because one of them (…) is more specific than the other. They both have their place. They are both useful in appropriate contexts. I don't think we should make do with one and not the other. As opposed to just Autism Spectrum or just Aspergers, you'd be like Aspergers which is [on the] autistic spectrum."

Overall, participants were divided in their opinions of the classification of ASD. However, they are generally united in their views of the barriers for funding and service provision.

Theme Six: Barriers to Funding and Service Provision

Theme Six is defined as the perceived challenges that occur in providing and accessing services for families and individuals with AS. Four subthemes were identified from the textual data: 1) Concerns with not meeting ASD criteria, 2) Access to services and treatments, 3) Impact on education, and 4) Impact on research.

6.1 Concerns with not meeting ASD criteria. Access to services and funding is often contingent upon having a formal diagnosis. Thus, the removal of a clinical diagnosis may result in a loss of services for people who held the former diagnosis. One concern that participants have is whether they and/or people with AS would meet diagnostic criteria for ASD given their mild symptomatology.

P12: "[The changes to the DSM-5] it's going to impact those who fall on the higher end definitely. (…) So, they probably would be very frustrated because the services and supports that they were receiving before might be removed."

Likewise, failure to qualify for ASD may result in individuals being denied access to funding and services despite their persistent and sustained impairments. Thus, the point here relates to the implications of a potential loss of diagnostic status arising from the adoption of an ASD framework. Participants nine and 11 explain:

> **P9:** "To be denied my Aspergers label because people are no longer thinking in that direction is a huge crime (…) and a complete disservice! It's denying service to those who really need it like me! (…) Even though they said that people who previously fit Asperger would meet criteria for ASD, there is still a slim possibility that they won't."

> **P11:** "I'm a little concerned that people who qualify as pervasive developmental disorder not otherwise specified might not fulfill autism spectrum disorder criteria. (…) So, we are going to lose something there. There might be people will no longer be eligible for [name of social program] or some other assisted support."

Although the APA insists that all persons on the spectrum should meet diagnostic criteria for ASD (2013), other researchers suggest otherwise (Matson, Belva, Horovitz, Kozlowski, & Bamburg, 2012; McPartland et al., 2012; Wilson et al., 2013; Worley & Matson, 2012). Regardless of whether participants are currently accessing services or not, they feel that any potential loss of services (for failure to qualify for ASD) is unjustified.

    6.2 Access to services and treatments. Another major area of contention is the limited resources and services available to adults with ASD. In particular, ASD services in Canada are predominantly focused on helping families and children, not adults. As such, participants including P3, feel unsupported given their challenges in life.

> **P3:** "I don't get any services. I don't really get any funding. The way autism funding is structured now, [although they claim] they are helping autistic people of all ages when in

fact its directed towards helping families with autistic children (…) not autistic adults."

However, for those few participants receiving support, the AS diagnosis was instrumental in their ability to access to services. Specifically, the diagnosis has helped participants connect with service providers to obtain the supports that they need. Thus, the removal of a clinical disorder may have serious repercussions for people trying to access and secure funding.

> **P5:** "[Having a diagnosis has] made it easier for me to understand and approach [service providers]. I talked to [name of autism organization] before I had my Asperger diagnosis and they wouldn't even talk to me. They basically shunned me. (…) But as soon as I got a diagnosis, they were willing to talk."

The quote below was coded for multiple themes as the data extract fit into more than one category. For participant nine, the diagnosis enabled her to access supports from a psychologist (that speaks to Theme Six – barriers to service provision) which helped her to rebuild her sense of self (Theme Four – Identity) – another example of how services can improve the lives of people with AS.

> **P9** "Since receiving my AS diagnosis [it's had a] great impact. Almost all of it positive because it did open the doors to better support. Supports that worked! (…) I used to feel that I had no self. All I was, was a series of masks. But the diagnosis allowed me to work with a psychologist to rebuild my sense of self and now it's quite strong."

However, with the unification of the PDDs, issues related to treatment efficacy were identified. Specifically, participants argued that interventions for all persons across the spectrum may be less effective than interventions that target a specific subset of individuals. Although the results will generalize to more people, participants believe its efficacy will diminish.

> **P7:** "Well the autistic spectrum is really broad. It's supposed to be helpful to psychiatrist

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and doctors in figuring out how to help [those on] the autistic spectrum [but] it isn't

specific enough to really tell them what they need to know in order to provide the kinds

of help that would be useful."

The following section discusses the potential implications the change in terminology and ASD

criteria may have on the education system.

6.3 Impact on education. Although it may be too soon to evaluate the effects of the

classification change on education, this subtheme underlines the reservations that participants

have regarding the loss of educational supports and classroom placements. Specifically,

participants feared the possibility of schools requesting that students with AS be re-evaluated for

ASD (an updated assessment to ensure that the student continues to meet diagnostic criteria for a

mental disorder). Should students fail to meet diagnostic criteria for ASD, their rights to

educational supports may be lost (Parsons & Kasari, 2013).

> **P11: "**If schools are requesting the students get re-evaluated for ASD and the student
>
> doesn't meet criteria for ASD, then school no longer have to give kids special
>
> accommodations or educational supports for learning, processing, and sensory
>
> sensitivities."

Participants also expressed concerns regarding the effects of the *DSM-5* on classroom placement

(consistent with previous research; Walker, 2012; Wilkinson, 2010; Zirkel, 2010). Participants

generally favoured the inclusion of mainstream education over special education classes. As

participant nine explains, special education may hinder a student's capacity to learn and their

ability to reach their potential.

> **P9:** "Kids who would met criteria for AS and are newly diagnosed with ASD, are being
>
> lumped in with the Special Ed kids which is harming their education. These kids (…)

learn at accelerated speeds. (…) Putting them in the bad environment that is often even slower is severely damaging their education and (…) they aren't being challenged to use their brains. So, they are not learning to their potential. (…) And if teachers think autistic students are less capable, then it becomes a self-fulfilling prophecy. Student won't try as hard. Cuz what's the point? They already think we're dumb. So, it's a vicious cycle."

Moreover, it was argued that special education classes do not take students' different rates and ways of learning into account.

P1: "When I was in school, all kids with special needs regardless of the diagnosis were [put] in the special ed classes. (…) You could have ADHD, a learning disorder, autism, disabled; it didn't matter. We were all taught the same thing and at the same rate regardless of our ability to achieve success or not."

Given the recent changes in the *DSM-5*, it will be interesting to see how schools and administration adapt to these changes and what impact it will have in the classroom.

6.4 Impact on ASD research. The final subtheme of Theme Six highlights participants' concerns regarding the impact that the *DSM-5* will have on research. In general, participants understand and recognize that the diagnosis of ASD has scientific utility as it reflects the current and evolving research.

P11: "The DSM-5 reflects the current research about the differences and similarities between Autism, Aspergers, CDD, and Pervasive Developmental Disorder, Not Otherwise Specified which is why they decided to move away from the different subtypes and more towards a spectrum."

However, participants believe that researchers may feel inclined to study the entire spectrum

given the collapse of the separate disorder, which may diminish the specificity of findings.

> **P9:** "Findings and research focuses on the entire spectrum will be too broad and general to have any real significance. (…) And the outcome of these studies will likely result in blanket recommendations that won't benefit anyone because the needs of each individual differ so greatly. So really, what is the point?"

As one participant points out, the challenge for researchers wanting to study a subsection of the spectrum under the DSM-5 definition comes with determining how they will make a distinction among people on the spectrum and define their inclusionary and exclusionary criteria.

> **P11:** "Say you do a study that happens to capture what would have been Aspergers and try to generalize [the results], especially if it really is a separate sub group. (…) Then you might have real problems applying it and vice versa. There's a risk of it being generalized when you group everyone under ASD. Because how do you group people differently? How do you bring them into your study? (…) You just have to be careful in your definition [and inclusion/exclusion criteria]."

In contrast, the next participant firmly believes that the unification of diagnoses will impact research positively as the funding and resources will be allocated towards the study of one rather than several related disorders.

> **P3:** "Well I think the [change in terminology] is going to make it better because they are not chasing two different things and getting the same answers. (…) It's redundant to do it twice. It divides the resources. There's probably a pre-determined set budget for research that gets cut it in half when they're studying the same yet different disorders. Instead we need all the minds to be working together."

Despite the removal of AS as a clinical disorder, participants generally believe that AS will continue to exist in the research and medical communities as many researchers have devoted their lives and careers to studying AS and are unlikely to abandon years of research.

> **P5:** "Some scientists have built their careers studying Aspergers. These people aren't going to throw everything out just because someone says so."

Overall, concerns regarding qualifications for ASD, lack of available services, the need for mainstream education, and impact on research were noted as barriers in the provision of services. Moving forward, it will be interesting to see how service providers respond to these obstacles

Summary

In sum, the themes and subthemes derived from this TA distinctively highlight the participants' experiences with living with AS, and knowledge of the shared similarities and differences between the individual subtypes. Furthermore, the level of perceived stigma associated with ASD mirrors the participants' opinions of the *DSM-5* and likely influenced their own social identity. Lastly, the changes to the diagnostic criteria have engendered great concern amongst participants as it has a direct impact on service provision and funding for the entire community. Chapter Five will provide an interpretation of the findings.

Chapter Five: Discussion

The current study sought to explore the experiences and opinions of individuals with AS regarding the identity terms related to the changing classification of ASD. Six unique themes were identified: (1) experiences with the disorder, (2) knowledge and understanding of the *DSM-5,* (3) perceptions associated with labels, (4) social identity, (5) opinions and reactions to the *DSM-5*, and (6) barriers to service provision. The importance of these themes and the information that was brought to light captured how participants dealt with and viewed the impact of this change in diagnostic classification and its effects on the AS community. Specifically, the findings revealed how the participants' experiences with the disorder, understanding of AS, and the meaning they derived from their diagnosis, informed their identity. Likewise, their interactions with other members of the ASD community, experiences, and understanding of the previous autistic subtypes, may have influenced the participants' opinions of ASD given the changes to the classification of the disorder. Overall, this chapter provides an in-depth interpretation of the results whereby the findings are compared and contrasted against related research, followed by a discussion of limitations, implications, and recommendations for future research. Finally, closing thoughts and conclusions will be presented.

