**"Sometimes labels need to exist" – Exploring how young adults with Asperger's Syndrome perceive its removal from the Diagnostic and Statistical Manual of Mental Disorders – Fifth Edition.**

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**Points of Interest**

- A researcher with a diagnosis of Asperger's Syndrome interviewed nine people with this diagnosis to see what they thought of the recent changes to the Diagnostic and Statistical Manual of Mental Disorders-5. These changes mean that people won't receive a diagnosis of Asperger's but will probably receive a diagnosis of Autism Spectrum Disorder instead.

- The people interviewed were not happy with the changes and they felt that the labels "High-functioning Autism" or "ASD Level 1" would not really describe them personally. They thought that Asperger's was different to Autism while still being part of the Autism family.

- Participants expressed some mixed feelings towards the Asperger's label, but mostly they view their diagnosis as positive.

- Participants identified strongly with a community of people with Asperger's (sometimes called the "Aspie" community) and they reported that this was very helpful to them. They worried that this identity would die out and people would not understand their experience without this specific label.

- They expressed concern that the new diagnostic criteria would mean that people with similar profiles to them would not receive diagnosis in the future. This might mean that they would miss out on the support from both professionals and peers that they had found so valuable in their own lives.

**Introduction**

The latest, fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM, American Psychiatric Association, 2013) contains significant alterations to the diagnostic criteria for Autism Spectrum Disorder (ASD). Most notable is the removal of the diagnosis of Asperger's Syndrome (AS), meaning that there will be no new diagnoses of AS by those who diagnose according to DSM-5 guidelines. Under these guidelines, severity levels for ASD are to be used (Levels 1-3), with "Autism Spectrum Disorder, Level 1" being the most likely label for an individual who would previously have met the criteria for a diagnosis of AS (McPartland, Reichow and Volkmar, 2012). The current study sought to ascertain the opinions of young adults who were diagnosed with AS in childhood in relation to the changes to the DSM.

There has been a distinct shift in recent years from a medical model of disability to a focus on the social and cultural factors that can act as barriers to certain individuals having their needs met and achieving their goals (Gillman, Heyman & Swain, 2000). Within this discussion, the nature of disability and impairment in autism has been the subject of particularly nuanced debate (O'Dell, Bertilsdotter Rosqvist, Ortega, Brownlow & Orsini, 2016). While the current report considers the potential impact of a change in label from Asperger's Syndrome to Autism Spectrum Disorder, the continued focus on a deficit model of disability inherent in words such as "disorder" is perhaps more problematic to some than the change in conceptualisation of autism described in DSM-5 (e.g., Woods, 2017). While acknowledging the impact of language in this area and the importance of sensitivity, this report will focus on the experiences of people with a diagnosis of AS and their thoughts on its removal from DSM-5, rather than providing an analysis of the implications of a medical or even a deficit model of autism or disability.

An in-depth discussion of the pros and cons of diagnostic labels is, similarly, beyond the scope of the current report. However, it can be accepted that, while a diagnosis can be useful for accessing specialist services (and indeed, it is often the only way to receive any services), having a label such as autism can be stigmatising in certain situations and it can place the focus of control away from the individual themselves and onto those making the diagnosis (Baines, 2012; Gillman, Heyman & Swain, 2000).

The DSM-5 changes described above have been the subject of much controversy, with some researchers claiming that they were not based on empirical evidence (Ritvo 2012). Kite, Gullifer and Tyson (2013) asked 547 health and education professionals about the proposed diagnostic changes and found that approximately 50%

of respondents were opposed, 28% expressed uncertainty, and only 22% supported the changes. Tsai (2013) has even predicted that the diagnosis of Asperger's Syndrome will return in the next edition of the DSM.

One of the main causes of concern is that some people who meet current criteria for AS may not meet the new criteria for ASD Level 1. This is likely to impede access to relevant support (San Lio, Petrosina and Aguglia 2014). McPartland et al. (2012) found that 39.4% of the participants meeting criteria for a PDD in the DSM-IV field trial (Volkmar et al. 1994) would not meet the criteria for a diagnosis of ASD using the DSM-5. Furthermore, only 25% of those with a diagnosis of AS would receive a diagnosis under the new criteria.

