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## The Change in Classification of Asperger Syndrome: An Exploration of its Effects on Self-Identity

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### Abstract

Recently, the American Psychiatric Association eliminated Asperger Syndrome (AS) and introduced the Autism Spectrum Disorder (ASD) diagnostic framework. This change in nosology socially implicates people who self-identify with and derive personal meaning from their AS diagnosis. The current study explored the opinions of adults with AS regarding their identity related to the diagnostic terminology of ASD. Twelve adults with AS completed a semi-structured interview that was transcribed and analyzed qualitatively using Thematic Analysis. The analysis revealed six themes: (a) Derived Meaning, (b) Knowledge and Understanding, (c) Perceptions and Labels, (d) Social Identity, (e) Opinions and Reactions to ASD, and (f) Barriers to Funding and Service Provision. Many participants socially identified and self-categorized as part of the AS community because their challenges matched those described by the DSM-IV. Importantly, many participants described the removal of AS as a threat to their identity, social status, and access to supports. Implications are discussed.

### Keywords

Autism Spectrum Disorder, DSM-5, Identity, Qualitative Analysis

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## The Change in Classification of Asperger Syndrome: An Exploration of Its Effects on Self-Identity

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*Recently, the American Psychiatric Association eliminated Asperger Syndrome (AS) and introduced the Autism Spectrum Disorder (ASD) diagnostic framework. This change in nosology socially implicates people who self-identify with and derive personal meaning from their AS diagnosis. The current study explored the opinions of adults with AS regarding their identity related to the diagnostic terminology of ASD. Twelve adults with AS completed a semi-structured interview that was transcribed and analyzed qualitatively using Thematic Analysis. The analysis revealed six themes: (a) Derived Meaning, (b) Knowledge and Understanding, (c) Perceptions and Labels, (d) Social Identity, (e) Opinions and Reactions to ASD, and (f) Barriers to Funding and Service Provision. Many participants socially identified and self-categorized as part of the AS community because their challenges matched those described by the DSM-IV. Importantly, many participants described the removal of AS as a threat to their identity, social status, and access to supports. Implications are discussed. Keywords: Autism Spectrum Disorder, DSM-5, Identity, Qualitative Analysis*

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Changes in diagnostic frameworks have occurred with each revision of the Diagnostic and Statistical Manual of Mental Disorders (DSM). The fifth edition (American Psychiatric Association [APA], 2013a) featured significant modifications from the previous edition (APA, 2000), particularly regarding Autism Spectrum Disorder (ASD). This paper explores the elimination of Asperger's Disorder (Syndrome; AS) in the DSM-5 and its integration into the new ASD diagnosis, with respect to personal identity implications that AS-diagnosed individuals associate with this change. From an introduction to clinical diagnoses and their potential identity implications, the evolving diagnostic criteria for ASD are discussed, followed by a focus on how the removal of AS may shape the personal identity of people with AS. The methodology, results, and implications of the investigation are then presented.

### Clinical Labels

Arguably, AS did not exist before the nineteenth century. 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). As psychological disorders are classified by symptomatic observations, diagnostic labels may be considered a social construct created as a by-product of identifiable behaviours (Dean & Lane, 2001; Hacking, 1995). In some respect, diagnostic labels are the most agreed upon scientific description by the mental health profession to classify observed behaviour (Dean & Lane, 2001).

For Ian Hacking (1995), human science (encompassing sociology, medicine, and psychology) is an endeavour of creating "kinds of people that in a certain sense did not exist before" (p. 2) through its diagnostic classifications. Thus, "systematic, general, and accurate knowledge" (Hacking, 1995, p. 394) is required for classification of people to draw inferences about another's characteristics based on their association with a particular group. The

application of clinical labels is used to explain maladaptive patterns of behaviour and determine appropriate interventions for the assumed underlying condition (Madsen & Leech, 2007). A clinical label can help some gain perspective of their experiences and past challenges (Giles, 2014). Thus, a clinical identity arises when someone embraces his or her diagnosis and internalizes the characteristics associated with the disorder (Singh, 2011). Unfortunately, clinical labels can also lead to increased stigma, discrimination, and prejudice when a person is diagnosed with psychiatric labels that they do not want and are helpless to remove as the label may become a defining characteristic (Charland, 2005; Madsen & Leech, 2007). Conversely, concerns surrounding identity may arise when clinical labels are removed, clinical terminology are changed, and/or aspects of original clinical 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). Indeed, the loss of a clinical identity may “invalidate a person’s experiences under the label” (Charland, 2004, p. 337) as the meaning of those experiences may be impacted.