Theme One: Experiences with the Disorder

The findings from Theme One revealed how the participants' experiences of living with AS affected the meaning that they derived from the diagnosis. In general, participants attributed many of their challenges while growing up to the core features of AS (i.e., social impairments and restrictive and repetitive patterns of behaviour [RRB]). While many challenges (i.e., difficulty with perspective taking, interpreting facial cues, being flexible, and understanding social demands) were reported, incidents of physical and psychological bullying, being

mistreated, misunderstood, and feeling different as a child was noted across participants. According to the Interactive Autism Network (IAN; Anderson, 2012), people with AS are easy targets for teasing, bullying, and verbal/physical abuse. Specifically, 63% of children with ASD surveyed in one study (n = 1,167) experienced bullying at some point in their lives and peer victimization has been correlated with a decrease in self-esteem, lowered self-confidence, and increased feelings of isolation, depression, anxiety, and suicide (Cappadocia et al., 2012). Furthermore, the participants' difficulty with social irony, social reciprocity, interpreting facial cues, and perspective taking, may have contributed to their experiences of being bullied and feeling misunderstood and different. Thus, by increasing awareness of these issues and providing families and children with ASD with effective strategies for dealing with bullying, some of these challenges may be mitigated.

Additionally, challenges with the diagnostic process was reported due to the high rates of misdiagnosis and/or under-diagnosis in people with AS (Beteta, 2009). Some participants were misdiagnosed with Attention-Deficit/Hyperactivity Disorder, Obsessive Compulsive Disorder, or Anxiety Disorder (Beteta, 2009) as a child, potentially due to the similarity in diagnostic features of these disorders to AS. Alternatively, other participants did not receive a diagnosis until later in life because their AS symptoms were difficult to detect as a child (Wing et al., 2011). It should be noted that the female participants in the current study experienced additional challenges with the diagnostic process to those presented above. Given that AS was predominately considered a male disorder (Attwood, 2017), doctors and clinicians had difficulty diagnosing AS in females. In fact, Asperger's (1991) initial account of AS was based on characteristics observed in male participants. However, researchers suggest that symptoms of AS in females manifests differently from their male counterparts (Attwood, 2017; Wing et al., 2014). As such, AS in girls and

females are often overlooked. When boys with AS make social errors, their immature social play skills are quite conspicuous and there is recognition that an assessment and intervention are needed. Conversely, "girls are more likely to apologize and appease when making a social error," thus "peers and adults may then forgive and forget without realizing that a pattern is emerging" (Attwood, 2017; para. 5). Indeed, the prevalence of AS in the female population may be underreported. Given the challenges with the diagnostic process, many participants felt confused about their behaviours and challenges for many years (Powell & Acker, 2015).

Living with AS, however, was not entirely negative. For many participants, the diagnosis was a source of important personal insight and pride. Specifically, the diagnosis provided an understanding into the many challenges that participants experienced in life. According to Singh's (2013) research that looked at the implications of the then proposed changes to the *DSM-5*, a medical diagnosis can legitimize a person's challenges by putting past experiences into perspective. Thus, by attributing their challenges externally to the diagnosis rather than internally to themselves, some participants reported feeling less ashamed of their impairments and stopped blaming themselves for their impairments (Weiner, 1972). Similarly, having a name for their challenges meant that participants could seek knowledge, help, and take action to improve their situation. In an article written for the National Centre for Mental Health in Schools at UCLA, Cheng (n.d.) suggests that a diagnostic label can help to define a problem and allow for a greater understanding into one's challenges. Thus, this reframing of past experiences led some participants to accept the diagnosis and embrace their AS differences (as it is what made these individuals unique). As such, many participants took pride in having AS.

The diagnosis also meant that a community of people who share similar challenges and experiences in life exists. Participants talked about the importance of the AS community and

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how it altered their perception of the disorder. Specifically, the social influence of the

community shifted the participants' view of AS from a stigmatized psychiatric condition to an

understanding of acceptance and neurodiversity that should be celebrated. According to Stets

and Burke's (2000) historical review of SIT and Self-Categorization Theory, when a person

becomes involved in a community, his or her commitment to the group increases thus leading the

individual to self-identify with the in-group and perceive them more favorably. Thus, in some

sense, AS was transformed from a clinical label into a community with cultural recognition, and

members identified with their diagnosis in part because there was a community that also did so.

Overall, participants' experiences growing up with AS played an important role in the

meaning that they derived from their diagnosis. Although receiving the diagnosis was

considered a positive 'turning point' for many participants, the process of 'coming out' and

acknowledging that one has a clinical disorder is seldom based on a single revelation (Cass,

1979). As such, members of the AS community are encouraged to work with appropriately

qualified professionals to uncover the meaning(s) that the diagnosis holds for each individual as

it will influence how a person interprets and understands the world around them. Thus, the

findings from Theme One provides a basis for the remainder of this chapter.

Theme Two: Knowledge and Understanding of AS, AD, ASD and *DSM-5*

The findings from Theme Two highlight the participants' knowledge and understanding

of the shared similarities and differences between AS, AD, and ASD, showing how they socially

categorized themselves into their respective groups. Much of the participants' information about

the diagnostic subtypes stems from the research and publications of distinguished researchers

(i.e., Baron-Cohen, Wing, Grandin, and Attwood) in the field (Giles, 2014). Although both the

APA and AS communities are ostensibly informed by the same scientific research, respective

parties may choose either to respect or dismiss the information. Known as confirmation bias, people will typically seek information that is consistent with their beliefs and disregard information that challenges their preconceived notions (Nickerson, 1998). Confirmation bias is particularly strong for emotionally charged individuals who hold deeply entrenched beliefs (Nickerson, 1998). Thus, participants who have a strong attachment to their AS diagnosis may seek information that supports the notion of AS as a distinct disorder while discarding research that counters their position. The findings also suggest that participants obtained their information about the diagnostic subtypes through interactions with other members of the AS and AD communities. Commensurate with Morton and Campbell's (2008) study that looked at the effects of peers' attitudes toward AD, people who are actively involved in their community tend to have a greater knowledge and understanding about their respective disorder(s) when compared to those less involved. The reason for this is that people interpret the world around them based on the information and feedback that they receive from others (Hacking, 1995). Hence, greater involvement in a community generally leads to an increase in knowledge about the group and its characteristics (Tajfel & Turner, 1979). Unfortunately, the information in question may have inaccuracies given its source (i.e., obtained online, through the media, or word of mouth; Morton & Campbell, 2008). Thus, careful consideration should be taken (especially considering social communication challenges) when presenting information to the ASD community as it can impact their interpretation and understanding of society.

In general, the participants' knowledge and understanding of ASD and changes to the classification of this disorder varied. Although they understand that ASD is an all-encompassing disorder that subsumes previous diagnostic subtypes, participants reportedly were not informed of the reasoning behind change in classification (although proposed changes to the *DSM-5* were

posted online for public viewing). Tajfel and Turner's (1978) SIT may be used to account for the discrepancy between the participants' understanding of ASD. Specifically, a relation exists between a person's commitment and their level of involvement (Tajfel & Turner, 1979) that strengthens upon identification with their in-group. Given that a change in classification has a direct impact on the AS population, participants who have a strong commitment to their diagnosis and are actively involved in the AS community may have greater knowledge of the controversy surrounding the *DSM-5* due to their affiliation with the group (Stets & Burke, 2000). In contrast, participants who are less committed to their social group (and identify with AS less strongly) may be less informed about changes replacing the ASD diagnosis due to their limited exposure and involvement with the community (Ochs, 1993). In general, the participants' involvement and understanding of ASD and the diagnostic subtypes were important to their opinions of the ASD framework (a more in depth discussion is presented in Theme Five).

Overall, the participants' understanding of the similarities and differences between AS and AD influenced how they socially categorized themselves into their respective groups. First, participants understood AS to be a social disorder and form of autism. Thus, a subset of participants socially categorized themselves as a member of the AS community and self-identified with their clinical diagnosis (discussed in greater detail for Theme Four) in part because they believe that their social challenges closely match those accounted for by the former AS diagnostic criteria. Of note, a few participants mistook personal idiosyncrasies (i.e., dyspraxia, motor clumsiness, poor executive functioning, giftedness, and intelligent) as being explained by the diagnostic criteria for AS. According to Chamak, Bonniau, Jaunay, and Cohen (2008) "the disparity between what people know and what people believe to be true highlights the fact that official diagnoses are not necessarily the same as lived experiences" (p. 274). Thus,

participants' understanding of AS characteristics may not necessarily pertain to their true experience. Powell and Acker (2015) examined adult experiences accounted for by the AS diagnosis and found that many people in the AS community lack a concrete understanding of the disorder. A poor understanding of one's condition can have considerable life implications as it may lead the person to blame him or herself for his or her challenges, poor treatment outcomes, diminished well-being, and sense of confusion for being lost in society (Powell & Acker, 2015). As such, greater education about one's condition(s) may compel people to obtain the necessary help to lead fulfilling lives. Relatedly, participants also recognize AD to be a social disorder. Although AS and AD share similar diagnostic features (i.e., social impairments and RRB), participants generally consider AD to be a more debilitating disorder. Consistent with Giles' (2014) research on the online ASD community's reaction to the *DSM-5,* AD is associated with lower cognitive abilities and an absence or delay in language acquisition as compared to AS. Thus, how similarly or differently participants perceive AS and AD will influence whether they socially categorize themselves as a member of the AS or ASD community.

In general, participants who perceive significant differences between AD and AS will socially categorize these diagnoses as distinctive entities while those who view AS and AD as a homogenous disorder, will unproblematically categorize AS and AD under the ASD umbrella. Beck's (1963) research on Labeling Theory and the Social Basis of Deviance suggests that "social groups create deviance by making rules whose infraction constitutes deviance" (p. 91). Thus, according to the 'rules of deviance,' a person who is not part of the inner group is considered an outsider, thus producing a "them" versus "us" segregation.

Theme Three: Perceptions Associated with Labels

Theme Three speaks to the effects of social stigma that can arise from perceptions that

people associate with different groups and label through the process of social comparison. In general, a change in diagnostic terminology is not a novel concept. Many clinical terms have been altered over the course of the *DSM*'s history (e.g., Mental Retardation has been changed to Intellectual Disability; APA, 2013). However, unlike Intellectual Disability (a politically correct term used to replace the former pejorative label), ASD (which encompasses the word Autism) generally has a negative connotation in comparison to the AS term. Nevertheless, the removal of the AS, AD, and PDD-NOS terms in favour of ASD was intended to provide a unified language for stakeholders in the ASD community and a more accurate representation of the disorder given current research (APA, 2013a; Giles, 2014). While some participants welcomed the new term as it unites individuals under a single diagnostic category and eliminates the perceived 'elitism' associated with certain subtypes (such as AS), others felt that the change in terminology does more harm than good. In particular, some participants believe that the ASD framework subjects people on the spectrum to greater social stigma – for being categorized and grouped as a member of the autistic group (Kite et al., 2013; Linton, 2014).