The attention that the removal of AS from DSM-5 has received makes sense in light of its socio-cultural significance. Since AS was first included in the DSM-IV (APA 1994), there has been a growing "Aspie" culture (Spillers, Sensui and Linton 2014), leading many individuals to identify with the label on a personal level (Giles 2013). The "Aspie" identity focuses on the benefits of being different and celebrates particular strengths. This sense of community is highly valued and advocacy groups have petitioned the APA to preserve the AS diagnosis (Hazen, McDougle and Volkmar 2013). This pride in a diagnosis or label is contrary to the stigma that is noted by Baines (2012) who found that participants often tried to conceal their diagnosis. Perhaps this can be explained by the fact that the participants in that study were still in school, a time where it is difficult to be different. On reaching adulthood, people with AS appear to find comfort in the label as it pertains to the community with which they identify.

Prior to the publication of the DSM-5, Singh (2011) interviewed 19 individuals with AS and found that their AS identity was positively embraced and enabled a sense

of belonging.  Participants described the importance of diagnosis and asserted that AS is much less stigmatised than autism, a finding supported by Spillers et al. (2014; views of people with AS) and Kite et al. (2013; views of healthcare professionals).

Studies that allow individuals who may be affected by the DSM changes to voice their own opinions have been scarce, although two studies have been undertaken using internet-based qualitative research.  Giles (2013) analysed comment threads on internet discussion boards from 2010 to 2012.  Commentators varied in their reactions; some saw the broadening of the ASD diagnosis as increasing acceptance of people across the spectrum.  However, a dominant theme was fear that some individuals would not be able to access services and accommodations in the future due to the more stringent criteria.

Spillers et al. (2014) conducted a phenomenological analysis on two threads on WrongPlanet.net, with comments posted between 2009 and 2012.  The theme of a "cure" emerged strongly in their analysis. Many participants reported that by removing the term 'Asperger's' an entire culture is eliminated, and some believed that the DSM-5 changes were maliciously designed to 'cure' people who might not retain a diagnosis under the stricter guidelines.  Similar to Giles (2013), strong concerns were found amongst the AS community about the DSM changes leading to support becoming more generalised and less accessible.  However, opinions also varied.  While some participants did not want any label, some were neutral, and others identified strongly with the AS label, likely reflecting the diversity of opinion on the relative merits of diagnostic labels. Whilst the studies by Giles (2013) and Spillers et al. (2014) provide an overview of the opinions of people with AS, internet-based qualitative research is limited to researchers 'listening in' to pre-existing conversations, rather than having direct dialogue.

Researchers in this area may analyse internet material for a number of reasons. Benford and Standen (2009) reported that people with AS found it liberating to communicate via the internet as face-to-face conversation could be challenging. Linhorst (2004) suggested that a common difficulty in establishing rapport is related to a mistrust or discomfort with 'professionals', which is likely to be exacerbated for people with AS. However, one-to-one interviews typically offer richer and more insightful data for analysis (Kvale and Brinkmann, 2009). Thus, the current study uses an interview design, whereby the interviews were undertaken with an 'insider' perspective by the first author, who shares the AS diagnosis. This was disclosed to participants with the aim of reducing the potential discomfort noted by Linhorst (2004). The study attempts to address the dearth of interview data through taking a qualitative, experiential approach to understand how young adults with AS perceive the removal of the AS classification from the DSM.

**Method**

*Participants*

Nine men, aged 18-25 years (M = 22.4, SD = 2.0) who had received a diagnosis of AS between the ages of 3-14 years (M = 22.1, SD = 1.8), participated in the study. All of the participants received a formal diagnosis from a licenced practitioner, the majority from a Psychiatrist. Participants were purposively recruited via Facebook and snowball sampling and they each chose a pseudonym to protect their anonymity. All participants identified as White British. Further participant information is presented in Table 1.

Table 1: Participant Characteristics

| Pseudonym | Age at Interview | Age at diagnosis | Secondary Education | Higher Education |
|-----------|------------------|------------------|---------------------|------------------|

| | | | | |
|---|---|---|---|---|
| Asper | 22 | 14 | Mainstream secondary | Completed degree |
| Bill | 22 | 6 | AS-specific secondary | Studying for degree |
| Cloud | 24 | 7 | Mainstream secondary | Completed degree |
| Ethan | 23 | 10 | AS-specific boarding school | Completed degree |
| Geminus | 23 | 9 | Special secondary school (not AS-specific | Completed diploma |
| Mr Blue | 21 | 3 | Mainstream secondary | Completed diploma |
| Nexus | 18 | 7 | Mainstream secondary | Studying for degree |
| Kev | 23 | 11 | Mainstream secondary | Studying for degree |
| Poe | 23 | 11 | Mainstream secondary | Completed diploma |

***Procedure***

*Data collection*

  Research and ethics approval was received from London South Bank University and the study followed British Psychological Society guidelines. Participants provided written informed consent and chose their own pseudonyms. Identifying information was obscured to protect anonymity. Data were collected using semi-structured interviews, lasting between 45 and 60 minutes. The interviewer used open-ended questions to explore the participants' experiences of initial diagnosis, treatment and support, their understanding of the diagnostic approach, the DSM, identity, and the

diagnostic changes.  Interviews were conducted in person and one-to-one by the first author. Each interview was audio recorded and transcribed verbatim.