Although the mental health community considers ASD to be the most agreed upon and scientific description of the specific constellation of symptoms (APA, 2013a), the removal of AS in the DSM-5 has important implications for people who derive personal meaning from their diagnosis; such a clinical identity is the focus of the current study. An overview of ASD is provided to familiarize readers with its history.

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

Autism was introduced in 1943 by Kanner to describe 11 children with severe social and communication abnormalities, and narrow/restrictive interests. Subsequently, Hans Asperger identified a similar condition in four socially isolated children who demonstrated repetitive behaviours, a preference for sameness, unusual interests, motor clumsiness, and a propensity towards rote memorization of facts and speech (Asperger, 1991).

Previously conceptualized as persistent impairments in social interactions coupled with restricted/repetitive patterns of behaviours and/or interests (APA, 2000), AS was categorized as a Pervasive Developmental Disorder (PDD). Although AS shared similar diagnostic features with other PDDs, it was distinguished by intact language and cognitive development (APA, 1994). 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 is 1 to 3 in 500 (Fombonne & Tidmarsh, 2003).

Despite these initial efforts to recognize AS as a unique clinical disorder, it was integrated into ASD in the DSM-5 (APA, 2013a). Changes to the ASD nosology addressed a number of limitations of the DSM-IV. First, the DSM-IV was 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 previous approach may inflate the rates of comorbidity (Bauman, 2010; Ozonoff, 2012). Third, the DSM-IV did not address the developmental changes that can occur with ASD (Volkmar et al., 2012). Fourth, the DSM-IV criteria for AS were applied inconsistently across clinicians, practices, and treatment centers (APA, 2013b; para. 4), resulting in disagreement amongst clinicians. Lastly, commonalities between PDDs complicated the process of a differential diagnosis (Autism Speaks, 2014). Despite these limitations, researchers agreed that the categorical model of classification should not be entirely abandoned as its original purpose is still well-served.

Unfortunately, reclassification of the PDD diagnoses may have engendered some unintended effects. Specifically, there are people who strongly self-identified and understood that they are AS as a result of their DSM-IV diagnosis (Giles, 2014; Singh, 2011). In some

sense, the DSM-5 may have significant implications for individuals whose identity is comprised in part by their diagnostic label. To demonstrate how and why a person with a psychiatric disorder might identify with their clinical label, it is important to understand the influence of a social group on one's self-identity.

## **Identity**

Identity is a global understanding about one's self that shapes how a person acts, behaves, believes, and perceives their world (Fearon, 1999). From Erikson (1968), identity as a concept has generated substantial theorizing and research. In the present study, identity refers to the categorical descriptions and evaluations used by participants to account for their self-understandings, including capabilities (Muhlhausler & Harré, 1990). Such descriptions are acquired from and sustained through interactions with others, including interactions enabled by social and other media resources such as the nosology in the DSM-5 (Hacking, 1995). The present study focuses on participants' self-descriptions, inclusive of diagnostic terminology.

Identity formation is situated in two senses: (a) personal (individual) and (b) social (group; Fearon, 1999). Social Identity Theory informed our primary theoretical framework for examining participant data as meaningful social experiences are central to identity construction (Tajfel & Turner, 1979). Social identity refers to a person's perceived social group membership as people define themselves in terms of their group membership and seek to have their group valued positively relative to other groups (Tajfel & Turner, 1979). A person's sense of pride and self-esteem comes from being embedded within social groups (i.e., of individuals who collectively self-identify as members according to a social category; Hornsey, 2008; Stets & Burke, 2000).

Developing, organizing, and integrating social identities into the self is based on three processes: (a) social categorization, (b) social identification, and (c) social comparison (Tajfel & Turner, 1979). Social categorization is accentuating "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). Social identification refers to identifying with a social group whereby a person adopts the attitudes, beliefs, actions, values, reactions, and behaviours consistent with the in-group (Hogg & Reid, 2006; Hornsey, 2008; Stets & Burke, 2000). Lastly, social comparison refers to applying the attenuated affects to engender group-enhancing outcomes for the self (Stets & Burke, 2000).