Despite positive associations with the AS term, stigma tends to surface when the term is associated with AD or as being a part of the Autism spectrum (Linton, 2014). Although the term spectrum is meant to 'soft' the impact of the label, the public has been quick to condemn ASD as odd behaviour (Shtayermman, 2009). In general, stigma is defined as an attribute, reputation, or behaviour that is socially discredited whereby the individual is classified in an undesirable way (Shtayermman, 2009). According to Goffman's (1963) Theory of Social Stigma, when a 'disease' label is associated with an individual, the label itself can have the power to "spoil the sufferer's identity" both personally and socially (Goffman, 1963; p. 56-62). As such, the act of labeling can have negative consequences on an individual's self-esteem and can lead the person

to become isolated and withdrawn from social situations (Goffman, 1963). As such, a person can feel stripped of their old identity when a new identity is ascribed to them upon diagnosis of a mental illness (Goffman, 1963). Thus, the labeled individual will internalize this new identity along with the associated roles and expectations that accompany the disorder (Goffman, 1963) and stigmatization soon follows. Given that a person's self-esteem is closely tied to their social group (Tajfel & Turner, 1979), the removal of AS in favour of ASD may result in a decrease in the participant's self-esteem, especially if their social identity is comprised in part by the AS diagnosis (Hornsey, 2008; Stets & Burke, 2000). Thus, the individual may engage in downward social comparison whereby the qualities of the inner group (AS) are evaluated positively against the opposing group (AD; Stets & Burke, 2000; Tajfel & Turner, 1979). The typical outcome of this downward comparison is the outer group being deemed inferior to the inner group (Stets & Burke, 2000). As such, the inner group is able to maintain its social status and protect the self-esteem of its members (Hornsey, 2008; Stets & Burke, 2000; Tajfel & Turner, 1979).

Additionally, the effects of stigma at the individual level may be so great as to deter some individuals and families from seeking professional help. Specifically, participants claim that the negative connotations associated with ASD (e.g., the risk of shame, stereotyping, and exclusion from employment, schools, and social circles) outweigh the benefits of obtaining a formal diagnosis and/or seeking treatment (Coury, 2013; Kohn, Saxena, Lavav, & Saraceno, 2003; Punshon, Skirrow, Nurphy, 2009; Spillers et al., 2014). However, given that research suggests that early diagnosis and intervention can improve the future prognosis and overall quality of life for individuals with ASD (Spiller et al., 2014), the decision to abstain from seeking a formal diagnosis may also have negative consequences.

Similarly, the effects of stigma can be seen in the workforce and educational systems.

Discrimination against adults with ASD in these settings still occurs. Research suggests that the extent to which people with ASD are able to lead positive and fulfilling independent lives often depends on whether their talents and unique skills are nurtured in vocational contexts (Spiller, et al., 2014). Unfortunately, very few adults with ASD obtain employment despite their desire to do so (National Autism Center, 2009). Of those adults with AS or AD who are employed, approximately 80% do not hold full-time positions (Powell & Acker, 2016). The paucity of AS or ASD individuals in the workforce is not due to their lack of ability but rather results from their poor social reciprocity (which may hinder their ability to get and hold a job independently) and lack of acceptance by society (Young & Rodi, 2014). As such, many people with AS will enter federally defined poverty levels and may require social assistance programs to support themselves (Coury, 2013). Although the public generally perceives people with AS as "highly intellectual" individuals (which may be seen as an asset to many companies; Powell & Acker, 2016), some participants fear that employers will only see the diagnosis and not the individual (if grouped under the ASD category) which may result in their qualifications and abilities being overlooked. Likewise, participants also worry that the change in clinical terminology will negatively impact educators, administrators, and peers' perception of students with ASD.

Kesterson (2012) studied the effects of labeling and teacher knowledge of AD on attributions made about students with AD and concluded that teachers generally hold negative outlooks regarding a student's ability to obtain a high school diploma, hold onto a job for a reasonable length of time, and the student's overall adjustment level in learning of the diagnosis. Further, teachers rated students with ASD as having more disruptive behaviours in the classroom, which would require greater levels of supervision for the student to succeed in school (Kesterson, 2012). Thus, the perceptions that teachers' hold of a student with ASD may limit the

student's potential academically, particularly for students previously diagnosed with AS if grouped under ASD. Additionally, participants raised concerns regarding the educational placement of students with ASD, arguing that the adoption of an ASD category would result in students being placed in special educational classes that promote stigma and segregation. Relatedly, research indicates that students in these classes are more susceptible to self-fulfilling prophecies that can manifest as helplessness, lowered self-esteem, an inability to perform, and lowered academic performance (Barnes, 2008; Kelly & Joseph, 2000; Parsons & Kasari, 2013). Additionally, Shobo, Meharie, Hammer, and Hixson (2012) found that students in special educational classes reportedly felt ashamed about their classroom placement and would lie about what classes they were taking as they did not want other students to know. Thus, the inclusion of students with ASD in mainstream education may mitigate some of these effects. To understand why some people who suffer from a clinical label self-identify with their psychiatric labels, the following section offers a discussion around social identity.

Theme Four: Social Identity

The findings from Theme Four speak directly to the research questions, which sought to capture the participants' identity related to opinions regarding changes to the classification of ASD. Despite the removal of AS as a formal diagnosis, the decision by some participants to maintain their AS identity seems to have arisen from both an unwillingness to alter their identity and their reluctance to accept the ASD label. Charland (2004) has studied how people with mental health issues become attached to their psychiatric labels and claims that the loss of a clinical disorder can cause serious "harm" (p. 336), particularly "if a person already suffers from a disorder that implicates their identity," (p. 347). Specifically, the removal of a clinical disorder may "threaten" (p. 347) the identity of people who derive personal meaning from their diagnosis.

As noted in Theme One, many participants socially categorized themselves as being a part of the AS community because their social challenges matched those accounted for by the AS diagnostic criteria. However, their engagement with the AS community contributed to their identity formation. As participants accommodated new experiences (both positive or negative) into their sense of self, it led them to accept and derive personal meaning (Giles, 2014) from their diagnosis. Thus, AS was transformed from a label into a community (Coury, 2013; Scheff, 1974) whereby the social influence of the Autism community helped to cultivate a collective identity for its members. Commensurate with Stets and Burke's (2000) research, as participants' involvement in the AS community increased, so did their commitment to the group. Thus, group-identification may lead to greater commitment and less desirability for people to leave, even when the group's status is low (Hornsey, 2008; Stets & Burke, 2000; Stryker & Serpe, 1982). As such, participants believed that the AS community itself would continue to flourish and that people would continue to identify with AS irrespective of the scientific evidence to support the ASD framework. Particularly, some participants chose to retain their AS identity in part because they rejected the new diagnostic classification and did not self-identify with ASD. Theme Five offers a more in depth discussion of the topic.

Despite the strong support and acceptance of the *DSM-5* by many participants, only one individual fully surrendered his AS identity in favour of that afforded by ASD. According to Cass (1979), the process of internalizing a psychological identity can take several months if not years, which reflects the lifelong process that is AS (APA, 1994). Thus, it cannot be ascertained whether this participant had sufficient time to process what it meant to have AS given that he had only been diagnosed with AS a year prior to the *DSM-5* publication. The researcher postulates a possible relation between the length since diagnosis and a person's commitment and identity

with the label. Consistent with Stet & Burke's (2000) SIT research, people who received a diagnosis in early age tended to be more committed to their social group compared to people that were recently diagnosed. Thus, these individuals are more likely to self-identify and internalize their clinical disorder. Likewise, it is believed that the developmental changes associated with AS could also influence how a person socially categorizes and self-identifies with a particular group. Specifically, as AS symptoms manifests with age, a person may perceive him or herself as being more similar or different from the AS group thus altering the individual's identity. Unfortunately, the ability to address these questions more rigorously was beyond the scope of what the research could claim from the data and methods of this study. Nevertheless, most participants incorporated ASD into their current AS identity (considering themselves as a person with ASD with AS falling under that umbrella). This reluctance to give up their diagnosis reflects the participants' neutral/mixed view of the ASD framework. As previously noted, participants who perceive AS and AD as homogenous disorders will socially categorize the two disorders within the same group, namely ASD. However, given that ASD encompasses the previous diagnostic subtypes, participants were less compelled to identify with ASD over AS, choosing instead to identify by both terms. This mixed reaction highlights the complexity of diagnostic labels, which rarely are neatly assigned to one social identity (Singh, 2011). Thus, by embracing both terms, participants are afforded the flexibility to interchange between labels to protect their social identity and self-esteem from potential stigma and/or discrimination from society (Linton, 2014).

Lastly, in light of the reclassification of PDD, the identity of a small group of participants was not tied to AS, AD, or ASD. Rather, these individuals identified with their personal identity or another social group more strongly. According to SIT research, personal identity is the lowest

form of social identity as social categories precede individuality (Hornsey, 2008; Tajfel & Turner, 1979). Thus, to understand why an individual's personal identity would be most salient, the researcher draws on Och's (1993) construction of a social identity. In her research, Ochs (1993) suggests that a "failure to establish a social identity may not be due to an individual's lack of understanding about a disorder but rather a lack of how a community's behaviours and attitudes are conventionally related to a particular social identity," (p. 291). Thus, a failure to understand how the values and beliefs of the AS or ASD community are analogous to their social identity, or how the values and beliefs of the group run counter to theirs, may result in participants not identifying with the in-group. Thus, the loss of AS as a clinical disorder stripped the identity of some participants resulting in an identity crisis. Given that an ASD identity was not taken up by this group of participants, there is potential for no change to occur or for another social identity to take its place. However, participants must first come to terms with the loss of AS. Thus, it may take months if not years for before a new identity is adopted. Taken together, the information from this subtheme revealed how the participants self-identified when faced with the loss of a diagnosis. Although the changes to the classification of ASD were well intended, they challenged the identity of an entire community.

Theme Five: Opinions Regarding the Reclassification of PDD and ASD

In general, the formation of opinions remains poorly understood. Although many mechanisms (including a person's experiences, understanding, and beliefs) are at play in the formation of one's opinion, Moussaid, Kammer, Analytis, and Neth (2013) concluded that "individuals adapt their opinions, revise their beliefs, or change their behaviour as a result of their social interactions with other people" (p. 2). In other words, people filter and integrate the information they receive through their interactions and experiences with others by adjusting their

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own beliefs accordingly (Hacking, 2007). The findings from Theme Five reveal the participants' thoughts regarding the change in classification of ASD.