*Data analysis*

Data were analysed using an experientially-oriented thematic analysis that prioritised understanding the lived experience of the participants.  Drawing on the method described by Braun and Clarke (2006), data familiarisation, and initial note-taking, was followed by generating codes to capture the experiences and meanings inherent in the transcripts.  Codes were then clustered into themes in an iterative process that distilled the key concerns of each participant into a thematic structure.  Departing from Braun and Clark's (2006) approach, each transcript was coded and thematised individually, before a cross-case analysis was undertaken, where the individual thematic structures were re-clustered into one master table of themes.  This enabled a deeper, more idiographic consideration of the experiential concerns of each participant.

**Results**

Three main themes were identified from across the whole data set, with a number of sub-themes within each (see Table 2).

Table 2: Thematic structure

| Main Themes | Subthemes |
| --- | --- |
| **The AS Diagnosis: *"A lot of positives"*** | *An explanation for self and others* |
| | *Diagnosis as the gateway to support* |
| | *A stigmatised identity* |
| **DSM-5:  A Step Backwards** | *The system was working* |
| | *"I'm a member of an endangered species"* |
| | *A move in the wrong direction: Specificity vs* |

|  | *generalisation* |
|  | *Future generations will suffer* |
|  | *Changes in the DSM reinforce negative* |
|  | *messages from society* |
| *"What they're doing is stupid as hell":* **Fear, anger and confusion** | *There is a difference… but that difference is hard to define* |
|  | *Rejecting the HFA label: Confusing and misrepresentative* |
|  | *"That's the label that works": Fear and anger about losing the AS diagnosis* |

### The AS Diagnosis: "A lot of positives"

Participants discussed benefits of the AS label, including increased self-understanding, being able to explain behaviour that would be otherwise be seen as inappropriate, and in some cases, taking up AS as a positive identity marker. However, participants also expressed rejecting attitudes towards their diagnosis, and many mentioned experiencing stigma. These views were not always mutually exclusive, and some participants described conflicting thoughts.

### An explanation for self and others

AS often provided a label that helped participants to make sense of their own experiences, and could even support a positive identity. It was seen as helping others to understand them. Indeed, Asper suggested there were "a lot of positives of having the

diagnosis." Receiving the diagnosis was seen as "a relief" (Kev) as it provided an explanation for the participants' lived experiences:

> I can clearly see I'm different from everyone. Other people can clearly see that I'm different, and I think without that label of Asperger's Syndrome, I've no longer got a definition, and that definition is what's got me through a lot of problems" (Nexus)
>
> "it's kind of almost comforting to know that there was sort of a reason for it, [something to] point to and say like almost this is why I'm different. (Bill)

For some, the diagnosis went beyond explanation to offering a sense of identity, pride, solidarity and community with others who shared the AS label. For example, Nexus strongly identified with his diagnosis: "it does make up my identity pretty much, it's the first thing you'd say about me". He described it as giving his life "meaning" and helping him find his "particular special area" of talent. Asper also found comfort in the AS identity during his adolescence, as it gave him a sense of belonging:

> "to be able to sit there when you feel really bad and go, it's okay. I have something that other people have. And I can get through it, 'cause they can get through it. […] labels in society are not normally a good thing, but this one I think is. […] I'd rather be told I have this, than told there's nothing wrong with me."

The ambivalence that surfaces here through Asper's acknowledgement that labels are problematic, was echoed throughout the data, and participants were frequently

negotiating conflicting feelings in an attempt for balance.  For example, despite his reservations about the diagnosis, Mr Blue felt there were also "lots of benefits" and seemed to feel some pride in being associated with "a long list of brilliant minds throughout the years, like Einstein" who are suggested to have had AS. Participants also felt their diagnosis helped others to understand them and their experiences:

"I think it helps to kind of, sort of explain certain things that you do" (Bill)

"People are more understanding when you've got a- a- a label for something that's wrong with your brain" (Geminus)

The AS label could smooth over difficulties by providing a legitimate explanation for particular behaviours.  Poe described getting into trouble at work for something he had said, but once he disclosed his AS diagnosis, his colleagues reacted more positively: "now you've said that we can totally get it now, we just thought you were being rude".