## **Clinical Identity**

A clinical label may be used to define a person by his or her condition (Lane & Stratford, 1985). Thus, a clinical identity arises when a person self-categorizes and accepts the characteristics associated with the diagnosis as being part of the self (Charland, 2004). Indeed, the labels that people use to describe themselves are complemented by the descriptions and connotations associated with those labels that influence how people construct their self-identity socially (Ochs, 1993). Such self-identification and personal identity is often evident for people diagnosed with AS in part because there was a community that also self-identified that way.

## **Asperger's Syndrome and Identity**

The emergence of an AS identity and community is traceable to its introduction in the DSM-IV (Giles, 2014; Singh, 2011). In particular, the autistic community strongly aligns with the neurodiversity perspective, believing that autism is a variation in human functioning rather than an illness to be cured (Autism Speaks, 2013). Relatedly, the autism rights movement

(ARM) advocates for accepting autistic behaviours, autistic community respect, and supporting autism social networks to enable people with ASD to socialize on their own terms (Autism Speaks, 2014). Indeed, the ARM has helped establish unique personal identities pertaining to neurological disorders, such as the term “Aspie,” referring to individuals who self-identify as having AS. As such, many AS community members self-identify with their clinical label in part because their community also self-identifies that way. Autism and AS can influence the ways in which an individual speaks and communicates, dresses, understands their world, and spends their leisure time. Thus, in some sense they function like a culture in that they yield distinctive characteristics and predictable patterns of behaviours (Brownlow & O’Dell, 2006; Giles, 2014).

Taxonomic changes to ASD in the DSM-5 raise considerable questions for Aspies. Specifically, what identity and other influences do Aspies report when the diagnostic label that they may have self-identified with was eliminated in the DSM-5? Has requiring Aspies to relinquish a professionally recognized, diagnosis-informed, identity raised ethical concerns? Answering such questions related to the change in clinical terminology is warranted.

## The Present Study

This study explored the identity-related opinions of adults with AS on what the elimination of AS means with respect to clinical identity. Since previous studies (Giles, 2014; Linton et al., 2013) have utilized only online discussion forums as a means by which to examine this topic, this study interviewed and analysed qualitatively the opinions of participating Aspies.

## Method

### Participants

Thirteen participants were recruited from a major Canadian urban setting through ASD-related community organizations. Participants were 18 years of age or older, English proficient, able to demonstrate average or greater performance on a brief measure of cognition, and previously diagnosed with AS (documentation required at intake). One participant did not meet eligibility criteria and was excluded. Table 1 summarizes the demographic information.

Table 1: *Participant Demographic Information*

	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
Time since Diagnosis (in years)	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*

## Measures

**Demographic questionnaire.** A demographic questionnaire was used to gather information regarding participant age, gender, date of diagnosis, name and profession of the diagnosing clinician(s), co-occurring conditions, and documentation of any cognitive or language impairments.

**Wechsler Abbreviated Scale of Intelligence – 2nd Edition (WASI-II).** The WASI-II (Wechsler, 2011) is a brief individually administered standardized measure of cognitive ability. Participants had to demonstrate verbal and nonverbal (perceptual reasoning) intelligence scores of > 85 as an indicator of intact cognitive functioning in alignment with the diagnostic criteria for AS. The WASI-II was administered and scored according to the standardized procedures outlined in the manual by a trained examiner.

**Interview protocol.** The interview (see Appendix A) consisted of 25 open-ended questions and follow-up probes designed to encourage participants' discussion of their understanding, appreciation, opinions, and identity related to the changing diagnostic framework of AS. Given that the construction of opinions is based on a person's knowledge, understanding, experiences, and interactions, the interview questions were developed to inquire into these topics. No a priori hypotheses were generated as the potential impact of changes in diagnostic terminology on participants' lives or their identity was unknown.