Hornsey's (2008) review of SIT and Self-Categorization Theory suggests that people will adopt the beliefs and attitudes consistent with the group upon identification with their inner group. The current research supports this assertion given that participants who self-identify with AS also rejected ASD when the framework did not align with the values of the AS community. Specially, these participants believe that AS is a distinctive disorder that is separate from the other diagnostic subtypes. Moreover, Wu and Huberman (2004) studied the interaction between social structure and opinion formation and found that the judgments of people who share similar opinions tends to strengthen after interacting with other members of the same group. The findings from the current study support Wu and Huberman's (2004) findings such that participants who self-reported as being actively involved in the AS community (i.e., online, organizations, or social groups) described having stronger assumptions and beliefs against the *DSM-5* when compared to others less involved. These individuals were particularly upset because the APA altered the classification of PDD without first consulting the AS community (although it could be argued that changes to the *DSM-5* were posted online for public commenting) as their decision has a direct effect on the AS population. Additionally, participants rejected the *DSM-5* revisions for fear that the changes to the ASD criteria would somehow mean a loss of benefits, a denial of services, a potential loss of an AS identity, and increased stigmatization. Theme Six addresses this topic in greater detail.

In contrast, a subset of participants supported the changes in the *DSM-5* and embraced the ASD framework. Consistent with SIT, people who socially identify with ASD will likely support the reclassification PDD as the new diagnostic framework aligns with the values of the

ASD group. Specifically, these participants believe that AS and AD are homogenous disorders, and the differences between them are minor. Although participants acknowledge that some individuals with PDD may "fall through the crack" (P3) using the *DSM-5's* criteria for ASD, they generally believe that the new diagnostic system is a better and more accurate way of classifying autism related disorders based on the current literature on ASD. Thus, accepting the *DSM-5's* ASD diagnosis hinges upon the belief that unifying the individual subtypes benefits the ASD community (i.e., greater accuracy, more inclusion amongst the community, and increased access to services).

Lastly, a group of participants hold neutral/mixed views about the *DSM-5* and changes to the classification of ASD. Despite understanding the APA's decision for change, this group of participants expressed apprehension about the application and impacts the change in classification and terminology could have on the ASD community. According to Levada (1993), knowledge and opinion do not necessarily equate to the same thing. Thus, regardless of evidence suggesting that ASD may be a homogenous disorder, participants continue to hold certain beliefs about the heterogeneity of the diagnostic subtypes, known as belief perseverance (Anderson, 2007). Nevertheless, this group of participants argue that the individual terms (AS, AD, and PDD-NOS) still have clinical utility for providing a language to describe a particular presentation that might not be captured in *DSM-5* and that these "labels are useful because they can point to more suitable intervention treatments for children" (Williams et al., 2007; p. 109). As such, these participants insist that both terms co-exist on the spectrum, which provides further evidence of their mixed opinions about ASD.

Theme Six: Barriers to Service Provision and Funding

The final theme, Barriers to Service Provision and Funding, was an area of contention for

participants. Specifically, changes to the *DSM-5's* ASD criteria may result in a reduction/loss of

services whereby members of the AS community may be deprived of valuable supports and/or

services if grouped under ASD (Coury, 2013). While it could be argued that people with AS are

high functioning individuals who do not require services, their social and RRB challenges impact

several areas of their lives including their ability to get and keep jobs, achieve academically,

access services, and develop meaningful relationships. Overall, the participants identified four

barriers to service provision and funding: meeting the diagnostic criteria for ASD, the limited

services and resources for the adult ASD population, challenges within the education system, and

the future ASD research.

One major concern of participants was whether members of the AS community would

meet diagnostic criteria for ASD given their mild symptomatology. Specifically, researchers

found that 20-30% of people previously diagnosed with AS will not meet the *DSM-5's* stringent

ASD criteria (Matson, et al., 2012; McPartland et al., 2012; Wilson et al., 2013; Worley &

Matson, 2012) which is troubling given that access to government funding and services is often

contingent upon the diagnosis of a clinical condition. Hence, the diagnostic changes have real

implications on the lives of individuals who do not meet the full diagnostic criteria (Clarke &

Van Amerom, 2007; Coury, 2013; Grant, & Nozyce, 2013). Given the lack of clear evidence to

suggest that AS and AD are homogenous disorders, critics argue that denying services, funding,

treatment, and tax credits to some individuals while providing a full range of services and

interventions to others on the spectrum is unethical - particularly if the differences between the

subtypes cannot be distinguished validly and/or empirically (Clark & Van Ameron, 2007; Coury,

2013; Grant & Nozyce, 2013). Additionally, participants fear that grouping people under the

broader spectrum may interfere with clinicians' abilities to understand the unique challenges and

needs of each individual, which can affect the types of services clinicians prescribe to patients. Therefore, it remains to be seen how service providers and diagnosticians will utilize the ASD criteria in their clinical work (Coury, 2013).

Another area of contention is the lack of resources and treatments available to the adult ASD population. Across Canada, the majority of ASD-related services and funding are allocated based on the needs of families and children (Dymond, Gilson, & Myran, 2007; Lamb & Murphy, 2013). For instance, in Alberta, a child with disability may receive up to $60,000 annually towards an intensive therapy of choice (Alberta Human Services [AHS], 2015). This program is offered through the Family Support for Children with Disabilities program. Children with special needs are eligible to participate until they are 18 years of age. However, upon reaching the legal age, they no longer qualify for this service (AHS, 2015) despite the presence of persistent and sustained challenges in adulthood. Although adults with ASD may apply for further provincial funding through Persons with Pervasive Developmental Disabilities (PDD; for persons with an IQ <70) or Assured Income for the Severely Handicapped (AISH; for persons with a disability in need of financial support; AHS, 2015), many individuals with AS do not qualify because of their high functioning level. Thus, the findings speak to the participants' impressions that more services are needed for the adult AS population. For without these supports, adults with AS may become further isolated and marginalized by society due to their social challenges.

Participants also identified challenges with the educational setting as a barrier to service provision. The number of students with AS in higher education has grown significantly in recent years, a trend that is anticipated to continue (Humphrey & Lewis, 2008). While schools and universities may have academic supports in place to assist individuals on the spectrum (Beardon,

Martin, & Woolsey, 2009; Humphrey & Lewis, 2008; Parsons & Kasari, 2013), these supports

often do not fully address the range of issues that students with AS face. In Alberta, school-aged

students diagnosed with AS are given an Individualized Program Plan that outlines their areas of

need and the provisions required to address his or her challenges (Alberta Education, 2006).

However, participants fear that the change in diagnostic criteria for ASD would somehow impact

the services and supports that students receive. Although the *DSM-5's* Neurodevelopmental

Disorder Workgroup insists that individuals previously diagnosed with PDD-NOS will not be

required to be re-evaluated for ASD under the guidelines (APA, 2013a), there have been reports

of insurance companies and school districts requesting students to do so (Autism Speaks, 2014).

Further, Parsons and Kasari (2013) examined some schools at the Center of Educational

Research in Autism and discovered that schools legally are not required to provide students with

special accommodations without confirmation of a formal diagnosis. Thus, if a student is

required to obtain a re-evaluation and fails to meet diagnostic criteria for ASD (despite being

previously diagnosed with AS), he or she may risk losing services (Parsons & Kasari, 2013).

Lastly, participants questioned how the changes to the ASD diagnostic criteria would

impact the future ASD research. Given the heterogeneity of people on the autism spectrum,

participants suspect that researchers will narrow their area of focus to study a specific subgroup

of ASD. This belief stems from the concept that people in the same subgroup are more

homogenous (in terms of their symptomatology and behaviours) than the ASD population as a

whole. Unfortunately, participants were uncertain as to how researchers would make such a

distinction given the removal of the subgroups. One approach would be to differentiate

individuals based on severity level. However, this approach raises issues surrounding cutoffs.

Perhaps a better approach to studying ASD is to analyze individuals based on biological markers

as opposed to disorders or behaviours. One supporter of this method is Tom Insel (2013), the

former director of the National Institute of Mental Health (NIMH). In his blog, he publicly

stated that the NIMH would be "re-orienting its research away from DSM categories" (para. 5),

because he believes that the diagnostic process should be based on concrete biological,

neurological, and genetic markers as opposed to behavioral observations (the current practice in

the *DSM-5;* Insel, 2013). Although the etiology for ASD is still unknown, the use of biological

markers coupled with the advances in technology would not only provide a larger sample size,

thus improving the generalizability of the findings, it would also reflect a future direction in ASD

research (Wilson et al., 2013). Overall, the decision by the APA to adopt a unitary diagnosis was

intended to support the service industry in making access to assistances easier for all (APA,

2013a). The findings from the current study indicate that further attention is required to

overcome the challenges to research and service provision. Recommendations to address some

of these issues are presented in the Future Direction section.

Limitations

The current study is not without its limitations. First, the researcher acknowledges the

restricted sample size. Although the sample was small, the current study concerned itself with

meaning rather than testing generalized hypothesis statements where statistical power may be of

concern. Hence, the sample size was large enough to ensure that most perceptions were

uncovered, but not so large that the data became repetitive (Braun & Clark, 2006). Thus, the

same size was determined through the process of saturation (Glaser & Strauss, 1967) – the point

at which the inclusion of additional data did not reveal new information about the study.

Second, a self-selecting sample (of participants self-identifying as having AS) was

utilized thus creating the potential for selection bias. Likewise, given the sample was

purposively drawn, it may not accurately represent the opinions and experiences of all members of the AS community. Although participants were required to provide documentation of their AS diagnosis, no independent assessment was conducted to confirm the validity of their diagnostic claims. This decision was based on the primary interest of the study, which was to explore the opinions associated with a loss of AS a clinical disorder rather than the opinions associated with having AS and through consultation with the researcher's supervisory team. However, given that the sample was recruited from AS- and AD-related community organizations, the researcher believes that the participants accurately self-identified.

Third, the generalizability of the findings was limited given the qualitative, exploratory nature, and regionally-based sample of the study. Thus, the findings may not be generalizable to the wider population. Although the findings are context bound, they are intended to provide readers with an in depth understanding into the opinions of adults with AS regarding the change in classification of disorders.

Fourth, though the use of semi-structured interviews has many advantages (i.e., allows for further querying and clarifications of participant responses), it also has several disadvantages. For instance, despite following an interview protocol, the researcher acknowledges that the wording, prompts, and order of each question were not delivered identically to each participant. Such an approach would have hindered the flow and rapport that the researcher established with the participants. Likewise, given that people with AS may have difficulties with introspection and describing their thoughts and feelings (McPartland & Klin, 2006), a semantic approach was adopted as the participants' ability to fully articulate and express their opinions may be limited.