*Diagnosis as the gateway to support*

 Participants talked about how important support is in dealing with AS, especially during earlier life.  Initially, the diagnosis "opened up pathways to support" (Asper) such as helping participants research what others found useful, or joining support groups:

"I think without having that sort of identification, I wouldn't have known what sort of steps to take and where to start. Sort of pointed me in the right direction." (Kev)

It helped participants communicate what help they required and access specialist services, which Asper, and others, saw as "life changing". Bill and Ethan both attended a specialist school for children with AS, and emphasised how essential that was to their success:

> "I can say with pretty much full confidence that if I hadn't have gone to the boarding school I wouldn't have passed my GCSEs, I would be nowhere near where I am today, I wouldn't be driving, I wouldn't have my degree, I wouldn't… have anything." (Ethan)

There was a general sense of gratitude from participants for the support they received, but a feeling that they were "lucky" (Ethan) or "fortunate" (Asper), and therefore that perhaps others had not been. Several participants noted that without that support, things would not have turned out so well:

> "if I did not have that diagnosis […] I would have failed college and definitely would never have made it to university." (Asper)
>
> "if I hadn't been diagnosed with it … there would have definitely been more issues" (Geminus)

The diagnosis was seen to help participants support themselves, as well as gain support from others:

"it made me to work on certain areas of myself that I wanted to improve. It also meant that I could get the- the support that I needed in school" (Kev)

Participants also saw benefits for their families. Geminus described how his mum was "desperate to get me diagnosed […] and get me the correct help". There was a sense that the diagnosis relieved stress and uncertainty as to whether or not there was "something wrong" (Asper) and led the way to much needed help:

"[It] opened sort of quite a lot of doors for, you know, both me and my parents, to kind of start getting help and support" (Bill)

*A stigmatised identity*

Despite the positive aspects of receiving the diagnosis, most participants also mentioned their struggles with stigma. In particular, participants described being seen as "different" (Nexus) and therefore treated differently:

"[it] makes you feel a bit of an outcast, a bit like you don't fit in [...] you feel something's wrong with you." (Cloud)

Both Ethan and Bill acknowledged the difficulties this could cause:

"I was that odd kid, I was that weird kid and, it was shit, quite frankly." (Ethan)
"In mainstream [school] you have to sort of hide everything because otherwise people start picking on you" (Bill)

Fear of stigma impacted on when and how they disclosed their diagnosis and with whom they would socialise.  Both Asper and Bill described taking care to form friendships with people of a "tolerant" mind-set, and several participants, including Asper and Ethan, mentioned not telling people unless they thought they really needed to know:

> "Most of the time I just keep it to myself, or never bring it up at all. It's got stigma attached to it." (Mr Blue)

### *DSM-5: A step backwards*

Participants universally felt that the changes in the DSM-5 were unhelpful, and that they would squander years of progress.  There was a general sense of confusion about how something that was seen to exist could disappear.  There were deep concerns for future generations, and a sense that the changes reinforced a deeper belief (possibly an internalised stigma) that AS did not matter, or was not important enough to deserve effort and resources.

### *The system was working*

The participants generally felt that there was no logical reason for changing the classification system, which appeared to be working, and they found the reasons for the changes unclear and the changes themselves frustrating.  Kev did not understand why changes were made: "if it ain't broke, don't fix it" and Mr Blue noted that things were going well, until this change came about. Nexus agreed:

"DSM four I thought nailed it with Asperger's, they had everything explained […] It should have remained as it was because the system they already had was working." (Nexus)

There was also a strong sense that the changes were actively "taking a backwards step" (Nexus), and would "not be a change for the better" (Bill). Participants were worried that the progress made to date would now be wasted:

"it's pretty much throwing away all the achievements that people have worked so hard, in research to bring forward, so that people like me and others can have that [support] (Asper)

"there's potential for, for like the classifications and all that intel to be almost erased from history" (Mr Blue)

*"I'm a member of an endangered species"*

A particular source of confusion for the participants was how a condition, for which they had received a diagnosis, could suddenly cease to exist. To the participants, diagnosis implied an immutable nature, so they felt baffled by the changes:

"I have no idea what mental process these people- like mental acrobatics they had to do to just like, decide that something doesn't exist anymore when it so clearly does." (Poe)

"I was a little bit surprised actually because I thought- people who have this I mean you can't really just ignore it. […] I do feel that perhaps it shouldn't have been removed." (Cloud)

The perceived annihilation of AS, resulted in Geminus feeling that his group identity

was facing an existential threat:

"it surprises me that they'd remove that label when it's very clearly something

that exists. […] I'm now a member of an endangered species." (Geminus)

*A move in the wrong direction: Specificity vs generalisation*

The absorption of AS within ASD in the DSM-5 was perceived to be a mistake.