## Procedure

This study was carried out in accordance with ethics approval obtained prior to participant recruitment. Upon providing informed consent, participants completed the demographic questionnaire and WASI-II to establish eligibility. Those who met the inclusionary criteria were invited to complete the interview. The interviews were audio recorded and conducted by the first author for consistency. Interviews were completed in one session and ended when the participant felt that they had exhausted the topic. Additional unstandardized probes were asked if the topic of interest was not organically generated through discussion or if greater insight and/or clarification was sought from the participant. The interviews ranged from 25:24 to 64:37 minutes (median = 42:48) in duration.

All interviews were transcribed verbatim with the following practices. 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. All utterances including "yeah," "um," or "okay," were omitted. Non-verbal communication was noted using square brackets (i.e., [chuckles]). Words emphasized by the participant were italicized. Word tenses may be altered to align grammatically with the statement made. When this 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 participant in square brackets (i.e., [friend]). Each transcription was checked for accuracy and audio recordings were compared to the transcription for anomalies. Each participant was given a copy of their transcribed interview and provided a week to review and address any perceived inaccuracies, make corrections to language (written versus spoken), and/or provide additional clarification.

## Personal Perspectives and Bias

Interest in this topic arose from previous research conducted by the first author. Participants in this previous study discussed the challenges they experienced in getting an ASD diagnosis later in life and the relevance of the diagnosis to their personal identity. This topic

was unexpected given the nature of the previous study and led to an interest in examining the potential identity implications of an ASD diagnosis (or its removal).

Upon reviewing the literature prior to the commencement of the current study, the first author 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 member check.

## **Results**

### **Data Analysis**

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 can be valid, reliable, credible, and rigorous (Malterud, 2001). The analysis and justifications for the final themes were reviewed by the second author for further credibility and member checks. To ensure that qualitative research rigor was met, the authors adopted Malterud’s (2001) guidelines, considerations, and standards for conducting and reviewing qualitative research.

Data were analyzed via Thematic Analysis (TA) as outlined by Braun and Clark (2006). 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 and any discrepancies between raters were discussed and a resolution was agreed upon before proceeding.

Given that a hallmark feature of AS is challenges with idiomatic or literal language (Ozonoff et al., 1991), a semantic approach was adopted whereby participants’ words and opinions were accepted as truthful for them and a unidirectional relation between meaning/experiences and language used in expression was assumed (Braun & Clarke, 2006). TA was also adopted for its flexibility in affording both inductive (data driven) and deductive (theory driven) approaches to identifying, analyzing, checking, and modifying themes and codes consistent with interview content and theory (Braun & Clarke, 2006). In other words, preliminary themes were derived inductively (establish clear links, categories, relations, and associations between the research questions and findings; Braun & Clarke, 2006) and then deductively analyzed (anchor the analytical claims made about the research to the theoretical framework) through TA’s process of constant comparison (Braun & Clarke, 2006).

Six primary themes (with several subthemes within each) were identified: (a) Derived meaning from their experiences with the disorder; (b) Knowledge and understanding about AS, Autism, ASD, and DSM-5; (c) Perceptions associated with labels; (d) Social identity; (e) Opinions regarding the reclassification of PDD and the DSM-5; and (f) Barriers to funding and service provision. Theme descriptions and relevant sample quotes appear in Table 2.



Table 2: *Definition of the Primary Themes*

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 <i>DSM-5</i>	The variable degree to which participants could demonstrate knowledge and understanding about AS, ASD and <i>DSM-5</i> .
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.

**Theme one: Derived meaning from their experiences with the disorder.** This theme captured participants' experiences with living with AS across four subthemes. Comparatively, symptoms of AS are more difficult to detect than other PDD diagnoses due to its mild presentation (Autism Speaks, 2014). The first subtheme, challenges, was indicated by comments such as:

P9: As a child I had a hard time making friends and I was bullied, isolated, and teased for being different. For example, I was never invited to birthday parties or play dates because I was the weird one. I always knew that I was different and would spend hours just watching the other kids. I have a hard time understanding what to do in social situations. Like I don't know what to do and have difficulty reading facial cues. So I would watch them and go home and practice being cool. It didn't come easy like the other kids. But as I got older and researched more about the disorder, I slowly came to realize that these challenges were part of having Asperger Syndrome.