Fifth, given the hallmark features of AS (i.e., impaired social interactions and social communication; APA, 1994), some interviewees found the open-ended format of the questions

challenging to answer. This difficulty was further compounded by to the social-interactive aspect of the face-to-face format of the interview that may have left participants feeling uncomfortable about disclosing personal thoughts and opinions with the researcher. Although paper and pen questionnaires may have alleviated this discomfort, this approach would have restricted the researcher's ability to ask the interviewees additional questions for further clarification.

Sixth, participants may have been susceptible to social desirability bias, which is the tendency for a person to respond in a way that he or she thinks the researcher expects to hear, and/or is deemed socially acceptable (Jacob & Furgerson, 2012). Being cognizant of this issue, the researcher attempted to mitigate its effects by asking straightforward questions free of presumptions and by maintaining a neutral body language.

Seventh, although it could be argued that the participants' experiences living with AS, involvement within the AS community, and understanding of the diagnostic subtypes and ASD likely impacted their opinions and reactions to the *DSM-5*, the researcher was unable to discern the quality of these experiences due to the semantic (i.e., identifying explicit and surface meanings based on the participants' responses) nature of this study. Likewise, the researcher was unable to evaluate how participants' culture and background shaped their responses to questions given the semantic nature of the study. Thus, cultural differences and participants' backgrounds should be taken into consideration when interpreting the current study's findings.

Eighth, a limitation of TA is its inability to "retain a sense of continuity and contradiction through any one individual account," (Braun & Clark, 2006). Hence, the researcher was unable to check for inconsistencies across individual responses due to the amalgamated data corpus.

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Ninth, although no participant formally lost their AS diagnosis due to a re-assessment for ASD, participants had strong opinions regarding the loss of a clinical disorder and invalidation of a community. Given that it can take months if not years for a person to mourn the loss of a clinical disorder and to adopt a new identity (Case, 1797), a replication of the current study is needed to assess whether there will be a shift in how members of the AS self-identify.

Lastly, the researcher acknowledges the impact that personal bias can have on the methodology of choice, data collection, and analysis of data. Hence, the author took pre-cautionary measures to minimize its effects (as outlined in Chapter 3) including the use of a second coder and consultation with her supervisory team as an additional peer auditing. Despite the limitations of the current study, the results have significant implications for research, intervention, and service provision that will be discussed in the following section.

Implications

Diagnostic labels are an essential part of the diagnostic process and serve an important purpose in research, advocacy groups, and empirically valid intervention programs (Ohan, Ellefson & Corrigan, 2015). Thus, the findings from the current study have practical utility for individuals, families, and clinicians as it can shed light on the loss of a clinical disorder. In general, the change in diagnostic terminology can result in an identity crisis for those whose identity social was strongly influenced by their AS diagnosis. Specifically, under the new ASD framework, members of the AS community may be subjected to higher levels of negative stigma for being grouped under the ASD category (Ohan et al., 2015) which has implications for a person's emotional well-being, self-esteem, and outlook on life (Singh, 2011). Additionally, the change in diagnostic criteria can have profound consequences for high functioning individuals who may be at risk for losing access to services and funding because of their mild presentation

(Coury, 2013). Moreover, the change in clinical terminology and diagnostic criteria may come at the cost of self-disclosure and identification for some people. Although, the decision to adopt an ASD diagnostic framework was well intended, it deprives people who would have met the diagnostic criteria for AS the potential to identify with the AS community. Consequently, some individuals diagnosed with ASD after 2013 may not experience the same sense of belonging as those who identify with AS and may be left feeling lost about their place in society. However, it could be argued that a new ASD community will develop, filling the same need and/or purpose for these individuals.

Overall, the findings from this study have important implications for professionals including health-care providers, health insurers, researchers, organizations, and educational providers. The findings provide a basis for understanding how a change in clinical terminology and diagnostic criteria can affect an entire community, including the identity of its members. Despite AS being formerly identified as a lifelong disorder with challenges persisting well into adulthood (APA, 2000), there is the potential for people diagnosed with AS to be stripped of the necessary services they require to function on a daily basis. It will be interesting to see how service providers and policy makers adapt to the new changes in the classification of ASD. Recommendations for future directions are presented below.

Future Directions

Given the paucity of research on social-identity and ASD (Bagatell, 2007; Brownlow & O'Dell, 2006), the current findings will add to the limited body of literature and provide a basis for future areas of research. A longitudinal study is necessary to evaluate the long-term effects of changes in the diagnostic classification at the individual and community level and to determine whether people formerly diagnosed with AS will adopt an ASD identity with time.

Additionally, the limited resources available to the adult ASD population suggests that further research is needed to develop new interventions and treatment programs to support the needs of this group of people. Further independent studies are also necessary to explore the validity and specificity of the ASD diagnostic criteria as researchers have found that a small percentage of people formerly diagnosed with AS do not meet the diagnostic criteria for ASD (Matson et al., 2012). Moreover, given that psychological labels (including ASD) are associated with discrimination, prejudice, and harassment (Goffman, 1963), labeling researchers should consider designing a stigma prevention program to minimize these effects (Ohan et al., 2015). Relatedly, researchers are encouraged to develop an ASD awareness program to educate the public and ASD community of the individual differences across the spectrum (DeLustro, 2013; MacLeod, Lewis, & Robertson, 2013; Mann & Himelein, 2008). Specifically, a greater awareness of ASD may promote acceptance of the disorder by the AS community and the public by reducing the level of stigma that society associates with the disorder. Similarly, greater education on the importance of diversity and the benefits of employing people with a disability may increase the number of people with AS who are employed.

Although there are a limited number of programs dedicated to creating employment opportunities for people on the ASD spectrum (Hendricks, 2010), there remains a shortage of appropriate vocational services for people with AS or ASD (Coury, 2013). While some accommodations may need to be put into place, according to the U.S. Department of Labour Job Accommodations Network's annual report (Loy, 2016), "such workplace accommodations are low cost and can positively impact the workplace," (para. 12). Lastly, future research should devise a model for helping people on the spectrum come to terms with their disorder and process what it means to be diagnosed with ASD. Specifically, evidence suggests that the process of

internalization can help an individual to make sense of his or her past challenges, engender a brighter outlook about one's future, and cultivate a sense of belonging to the person's community (Giles, 2014) - all factors that can promote a positive social identity.

Final Thoughts and Conclusion

Overall, the primary interest of this study was to explore the opinions of adults with AS regarding the reclassification of PDD and their thoughts related to the identity terms (AS, AD, and ASD). While some participants support the unification of PDD into a single diagnostic category, others are less inclined to give such support. Specifically, the adoption of the ASD framework created a sense of invalidation for some participants who self-identified according to an AS diagnosis. Given how deeply the AS diagnosis is entrenched in the AS culture, its removal in the *DSM-5* has significant implications for a community that also identified with the disorder (Singh, 2011). Although the APA claims that people in receipt of an AS diagnosis will be grandfathered into the new ASD diagnosis and that individuals with a history of this diagnosis will not automatically lose their diagnosis or be required to be re-evaluated under the new criteria, it is the invalidation of an AS culture, loss of an identity, and way of being that was the central focus of this study. As participant nine explains, "it's not a matter of *what was done* but rather *what the diagnosis meant"* and the hurt that was caused that is of utmost importance.

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Table 1.

DSM –IV-TR (American Psychiatric Association, 2001; p. 75) diagnostic criteria for Autistic Disorder.

Autistic Disorder

A. A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):
    (1) Impairment in social interaction, as exemplified by at least two of the following:
        (a) Poor use of multiple nonverbal behaviours including eye contact, facial expression (e.g., no social smile), body posture (e.g, facing respondent with their back) and limited use of proximal and distal gestures (e.g., waving and nodding) to regulate social interactions
        (b) Difficulty developing peer relationships appropriate to developmental level (e.g., prefers the company of adults or much younger children, prefers to spend time alone)
        (c) Lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (i.e., limited motivation to show, bring, or point out objects of interest)
        (d) Poor social or emotional reciprocity (e.g., difficulty with social empathy and identifying feelings)
    (2) Impairment in communication as evident by at least one of the following:
        (a) Significant delays or lack of acquired language (not accompanied by an attempt to compensate through other forms of communication such as gesture or mime)
        (b) Individuals with speech may have difficulty initiate and/or sustaining a conversation
        (c) Stereotyped and repetitive use of langue or idiosyncratic language may be present (e.g., repetitive use of favourite phrases from a video, echolalia, rote phrases out of context)
        (d) Lack of varied, spontaneous, make-believe play or social imitative play commensurate with developmental level
    (3) Restricted repetitive and stereotyped patterns of behaviour, interest, and/or activities as indicative of:
        (a) Preoccupation with one or more stereotyped and restricted patterns of interest that is atypical in intensity or focus (e.g., so great that it is difficult to transition to another topic, activity or toy)
        (b) Inflexible adherence to specific, nonfunctional routines or rituals (e.g., strong desire to have objects and situations ordered in a way with which they are familiar)
        (c) Stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole body movements such as spinning)
        (d) Preoccupation with parts of an object (e.g., playing with wheels, switches, or knobs)

B. Delays or abnormal functioning in social interactions, language as used in social communication, and/or symbolic or imaginative play with onset prior to the age of three years
C. Disturbances are not better accounted for by Rett Disorder or Childhood Disintegrative Disorder
Note: The information summarized in the table above has been paraphrased

Table 2.

DSM –IV-TR (American Psychiatric Association, 2001; p. 84) diagnostic criteria for Asperger Syndrome

Asperger Syndrome

A. Marked impairment in social interaction, as exemplified by at least two of the following:
    (1) Limited use of multiple nonverbal behaviours including eye-to-eye contact, unusual facial expression, body and gestures to regulate social interactions may be somewhat clumsy
    (2) Difficulty developing peer relationships appropriate to developmental level (e.g., trouble relating with others)
    (3) Limited or lack of spontaneous seeking to share enjoyment, or achievements with other people
    (4)   Poor social or emotional reciprocity

B. Restrictive repetitive and stereotyped patterns of behaviours, interests, and activities as indicative of at least one of the following:
    (1) Consuming preoccupation with one or more stereotyped and restricted patterns of interest that is atypical in intensity or focus
    (2) Strict or inflexible adherence to specific, nonfunctional routines or rituals (e.g., difficulty with transitions)
    (3) Stereotyped and repetitive motor mannerisms (e.g., knee bouncing, or finger twisting)
    (4) Persistent preoccupation with parts of an object (e.g., fixation on door handles)

C. Disturbance causes clinical significant impairment across multiple areas of functioning (e.g., social, occupational, or school)
D. No clinical significant delay in language (e.g., single words used by age two years, communicative phrases used by age three years)
E. No clinically significant delay in cognition or in the development of age-appropriate self-help skills, adaptive behaviour (other than in social interaction), and/or curiosity about the environment in childhood.
F. Disturbance not better accounted for by another specific Pervasive Developmental Disorder or Schizophrenia
Note: The information summarized in the table above has been paraphrased.