Participants believed AS was something specific that should not, or cannot, be

subsumed by another category:

"why would you need to remove it when it's something specific in itself? You

can't- you can't group it up with anything else really." (Nexus)

Two-thirds argued that diagnostic trends were going in the wrong direction by

becoming more generalised:

"they've brought all of these conditions under the- the umbrella of autism

spectrum disorder. […] See I don't think it's like that, I think it branches off in a

few places […] you can find different groups of people that- that collectively

have different groups of symptoms" (Kev)

Participants expressed fears that the generalisation was misleading and would result in people being "more ignorant about the condition" when in actuality there were "massive differences" (Nexus)

"[It's] misleading, like… like calling blue 'yellow' just because they're both colours. It's not gonna be the same thing" (Poe)

There was a strong concern that the broad diagnosis of ASD, rather than a more specific classification of AS, was likely to be detrimental and lead to poorer, less individualised support. Bill emphasised that support needs to be "tailored to the person" and that this change countered that. Kev was worried that the changes were "making it harder for those that provide support" by taking away valuable information for personalised assessments, something which he had struggled with in secondary school, where he received generic support for students with learning disabilities. Ethan agreed:

"if you […] just say, 'I'm on the autistic spectrum' and they're gonna go, 'well that's great, you could have any number of a thousand different things', whereas if you turn around to them and go 'I have Asperger's' they go,' Ah! Ok, we know exactly'." (Ethan)

For Mr Blue, the changes represent an over-generalisation, which he emphasises with a blunt comparison:

"wouldn't the world be a much more bad place if, instead of being classified with cancer you were just classified with dying?" (Mr Blue)

However, some participants did also tentatively suggest some potential positives to generalisation, namely the simplification, although Kev felt this was unlikely to translate into practice:

> "putting it under one big umbrella can make it easier for some people to understand" (Ethan)
>
> "It does simplify it down, um… but I- I think perhaps that only looks good on paper." (Kev)

*Future generations will suffer*

Whilst many participants felt that the changes would have little impact on them personally, they voiced strong concerns about younger people, believing they would find it "a lot harder for people to actually get a diagnosis" (Bill), and thereby receive appropriate support. Ethan felt that his opportunity to go to a specialist school may be unavailable in the future when individuals "could be much, much worse off". Others agreed that support will not be as easy to come by and people will "struggle to get the help they need" (Geminus), and be more isolated.

> "it makes me concerned about my brother, although he's already been diagnosed, I worry he won't get enough support, and it won't be the same quality as the support I got, and the possibility of that makes me very upset." (Bill)

Asper believed that the changes meant *"a lot of people are going to obviously suffer"* because an uninformed general public will think that people are "making too much out

of it, they're exaggerating it".  He also felt there would be an indirect, psychological impact on him and his generation:

"now we are the ones that have to feel guilty, because other people aren't going to get the same chance" (Asper)

*Changes in the DSM reinforce negative messages from society*

Most participants inferred that the changes showed people with AS were not a high priority for the medical establishment.  Cloud felt AS "should matter" because people are still experiencing problems and need support.  The 'should' implies that he believes AS experiences do *not* matter.  Asper agreed:

"people will think that it's- that because of the mildness of [high functioning autism], that it's not as important […] people can just brush it aside, and go it doesn't matter, when it can still cause a lot of damage." (Asper)

Several participants agreed the change was undermining of the severity of their symptoms, could mean that "that people stop taking the Asperger's Syndrome diagnosis seriously" (Geminus), and may lead to less support:

"they'll consider it less serious, because if it's in a position where it can be removed then people must assume that it's not as bad as first thought" (Cloud)

Some inferred that the medical establishment simply "don't think it's worth the time" (Cloud):

"it's like they don't want to put the time into it […] when I originally found out it was, wow I'm stunned […] it seems more as though they've just gone, 'oh there's just too much work, scrap it'." (Mr Blue)

Others though suspected it had more to do with financial than clinical decisions, blaming lack of money:

"people don't want to do the expensive research […] it makes you feel guilty and it makes you feel, just really angry that […] people are gonna go through the same [as me], and they're not gonna have the happy story at the end." (Asper)

### *"What they're doing is stupid as hell": Fear, anger and confusion*

Participants on the whole disagree with the changes in DSM-5. They felt AS was distinct from other forms of autism, and that the High Functioning Autism (HFA) label was misrepresentative of their experiences. However, some did feel the HFA diagnosis might reduce stigma. Ultimately though, participants felt a renewed sense of identification with the AS label and rejected the current model. They expressed fears around the impact that the changes would have on them in future years.