Not all textual data was as meaningful in interpreting themes as other data. Information deemed unrelated to the research question was not analyzed and instead represented by three dots surrounded by ellipses (...) to indicate that textual data was removed. The excerpt below presents a parsed version of the statement above to illustrate this process in excluding certain words/parts of the participant's statement while maintaining the essence of the quote.

P9: As a child I had a hard time making friends and I was bullied, isolated, and teased for being different. (...) I have a hard time understanding what to do in social situations (...) and difficulty reading facial cues. (...) But as I got older and researched more about the disorder, I slowly came to realized that these challenges were part of having Asperger Syndrome.

For many participants, the diagnosis led to significant discoveries, and knowledge about themselves and the community. Specifically, the diagnosis helped participants to legitimize their challenges and eccentricities, and to frame their social issues so they understood their challenges and past behaviors better. The second subtheme, personal insight, was indicated by:

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

The diagnosis also enabled participants to connect with other individuals with AS who face similar challenges, which created a sense of belonging whereby they felt accepted for being different. The third subtheme, a different kind of normal, was indicated by comments including the following. 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.”

Lastly, the fourth subtheme, involvement in the AS community, was indicated by:

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. (...) I feel drawn to these people because we are all alike. We all belong to the same group if you will.

### **Theme two: Knowledge and understanding about AS, autism, ASD, and DSM-5.**

This theme encapsulates participants’ knowledge and understanding of AS, autism, ASD, and the DSM-5. In general, participants’ understanding of these terms varied greatly. The first subtheme, understanding of AS, was based on comments such as:

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.

The second subtheme, understanding of autism, reflects the following comments:

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.

The third subtheme, understanding of ASD, was associated with comments including P1's statement: "[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."

**Theme three: Perceptions associated with labels.** This theme focused on participants' perceptions of society's awareness of AS, autism, and ASD, and how participants coped with these understandings. It consisted of two subthemes. Participants believed that the public holds certain pre-conceived notions about individuals with AS, autism, or ASD. Specifically, comments pertaining to the first subtheme, the public's perception, included the following. 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." Given the negative connotations associated with autism and ASD, stigma tended to surface when AS was associated with either disorder. The second subtheme, stigma, was indicated by experiences such as the following. P11: "That's not to say that there isn't stigma with Asperger, cuz there is. Just less [compared to Autism]."

**Theme four: Social identity.** This theme captures the labels and identity terms with which participants identified. Participant responses yielded four subthemes. Participants described how they came to identify with AS. The first subtheme, maintain an AS identity, stems from comments such as:

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!

Most participants incorporated ASD into their current AS identity (often using both terms interchangeably). The second subtheme, an incorporated ASD identity, is represented by: "P8: I identify first as Aspie, but I also recognize myself as autistic. I have no problem with that and using both terms."

A small group of participants did not identify with either AS or ASD. Specifically, these participants feel that neither diagnosis represents who they are as a person and instead chose to self-identify with another social group. The third subtheme, a label does not define me, is based on comments such as: P5: "To be honest, I don't identify with [my diagnoses] (...). 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."

The last subtheme, identity of the AS community, refers to the participants' opinions regarding the classification of ASD and its effects on the AS community. This subtheme is represented by:

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 everyday conversations.

In general, participants' opinions about the reclassification of PDD and the DSM-5 coincided with their social identity.

**Theme five: Opinions regarding the reclassification of PDD and the DSM-5.** This theme captured participants' opinions regarding the classification of ASD and change in diagnostic terminology. Participants' views differed across three subthemes.

Many participants contend that the removal of AS is a "huge disservice" to the community (P2) as it signifies the "end of an era" (P1). Thus, the first subtheme, reject the removal of AS, was indicated by comments such as the following. P2: "I'll say very few people welcome the changes because they felt that Asperger and Autism are two separate things, similar but different you know."

The second subtheme, support for the DSM-5, is based on comments including the following. 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."

While most participants held to their beliefs firmly (whether for or against the changes in the DSM-5), some took a more neutral stance on the topic. The third subtheme, neutral/mixed feelings about ASD, was indicated by:

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.

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

**Theme six: Barriers to funding and service provision.** This theme represents the perceived challenges in provision and access to services for families and individuals with AS. Four subthemes were identified.