Table 3.

Changes between DSM-IV-TR (APA, 2001) and DSM-5 (APA, 2013a) on the diagnostic criteria for Autism Spectrum Disorder.

DSM-IV-TR	DSM-5
Rett Disorder considered as one of five autism related conditions	Rett Disorder has been eliminated because it is considered a genetic mutation (the DSM is about behaviours and not etiology).
Four distinctive disorders: a. Autistic Disorder b. Asperger Syndrome c. Childhood Disintegrative Disorder d. Pervasive Developmental Disorder-Not Otherwise Specified	These four disorders have been amalgamated to form the all-encompassing Autism Spectrum Disorder category
Triad of core symptoms: a. Impairments in social interactions b. Impairments in communication c. Repetitive and restrictive patterns of behaviours or interests	Impairments in social interaction and communication have been unified to form dyadic core symptoms: a. Deficits in social interactions and communication skills b. Repetitive and restrictive patterns of behaviours or interest
Severity levels were not available	The inclusion of severity specifiers (Level 1 "Requiring support," Level 2 "Requiring substantial support," and Level 3 "Requiring very substantial support)
Unusual sensory behaviours was not an inclusionary criterion	Unusual sensory behaviours is listed as a criterion
Social Communication Disorder	Social Communication Disorder introduced to reflect individuals with social communicative impairments but without RRB

Table 4.

Severity level for ASD (APA, 2013a; p. 52).

Severity Level for ASD	Social Communication	Restricted interest and repetitive behaviours
Level 3 – "Requiring very substantial support"	Severe deficits in verbal and non-verbal social communication skills causing severe impairments in functioning, very restricted initiation of social interaction, and minimal response to social overtures from others.	Inflexibility of behaviour, extreme distress coping with change, and/or other restricted repetitive behaviours that cause significant impairment across multiple functioning areas. Pervasive distress/difficulty changing action or focus.
Level 2 – "Requiring substantial support"	Persistent deficits in verbal and nonverbal social communication skill; social impairments are evident despite supports received; limited initiation of social interactions; and diminished or atypical responses to social overtures from others.	Inflexibility of behaviour, difficulty adjusting to change, or the frequency of restricted/repetitive behaviours become apparent to the casual observer and interferes with functioning within a variety of contexts. Changing focus or action can be distressing/difficult
Level 1 – "Requiring Support"	Impairments cause noticeable deficits in social communication without supports in place, significant impairments in the ability to initiate social interactions, clear examples of atypical or unsuccessful responses to social overtures from others, markedly decreased interest in social interactions.	Inflexibility of behaviour causing significant interference with functioning across multiple contexts. Difficulty transitioning between activities, and with organization and planning that can limit independence.

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

Table 5.

DSM – 5 (American Psychiatric Association, 2013; p. 50) diagnostic criteria for Autism Spectrum Disorder.

Autism Spectrum Disorder
Currently, or by history, must meet criteria A, B, C, and D:

A. Continued deficit in social communication and social interaction across multiple contexts. Examples include:
      (1) Poor social-emotional reciprocity, which may include atypical social behaviour, a lack of typical back-and-forth conversation; decreased sharing of interests, emotions, or affect; and difficulty initiating or responding to social interactions
      (2) Deficits in nonverbal communicative behaviours during social interaction as indicative of an impaired integration of verbal and nonverbal communication; atypical eye contact, body language, gestures use and comprehension; and an absence of facial expression and/or nonverbal communication
      (3) Impairments in the development, maintenance, and understanding of relationships as exemplified by challenges with adjusting behaviour to align with various social contexts; sharing, imaginative play, making friends and/or a lack of interest in peers

B. Restricted, repetitive patterns of behaviour, interests and/or activities. Examples include:
      (1) Stereotyped or repetitive motor movements (e.g., simple motor stereotypies - hand or finger flapping), use of objects (e.g., lining up of toys), or speech (e.g., echolalia or idiosyncratic phrases)
      (2) Insistence on sameness (e.g., need to take same route or eat same food every day); inflexible adherence to routines (e.g., extreme distress at small changes, or difficulties with transitions); ritualized patterns of verbal or nonverbal behaviour (e.g., greeting rituals); inflexible or rigid thinking patterns (e.g., difficulty with abstract concepts)
      (3) Restricted, fixated interests that are atypical in intensity or focus (e.g., robust attachment to or strong preoccupation with unusual objects or interest)
      (4) Hyper-or hypo-reactivity to sensory stimuli or exhibiting atypical interest in sensory aspects of the environment (e.g., Seemingly indifference to pain/temperature, adverse response to particular sounds or textures, atypical touching or smelling of objects, and visual fascination with lights/ movement).

C. Symptoms are present in the early developmental period (but may not become apparent until social demands exceed limited capacities and/or may be masked by coping and learned strategies in later life).
D. Symptoms must cause clinically significant impairment across multiple areas of functioning (e.g., social, occupational, or school).
E. Symptoms are not better accounted for by global developmental delay or intellectual disability (ID). Autism Spectrum Disorder and ID are commonly co-morbid of which social communication should be lower than the expected typical developmental level
Note: The information summarized in the table above has been paraphrased.

Table 6.

Descriptive Information about Participants

	N	Range	Mean	Std. Deviation
VIQ	12	91 to 129	110	10.944
PIQ	12	96 to 143	115	14.859
FSIQ	12	96 to 135	113	12.004
Chronological Age	12	23 to 58	36.5	12.25
Age at Diagnosis	12	4 to 55	24.0	7.5
Length since Diagnosis	12	1 to 23	8.0	18.0

Note: Participant age presented in years format. VCI, PIQ, and FSIQ scores from the WASI-II are presented as standard score

Table 7.

Data Extract, with codes applied (illustration of coding line by line)

Participant	Data Extract	Codes	Theme
1	I don't mind it [being grouped with AD] for the most part because I've been very open anyways and a lot of the people I've kind of had to explain Aspergers anyways and I've always explained it with autism. Before the merger because it was a lot easier for some people to understand when I'm explaining it, so to me it doesn't really matter.	1. Accept *DSM-5* 2. Explain AS in relation to ASD	Opinions and Reaction to loss of clinical disorder and *DSM-5*
2	"I've read about that [people with AS] have average to above average intelligence, their verbal capacity is also above average intelligence and what else. [Pause] Hmm… That [AS] has been on the rise [and] that a lot more people that were diagnosed [when it was] introduced in the 1994 DSM manual."	1. Understanding 2. AS features 3. Prevalence has been on the rise 4. AS introduced in DSM in 1994.	Knowledge and Understanding
2	It is more confusing now that you know we are all grouped under the ASD thing cuz I guess before when you have Asperger treatment you do this one and treatment. Where for the other Autism group you do the other treatment. But now they are lumped all together, they probably face the same treatment and its probably less effective for [everyone]. So what I'm trying to say is lumping everyone together under one giant thing may it doesn't respond to the specific needs of the group you know.	1. Efficacy of Treatment • Less effective under ASD	Barriers to Service and Funding
9	"I refuse to let go of my name. I fought hard to get it. I suffered years to finally get that answer. I will not let go of my answer. I am very proud of my Asperger syndrome because it has given me enormous gifts. It has given me a lot of challenges and a lot of rough times in life, but its also given me a lot of gifts that I will not give up. "	1. Maintain AS identity 2. Provided many answers 3. Enormous gifts 4. Experience - challenging	Social Identity

Table 8.