### *There is a difference … but that difference is hard to define*

The majority of the participants felt that AS was experientially distinct from other forms of ASD. Several participants suggested it was "quite easy to identify whether somebody has one or the other" (Kev).

"not only do I have [AS] myself, I've known many people who've got it and, there's a clear you know, difference in their behaviour from [others with HFA] (Geminus)

However, participants were aware of that it was "difficult to, to define exactly what [AS] is" (Kev) and the difficulty of the diagnostic task:

"I think the trouble they've probably got though is that AS is sort of, the terms are so broad, that where does it branch out from being AS into other things?" (Bill)

*Rejecting the HFA label: Confusing and misrepresentative*

There was a rejection of the HFA label from the majority of the participants, most strongly expressed by Geminus:

"[I'd be] insulted to be honest. [...] I'm not sure what they'd diagnose me with anymore, but… if they did diagnose me with that, I don't think I'd be pleased." (Geminus)

For some participants this rejection of the diagnosis involved an angry resistance toward professional perspectives more generally, not least because psychiatrists were seen as disconnected from the experiential realities and "aren't the ones having to live with it." (Cloud)

"you can call me whatever the f- like the hell you want […] I know who I am and I'm always gonna be this way […] what they're doing is stupid as hell like." (Poe)

"I've got a better grasp on this than the people in the white coats, so they can say what they want, but it's not gonna change anything. […] I feel assurance, that while they're saying that up is down, I'm still saying that up is up" (Mr Blue)

Many felt HFA was inappropriate because they believed it implies a higher level of impairment than AS. Geminus suggested that the public view ASD hierarchically, with AS as the "superior of the autistic species", and that they would assume that people with HFA were "less intelligent" than those with AS. Others also felt the HFA label would have consequences in the social world:

"I get the impression high functioning autism is considerably… worse than, erm or higher up on the spectrum […] I wasn't even 100% comfortable with being diagnosed with Asperger's Syndrome so to be even then shuffled up even higher on it is like, well, now you're just clearly misrepresenting me" (Poe)

"I consider autism to be a bit more of an impairment. So perhaps […] I'd feel even more sort of put out from people and stuff like that." (Cloud)

There were also concerns that the word 'high' in HFA could be confusing to the general public, who may equate that with higher impairment (Ethan), or with chaotic or hyper behaviour (Asper). However, Nexus rejected the label 'high functioning' because he felt it misrepresented his level of need in the other direction:

"the fact that it's saying we're all high functioning is wrong 'cause, I'm not high functioning, and yet it's trying to label me as that."

Most participants found the HFA label damaging, however, some did think it could represent a "nicer way to spin it" (Mr Blue), potentially implying better functioning, and therefore possibly resulting in less stigma:

"actually to me it sounded better. That makes it sound like really like mild and like it doesn't really affect you too much, but there'd maybe be slightly less stigmatism" (Poe)

"maybe people won't be so scared of it. […] If I had said I have High Functioning Autism, more people would probably accept that" (Asper)

*"That's the label that works": Fear and anger about losing the AS diagnosis*

Ultimately, and despite some attempts to be optimistic about the changes, the typical rejection of HFA was complemented by a strengthened sense of identification with the AS label, even for those who were not entirely happy with it:

"I'm not having someone say that I don't have Asperger's, 'cause like… yes I very much do. That's the label I've had, that's the label that works, that's the label I'm sticking with." (Geminus)

"if that label was just to be removed, my life is pretty much down the drain there […] I wanna keep the label, despite all the problems it's caused." (Nexus)

"I wouldn't want them to say 'oh no you don't have Asperger's'. […] I've based a lot of my self-learning, about myself, on- on that." (Kev)

Despite the participants' focus on future generations' suffering, there were also concerns expressed for themselves. The changes were perceived to threaten how AS is viewed publicly, which could lead to poorer understanding, and a return to "thinking he's just throwing a sickie" (Asper).