Access to services and funding is often contingent upon a formal diagnosis. Although the APA (2013) insists that all persons on the spectrum should meet diagnostic criteria for ASD, other researchers suggest otherwise (Matson et al., 2012; McPartland et al., 2012; Wilson et al., 2013; Worley & Matson, 2012). The first subtheme, concerns with not meeting ASD criteria, pertain to comments such as the following. 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."

Another major area of contention is the limited resources and services available to adults with ASD. The second subtheme, access to services and treatments, is based comments such as:

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 it's directed towards helping families with autistic children (...) not autistic adults.

Lastly, participants expressed concerns regarding the impact of the DSM-5 on research and was indicated by comments such as:

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?

## Summary

The identified themes and subthemes highlight 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.

## Discussion

The current study explored the experiences and opinions of individuals self-identifying as having AS regarding clinical identity changes pertaining to the DSM-5's classification of ASD. Six themes captured how participants dealt with and viewed this diagnostic change, including its effects on the AS community.

Many participants socially identified and self-categorized as part of the AS community because their social challenges matched those described by the DSM-IV. Hence, participants began to accept and derive personal meaning (Giles, 2014) from their diagnosis, thus transforming AS from a label into a community (Coury, 2013; Scheff, 1974) that cultivated a collective identity for its members. For many participants, the removal of a clinical disorder "threaten[s]" (Charland, 2004, p. 347) the identity of those who self-identify as being a part of that community. For Charland (2004), people with mental health issues become attached to their psychiatric labels and claim that the loss of a clinical disorder can cause "harm" (p. 336).

A major concern of participants was whether members of the AS community would meet DSM-5 criteria for ASD. The results of the DSM-5 field trials (Clark et al., 2012; Regier et al., 2012) suggest that DSM-5 ASD diagnoses were made reliably and the majority of children retained their ASD diagnosis. Given that the field trials were conducted on school-aged children and that adults or very young children with autism were not included, it remains to be seen how the proposed diagnostic criteria might affect them. As such, it is important that larger samples inclusive of individuals from all ages be included.

Interestingly, independent studies from the field trials found that 20-30% of people previously diagnosed with AS will no longer meet the DSM-5's criteria (Matson et al., 2012; McPartland et al., 2012; Wilson et al., 2013; Worley & Matson, 2012). Given the changes in the DSM-5, some AS community members may be deprived of valuable supports and/or services if recognized as not having ASD (Coury, 2013). These findings are troubling given that access to government funding and services often requires formal diagnosis. Without clear evidence supporting AS and ASD as homogenous disorders, critics argue that denying services, funding, treatment, or tax credits to some individuals—while providing a full range of services to others on the spectrum—is unethical. This is especially the case if differences between these subtypes cannot be distinguished validly and/or empirically (Clark & Van Ameron, 2007; Coury, 2013; Grant & Nozyce, 2013).

Despite seeing the AS term positively, stigma tends to surface when AS is associated with autism or ASD (Linton, 2014). While meant to "soften" the impact of losing the AS label, the public has been quick to condemn ASD as odd behaviour (Shtayermman, 2009). Thus, removal of AS for some represents a loss of a social status. Arguably, while people on the spectrum may self-identify (or continue to identify) with AS, AS was replaced with the arguably more stigmatized ASD. In 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 (pp. 56-62).

Another area of contention relates to education and employment. While many schools and workplaces have supports in place to assist individuals on with ASD (Beardon et al., 2009; Humphrey & Lewis, 2008; Parsons & Kasari, 2013), participants feared that the DSM-5’s changes could impact the services and supports provided to them. Although the DSM-5’s Neurodevelopmental Disorder Workgroup insists that individuals previously diagnosed with AS need not undergo reassessment (APA, 2013b), there have been reports of insurance companies and school districts requesting individuals to do so (Autism Speaks, 2014). Given that schools and workplaces are not required to provide individuals with special accommodations without a formal diagnosis, those with AS may risk losing services should they be required to obtain a re-evaluation and fail to meet diagnostic criteria for ASD (Parsons & Kasari, 2013).

Although refinement of previous criteria and enhancement of consistency across clinicians were goals of the revisions, the professional community appears divided in their support of the DSM-5 (Kanne, 2018). Specifically, some clinicians prefer the previous framework, perceiving AS and ASD to be distinct (Kanne, 2018). In contrast, other clinicians prefer the new criteria as it enables “more clinical judgement in allowing diagnosticians to better capture the nuances of the disorder” (Kanne, 2018, para. 8). Regardless of practitioners’ stances, clinicians must change their assessment practices to accommodate this new framework.