Definition of the Primary Themes and Subthemes

| Theme	Definition
1. Derived meaning from their experiences with the disorder	Participants' experience of living with AS (both positive and negative) as they derive meaning from their diagnosis.
2. Knowledge and Understanding about AS, ASD, and *DSM-5*	The variable degree to which participants could demonstrate knowledge and understanding about AS, ASD and *DSM-5*.
3. Perceptions associated with labels	The perceptions society associates with the AS, AD, and ASD terms and the way in which participants handle the connotations attached to the respective labels.
4. Social Identity	The manner by which participant's self-identity given the challenge to their AS social identity.
5. Opinions regarding the reclassification of PDD and ASD	The varying opinions and reactions to the loss of a clinical disorder and the adoption of the ASD framework.
6. Barriers to Funding and Service Provision	The perceived challenges and difficulties that occur in the provision and access to services for those with AS including education, treatment, employment, and research.
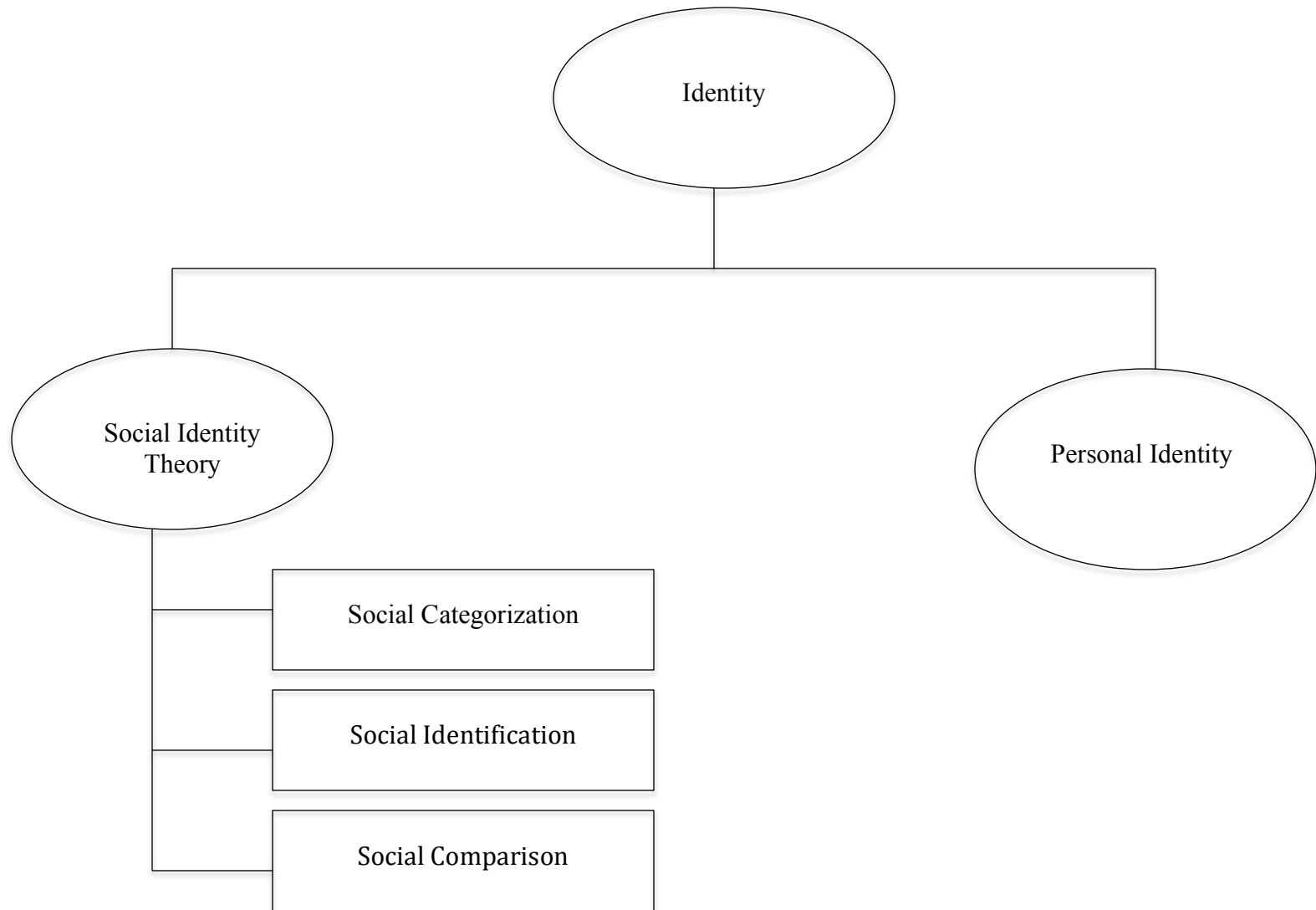
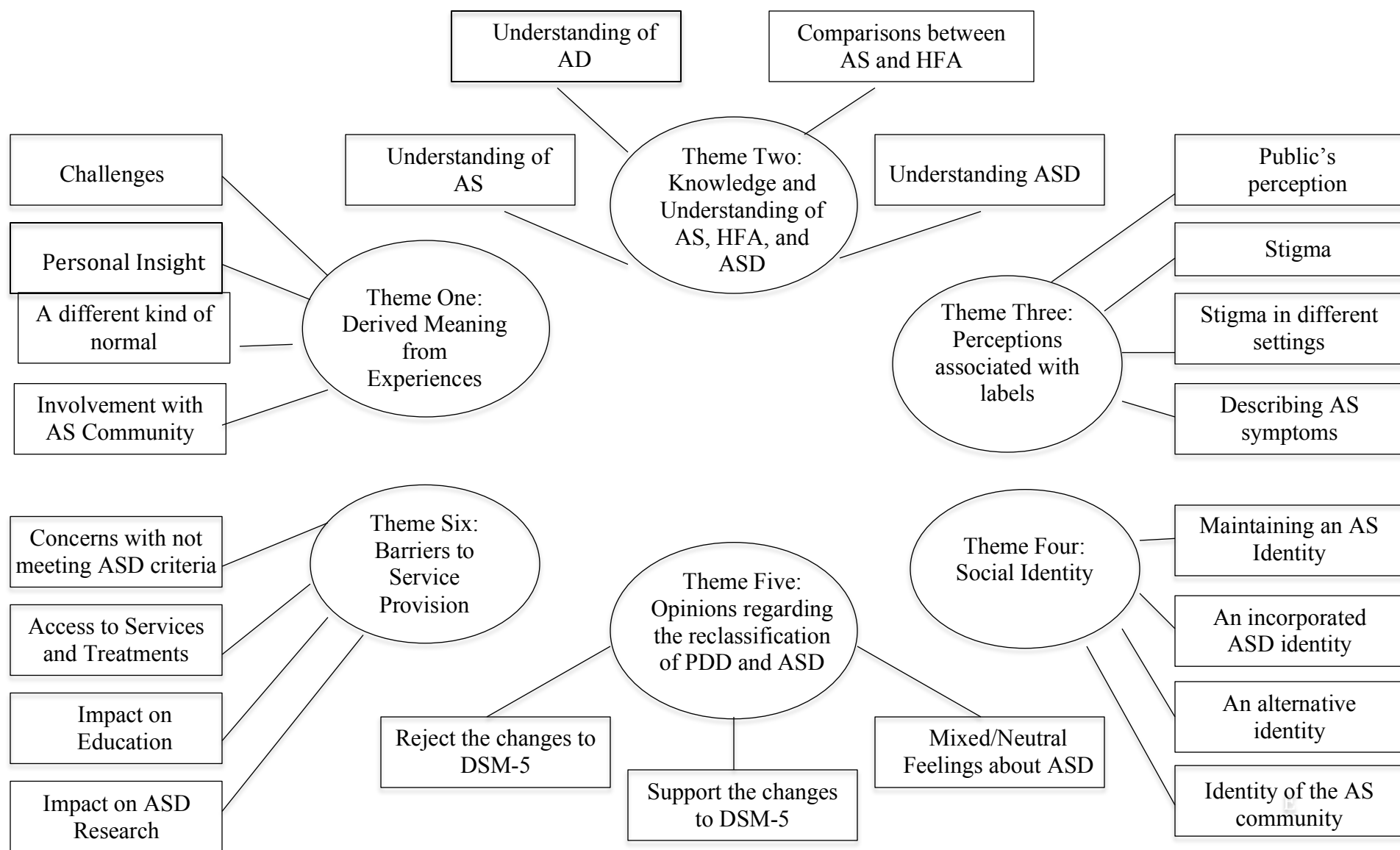Figure 1: *Identity as a theoretical framework*

Figure 2: *Thematic Map showing primary and secondary themes*

Contact Information

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

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With the release of the recent Diagnostic Statistical Manual of Mental Disorders (5th ed.), Asperger's Syndrome (AS) is no longer clinically recognized as a distinct disorder, and has been categorized into a new Autism Spectrum Disorder diagnostic criterion.
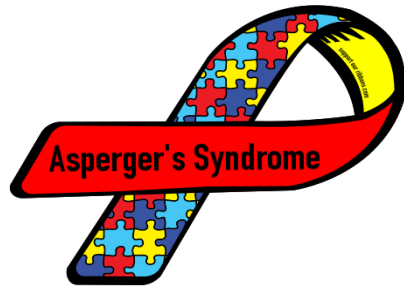

UNIVERSITY OF CALGARY

Perspectives of the Changing Nature of Asperger's Syndrome
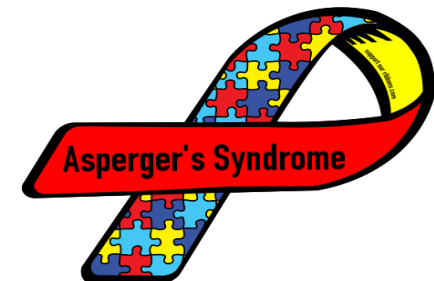
Our Study

- The aim of this study is to explore the opinions of individuals with Asperger's Syndrome on the changing nature of the disorder using thematic analysis.

- To date, this topic has been ignored in the research literature.

- Findings from this study will provide professionals a more in depth understanding of the potential implications that may accompany the loss of a clinical diagnosis.

What will I be asked to do?

- You will be invited to participate in an approximately 30 minute interview.

- This interview will be audio-recorded for the purpose of being transcribed to text at a later time.

- Themes embedded within the collective interviews will be identified and analyzed for the purpose of this research. All identifying information will be removed.

- Participation in this is completely voluntary.

Risks & Benefits

RISKS: participants may experience psychological distress and discomfort in discussing their opinions of the changing nature of Asperger's Syndrome.

BENEFITS: understanding of their self-identity, avenue to voice their concerns, develop a deeper understanding into the potential implications accompanying the loss of a clinical diagnosis, provide a basis for future research.

UNIVERSITY OF
CALGARY

Name of Researcher, Faculty, Department, Telephone & Email:

Ms. Stephany Huynh, B. Sc., Faculty of Education, Werklund School of Education

Supervisor:

Dr. Adam McCrimmon, School and Applied Child Psychology; and
Dr. Tom Strong, Counselling Psychology; Faculty of Education, Werklund School of Education

Title of Project:

The loss of Asperger Syndrome: An exploration of its effects on self-identity

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

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

Purpose of the Study

Asperger Syndrome (AS) is a clinical term previously used to describe a person with a neurodevelopmental disorder characterized by persistent deficits in social communication and social interactions in conjunction with restrictive, repetitive, stereotypic patterns of behaviors and interest (American Psychiatric Association [APA], 2000). However, given the recent release of the Diagnostic and Statistical Manual of Mental Disorders (5th ed.; DSM-5; APA, 2013a), AS is no longer clinically recognized as a unique disorder, and is instead grouped into a new Autism Spectrum Disorder (ASD) diagnostic framework. While many professionals have challenged the imposed changes (Tryon, Mayes, & Rhodes, 2006; Wing, Gould, & Gillberg, 2011), ultimately the removal of AS signifies the loss of a diagnostic category. Although the transition in clinical terminology was based upon scientific evidence indicating that the unification of the previous diagnostic terms was warranted, the change in terminology may have a negative impact for individuals with AS whose self-identity is comprised in part by the diagnosis. Given the possible noisome psychological consequences associated with the loss of one's identity (Charland, 2004), the aim of this study is to investigate the perspectives

of the changing nature of Asperger Syndrome. To date, this topic has been ignored in the research literature.

What Will I Be Asked To Do?

You will be invited to participate in an approximately 30 minute interview with the researcher discussing your opinions of the changing nature of AS, given the removal of a clinical diagnostic criteria based on the release of the DSM-5. This interview will be audio-recorded for the purpose of being transcribed to text at a later time. Themes embedded within the collective interviews will be identified and analyzed for the purpose of this research. All identifying information will be removed.

Participation in this is completely voluntary and individuals may refuse to participate altogether, refuse to participate in parts of the study, decline to answer any and all questions, and may freely withdraw from the study up until one week following receipt of the transcribed interview.