> "I guess some people will start to question what is actually wrong with me, you know, because people are gonna start to go, but Asperger's Syndrome isn't a thing anymore is it? So what is wrong with you?" (Geminus)
>
> "there may come a point where you sort of start saying 'I've got Asperger's' and people start saying 'what's that?'" (Ethan)

Some participants even felt that the changes were likely to cause identity confusion in themselves:

> "to be reassessed now and them to tell me I don't have it, I think in one way that might throw up a lot of confusion for me and be like, well… what am I then?". (Poe)
>
> "I certainly feel that I do definitely have it, if I was all of a sudden to be told that I didn't… I think I would start wondering, so why do I feel like this so often…" (Ethan)

However, both Kev and Poe, took a more sanguine approach, believing that changes in the DSM were unlikely to filter down, and that the "stereotypical perception of Asperger's will still stick about" (Kev).

"Even if the government said [AS is] no longer a classification, people are

gonna still know about it and talk about it. (Poe)

But Mr Blue put more emphasis on the perspective of people in power – psychiatrists,

service-providers and researchers:

"to diagnose, classify and research we need these things, not just for my

condition, just for like conditions in general. Sometimes labels need to exist."

**Discussion**

The current study investigated the opinions of young adults with a diagnosis of

AS about the removal of their diagnosis from the DSM-5. The main themes that

emerged from the findings were related to the experience of the AS diagnosis itself, the

DSM-5 representing a step backwards and the fear, anger and confusion felt by

participants as a result of the changes. Reactions to the removal of the AS diagnosis

from DSM-5 were predominantly negative, with participants rejecting the changes for a

variety of reasons.

Participants in this study identified strongly with the AS diagnosis and were

grateful for it. The diagnosis provided reassurance for why they felt and behaved

differently to others and it provided an explanation to others so that certain allowances

would be made, for example, at work. The view that the AS diagnosis is a useful

explanation for behaviour that deviates from social norms, thus facilitating social

acceptance, is supported by Brosnan and Mills (2015).

The current participants did not find their AS diagnosis stigmatising. This speaks to the relationship between identity and stigma. By identifying enthusiastically with the label they are strengthening their "Aspie" identity and, in doing so, rejecting any stigma that they may have felt previously, the stigma reported in previous work with younger participants (e.g., Baines, 2012).

The perception of stigma associated with AS compared to ASD is of interest in this discussion. The participants in this study indicated that ASD would be a more stigmatised diagnosis or identity than AS. Ohan, Ellefson and Corrigan (2015) compared responses to vignettes that had labels of AS, ASD or no label and found no differences in stigma for the different labels among a sample of the general public. They noted that their findings did not support the concern regarding DSM-5 that the ASD diagnosis was more stigmatising. However, the subject of the vignette was a child so adults may be subject to different attitudes.

It is likely that the participants perceive a diagnosis of ASD as being related to a greater degree of impairment than one of AS. Perhaps Woods (2017) suggestion that the term "Autism Spectrum" be used, without the word "Disorder", is of relevance here? Kenny et al. (2015) surveyed a large number of adults in the UK who were members of the autism community (including parents and supporters of autistic people). Autistic people and their families and friends preferred the term "autistic" while professionals tended to endorse "person with autism". This use of identity-first language among the autism community indicates acceptance of the diagnosis as part of a person's identity (Hulbert & Chalmers, 2002). Thus, is makes sense that if an individual's identity is formed around an "Aspie" community, as indicated by the participants in this study, it may be difficult to adapt to a new description of their identity, even if that new description is not so dissimilar to the previous one. While the broader autism

community may be just as supportive as the "Aspie" community, it can take time to acclimatise to such a change.

While, the overall sense was that receiving an AS diagnosis was positive for participants, allowing them to access services, understand their differences, and engage with the AS identity some participants did acknowledge AS as a stigmatised identity. This conflict was reflected in Singh's (2011) study, where some participants noted that they were slow to disclose their diagnosis in certain social or vocational settings despite the fact that the diagnosis was embraced for the most part, indicating that this is an ongoing source of conflict for those diagnosed with AS, though adults with a diagnosis of ASD report similar conflict (Davidson & Henderson, 2010).

Along with greater social acceptance, the participants in the current study also reported that the AS diagnosis had resulted in access to services that mainly proved beneficial and helped them to achieve personal and professional satisfaction. They expressed gratitude that they had received such support but they were very concerned that young people who share similar traits may not receive such support in the future or, if they do, that it could be more generic in nature. It was clear that the specialised nature of the support was what was so appreciated.

Participants in this study were generally happy with AS diagnosis as they felt that DSM-IV "had it covered". If anything, they reported it could become even more specific (e.g., subtypes of AS), echoing the views of participants in Singh's (2011) study. There was a sense of defiance observed as current participants felt that the AS diagnosis worked for them so there was no good reason to change it. They felt that their very identity was under threat by its removal from the DSM-5.