Lastly, labels are essential to the diagnostic process and serve an important purpose in research, advocacy groups, and empirically valid intervention programs (Ohan et al., 2015). The findings from the current study have utility for individuals, families, and clinicians, for identifying meanings associated with the loss of a clinical disorder. Changes in clinical terminology and criteria may impact self-disclosure and identification for some people. Specifically, the loss of a clinical disorder may deprive people who would have met the diagnostic criteria for AS the potential to self-identify as members of the AS community. Consequently, some individuals diagnosed with ASD after 2013 may not experience the same sense of belonging as those who self-identify with AS and thus may lose their sense of social status. Overall, 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. Professionals may opt to encourage individuals with AS to develop or maintain a social identity that aligns best with their personal understandings and beliefs. It will be interesting to see how service providers and policy makers adapt to the changes in the classification of ASD.

## **Limitations**

Although the sample is small, the current study focused on participants’ meanings rather than hypothesis testing where statistical power may be of concern. Second, the sample was purposefully recruited and so may not represent the opinions and experiences of all individuals with AS. Thus, no generalizability is claimed for the findings given the qualitative focus, exploratory nature, and regionally-based sample of the study. Third, while semi-structured interviews have many advantages (i.e., allowing for further querying and clarifications of participant responses), they also have disadvantages. Some interviewees found the open-ended format of the questions challenging to answer. This difficulty was further compounded by the social-interactive aspect of the interview as participants may have felt uncomfortable about disclosing personal thoughts and opinions with the researcher. Although paper and pen questionnaires may have alleviated this discomfort, they would also have

restricted the researcher's ability to probe for further clarification. Additionally, participants may have been susceptible to social desirability bias (Jacob & Furgerson, 2012). We attempted to mitigate these effects by asking straightforward questions free of presumptions while maintaining neutral body language. Fourth, a limitation of TA is its inability to "retain a sense of continuity and contradiction through any one individual account" (Braun & Clark, 2006). Hence, we were unable to check for inconsistencies across individual responses due to the amalgamated data corpus. Lastly, we acknowledge the impact that personal bias can have on the methodology of choice, data collection, and analysis of data. Hence, a second coder was engaged and consulted to enhance the analyses reported.

### Future Direction

Given the paucity of research on social-identity and ASD (Bagatell, 2007; Brownlow & O'Dell, 2006), the current findings add to the literature and suggest future areas of research. A longitudinal study is necessary to evaluate the long-term effects on identity arising from diagnostic changes at the individual and community levels to determine whether those with AS will adopt an ASD identity with time. Additionally, researchers should devise a model for helping people on the spectrum come to terms with their diagnosis and process what it means to have ASD. Specifically, evidence suggests that the process of internalizing a clinical identity can help an individual to make sense of past challenges, engender a brighter outlook about the future, and cultivate a sense of belonging to a community (Giles, 2014)—all factors that can promote a positive social identity.

### Final Thoughts and Conclusion

The focus of this study was exploring the opinions of adults with AS regarding the reclassification of PDD and the impact to their identity. Given how deeply the diagnosis is entrenched in AS culture, its removal in the DSM-5 has significant implications for a community whose identity is influenced by the label (Singh, 2011). Although the APA claims that people with AS will be grandfathered into the new ASD diagnosis (APA, 2013b), it is the reported invalidation of an AS culture, loss of a clinical identity, and AS-related way of being that are central to this study's outcomes. As one participant explained, "it's not a matter of what was done but rather what the diagnosis meant" and the hurt this brought that is of importance.

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## Appendix A

### 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?
  - 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?
  - Where did you obtain this information?
4. What are your views on Autism versus Asperger?
  - 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 you know about the DSM-5 and the change in diagnostic classification?
  - 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*?
  - 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 your 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?
  - 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?
  - Has it changed the way that you define yourself? If so, in what way?
15. What are your 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?
  - And if so, in what regard?
17. What do you self-identify as now since the removal of Asperger Syndrome?
  - 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?

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