What Type of Personal Information Will Be Collected

Your first and last name will be collected for identification purposes. Your date of birth will allow the research team to determine your chronological age at the time of data collection. Your email address will provide an avenue for correspondence. Your telephone number will be collected as a means to conduct the interview over the phone, should you prefer. Lastly, the date of your diagnosis will enable the research team to determine the length of time since you received your AS diagnosis.

The anonymity of participants and the confidentiality of the data will be protected by the research team. All contact information, demographic information, cognitive measures, and transcribed data will be stored in a secure filing cabinet in the Autism Spectrum Educational, Research Team (ASERT) laboratory. Only members of the research team will have access to the data. All audio recordings will be transferred onto a password-encrypted computer and permanently deleted from the recording device upon transfer. Audio recordings will be transcribed, and audio files will be deleted upon transcription. All transcribed data and completed questionnaires will be kept for a period of 5 years, after which all documents and audio recordings will be destroyed/deleted following this study.

Are there Risks or Benefits if I Participate?

Participating in this research will provide participants and the research team with a greater understanding of participant self-identity pertaining to their AS diagnosis. This study will also provide members of the AS community an avenue to voice their concerns that will be heard by the scientific community. From this project, both professionals and individuals with AS may develop a deeper understanding into the potential implications accompanying the loss of a clinical diagnosis, including issues related to self-identity, policy changes, and service provisions. Given the paucity of research on self-identity and ASD, the information from this study will add to the body of literature and provide a basis for future research.

There is the slight possibility that you may experience minor psychological distress and discomfort in discussing your opinions of the changing nature of AS. The researcher will attempt to avoid asking potentially sensitive questions that may elicit discomfort, or rephrase questions if you are uncomfortable. However, should you experience emotional distress and discomfort, this will be reported to the principal investigator, a registered school psychologist, and counseling psychologist who will follow-up with you to discuss your emotional distress and cognitive dissonance and who may provide you with a handout that includes a comprehensive list describing the various types of psychological services available within the city.

What Happens to the Information I Provide

Participation is completely voluntary, anonymous and confidential and only the research team will have access to the files. All interviews will be audio recorded, and audio recordings will be transferred onto a password-encrypted computer and permanently deleted from the voice recorder after completion of the interview. Subsequently, all interviews will be transcribed for analysis and audio files will be deleted. You will receive a copy of your transcribed interview so that you may check it and report any inaccuracies to the research team. You are free to discontinue participation at any time prior to one week following receipt of the transcribed interview. All written transcripts of the interviews will be stored in a locked cabinet within a locked room, and retained for 5 years. At the end of the 5 years, all written documents will be destroyed, and all audio recordings will be permanently erased from the computer desktop at the end of the study.

Signatures (written consent)

Your signatures on this form indicate that you 1) understand the information provided to you about your participation in this research project, 2) agree to participate as a research participant, and 3) agree to have your adolescent participate as a research participant. In no way does this waive your legal rights nor release the investigators, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from this research project at any time. You should feel free to ask for clarification or new information throughout your participation.

Participant's Name: (please print) _____

Participant's Signature: _____ Date: _____

There are several options for you to consider if you decide to take part in this research. You can choose all, some, or none of them. Please review each of these options and choose Yes or No:

I wish to remain anonymous: Yes: ____ No: ____

You may quote me and use my name: Yes: ____ No: ____

I wish to remain anonymous, but you may refer to me by a pseudonym (e.g., "Darren", "Susan", etc.): Yes: ____ No: ____

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

I give consent to be contacted by the ASERT team for future research opportunities: **(check one) Yes** ____ **No**_____

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:

Ms. Stephany Huynh, M.Sc.	Dr. Adam McCrimmon, Ph.D.	Dr. Tom Strong, Ph.D.
School & Applied Child Psychology	School & Applied Child Psychology	Counseling Psychology
Werklund School of Education	Werklund School of Education	Werklund School of Education
Faculty of Education	Faculty of Education	Faculty of Education

If you have any concerns about the way you've 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.

GENERAL DEMOGRAPHIC QUESTIONNAIRE

NOTE: This information will be kept strictly confidential and will be used for research purposes only.

Participant ID #: _____

Date of birth: _____

Age: _____

Gender: M / F

Diagnosis

1. Have you been identified as having autism spectrum disorder (ASD)?   Y / N

2. What is your formal diagnosis (e.g., autism, high-functioning autism, Asperger syndrome, pervasive developmental disability – not otherwise specified)?

        Diagnosis: _____

3. Who has most recently diagnosed your condition and what is their title?

        Name: _____

        Title: _____

4. When were you given the diagnosis? (Year, month): _____

5. Do you have any other formal diagnosis? Y / N

6. If so, what diagnosis did you receive? _____

7. What is the name of the profession that diagnosed you?

        Name: _____

        Title: _____

Language

1. What language(s) do you speak or understand? _____

2. Is English your first language, or the language that you use most frequently?   Y / N

3. What language(s) were you educated in? _____

4. Did you receive speech therapy in the past or present?
_____

5. As far as you know, how old were you when you began speaking single words?
_____

6. How old were you when you began speaking in short, but meaningful phrases?
_____

Cognition

Have you ever been hospitalized because of a head injury, lost consciousness, or experienced seizures? Please explain.

_____

_____

_____

Are you willing to participate in other research projects that we are conducting or will be conducting?

If you are interested in potentially participating in other research projects involving adults with ASD and/or Asperger Syndrome please indicate your preference below, and provide an email address that we can contact you at. Please note, we WILL NOT provide your contact information to any other third parties, and all contact information will be kept secure and confidential.

Would you like to be informed of other research projects? Y/N

Please provide us an email address: _____

Please provide your phone number: _____

We appreciate you taking the time to consider this research project!

ASPERGER STUDY - INTERVIEW SCRIPT

"Welcome. Thank you for your interest in participating in our research. To start off, I just wanted to briefly tell you a bit about the aims of this project before we begin the interview portion of the study.

In the new Diagnostic and Statistical Manual of Mental Disorders (DSM-5), Asperger Syndrome has been removed as a clinical disorder, and replaced with the all-encompassing new Autism Spectrum Disorder (ASD). Although research suggests that the new ASD term may be a better representation of autism, Asperger Syndrome, and other similar clinical conditions, a change in terminology may have potential implications for individuals with AS who strongly identify with their diagnosis.

Therefore, the aim of this study is to explore the changing nature of Asperger Syndrome and I'll be asking you a series of questions to get a better understanding as to your own personal experience and opinions on the topic.

The interview should take roughly 30 minutes to an hour depending on the length of your responses. Being mindful of the time, I may move onto the next question if I feel that we've fully captured the essence of that question.

Before we begin, do you have any questions?

_____

Knowledge
1. What is your understanding of Asperger Syndrome?
    o Where did you obtain this information?
2. How did you come to understand that you have Asperger Syndrome?
3. What is your understanding of Autism?
    o Where did you obtain this information?
4. What are your views on Autism versus Asperger?
    o How are they the same, how do they differ?
5. Describe any connections or involvements you may have with the ASD community.
6. What do know about the DSM-5 and the change in diagnostic classification?
    o What sources did you obtain this information from?

Opinions
7. What are your thoughts about the changes in the *DSM-5*,
8. Are you in support of the changes in the *DSM-5*?
    o Why/Why not?
9. To your knowledge (and from what you have read or heard), what has been the reaction of the Asperger Syndrome community (whether that be online or offline) to the changes in the *DSM-5*?
10. What are you thoughts about the removal of Asperger Syndrome as a clinical diagnosis?
11. What are your feelings and/or perspectives on being grouped with individuals with Autism?

Self-Identification

12. What did you self-identify as before the changes in the DSM-5?
    o What lead you to identify that way?
13. What did the diagnosis of Asperger Syndrome mean to you?
14. Since receiving a diagnosis, how has it impacted your life, if at all?
    o Has it changed the way that you define yourself? If so, in what way?
15. What are you views on the Autism culture and community?
16. Now that Asperger Syndrome is no longer recognized as a clinical disorder, has it changed the way that you identify yourself?
    o And if so, in what regard?
17. What do you self-identify as now since the removal of Asperger Syndrome?
    o What lead you to identify this way?
18. What influence do you think the changes in the *DSM-5* may have on the Aspie community?

Impact

19. What challenges might individuals diagnosed with ASD based on the *DSM-5* criteria face as compared to those diagnosed with Asperger Syndrome using the *DSM-IV-TR*?
20. What changes (positive or negative), if any, have you experienced since the release of the *DSM-5* with regards to services, funding, or policies for individuals and families with Asperger Syndrome?
21. What challenges do you think the professional community will face in light of the changes in the *DSM-5*?
22. What impact do you think the change in diagnostic terminology will have on research?
23. What would you like the members of the research and/or professional communities to know about your experience in living with Asperger Syndrome, and now that it was been removed?
24. What do you think will happen with the AS and ASD diagnosis in the next version of the DSM?

General

25. Now that we've discussed a broad number of issues surrounding one's opinions on the changing nature of Asperger Syndrome, is there anything that we haven't covered that you would think would be important to the objectives of this study?

[Thank the interviewee for their time and interests in participating in the research. Provide the participant with a handout with includes a comprehensive list of psychological services should they experience any emotional distress or discomfort following their involvement in the study.]

Appendix E

Debriefing Form – Printed on U of C Letterhead

Research Project Title:
The loss of Asperger Syndrome: An exploration of its effects on self-identity

What was this study about?
This study investigated the usefulness of several tests used to assist in the diagnosis of Asperger syndrome. The purpose of the study was to determine if any single test was better at identifying those with the diagnosis, or if a combination of tests improved accuracy of identification.

How can you find out more about this topic?
If you would like to find out more about the diagnosis of Autism and the changes in the *DSM-5*, we recommend the following article:

Lohr, W. D., & Tanguay, P. (2013). DSM-5 and proposed changes to the diagnosis of autism. *Pediatric annals*, *42*(4), 161-166.

Where to find additional resources?
Should you experience any distress, please contact the following resources for assistance:

- Autism Calgary - http://www.autismcalgary.com

- AAFS - http://www.aafscalgary.com

- The Ability Hub - http://www.theabilityhub.org

Researchers:

Ms. Stephany Huynh, B.Sc.	Dr. Adam McCrimmon, Ph.D.	Dr. Tom Strong, Ph.D.
School & Applied Child Psychology	School & Applied Child Psychology	Counseling Psychology
Werklund School of Education	Werklund School of Education	Werklund School of Education
Faculty of Education	Faculty of Education	Faculty of Education

Thank you for your participation! It is greatly appreciated.