This level of identification with, and commitment to, a diagnostic label is in contrast with various service user groups in the mental health literature, where

advocates are actively rejecting such labels (Timini 2013). A major benefit of the diagnosis that was prevalent across the current study may explain the difference in the lived experience of a diagnosis of AS and a mental health condition. This was related to identity and the Aspie culture. This identification with others who have the same diagnosis allowed the participants to focus on the positive aspects of being an Aspie. Pride in the AS identity facilitated a sense of belonging through recognising that others have similar experiences, including many gifted individuals throughout history.

In contrast to other service-user groups, Aspie activists take pride in the label and place it at the centre of their culture (Singh 2011). They focus on the strengths of people with AS, including enhanced memory and intellectual skills (Smith Myles and Simpson 2002). This may be protective, compared to a label like schizophrenia, which is highly stigmatised (Thornicroft et al. 2016) or Autism, which may be associated with greater difficulty than AS (Ruiz Calzada, Pistrang & Mandy, 2011). Furthermore, the prevalence of positive Aspie role models may help people with that diagnosis to realise their potential. By making the diagnostic category less specific, the DSM-5 guidelines make it more difficult to identify with such role models.

A small number of participants mentioned that the new guidelines are more parsimonious, though they too had reservations about the real world implications of the changes in terms of support for people with AS. As well as the support provided being less individualised and, therefore less useful, participants highlighted that support will become less accessible for people with symptoms characteristic of AS because the DSM changes will make it more difficult for them to receive a diagnosis. The emotions reported across the nine interviews in the present report reflected previous analyses of online comments, particularly the theme of "fear, anger and confusion" as these

emotions were reiterated in previous analyses of online comments (Giles 2013; Singh 2011).

For those who provide support for people with AS, or ASD Level 1 in the future, the current findings should be considered. The specificity of the AS diagnosis should not be forgotten as the current sample of people who live with this diagnosis feel that it represents them well for the most part. They report an in-group experience that has helped them come to terms with, and celebrate, how they differ from members of mainstream society. By broadening the diagnostic criteria, there is a danger of making the group too large and too heterogeneous to share these experiences.

Perhaps there is a lesson to be learned from other service-user groups who provide support for specific symptoms, such as Hearing Voices Groups, which are often preferred by service-users to individual therapy (Ruddle, Mason and Wykes 2011). Such groups sit outside of mainstream psychiatry and no formal diagnosis is necessary. By focusing on shared experiences, such groups offer support in a similar way to the Aspie culture.

It is important to note that ICD-10 guidelines are predominantly used in the United Kingdom (UK), where this study was conducted, though the DSM is also consulted (Rogers et al. 2016). However, the Aspie culture is global and is facilitated by the internet and popular culture in general. The reactions of the participants in this study illustrate that the changes are salient for people with a diagnosis of AS in the UK and, as such, warrant discussion and analysis.

To the authors' knowledge, the current study is the first of its kind to be published since the DSM-5 changes were made as interviews were conducted face to face with people with AS. This allowed for a more thorough engagement with each participant. The interviewer in the current study had insider status due to having a

diagnosis of AS, received in childhood. For those who have difficulty with face-to-face interactions, the knowledge that the researcher shared a similar identity and experience appears to have made it easier to build trust. The authors believe this to be a strength of the current study. However, potential participants may still have felt discomfort facing an unfamiliar situation, and it can be difficult to recruit participants for studies of this kind.

The relatively small and homogenous sample may impact on the generalisability of the findings from this group to the wider community of people who have a diagnosis of AS. In particular, the all-male sample is a limitation and future work should include a gender-balanced sample. In this case, the participants who came forward were exclusively male. Future work should identify optimum methods for recruiting a heterogeneous sample, particularly in terms of gender and ethnicity.

Despite the above limitations, the data gathered in the current study were rich and informative. Previous work, analysing online comments, has a wider reach in terms of numbers of contributors but the current work reflected an important opportunity to conduct in-depth, face-to-face interviews with the individuals most affected by the DSM-5 changes after those changes had occurred and the initial transition period had passed.

The current findings reflect the voices of those most affected by changes to ASD diagnostic labels and have implications regarding the suitability of the new DSM-5 criteria and the ongoing support available to individuals across the autistic spectrum. They emphasise the protective nature and sense of belonging engendered by being part of a community of people with similar experiences and by having strong role models to look up to. Furthermore, they highlight the need to include the autism community in meaningful consultation before changes to diagnostic labels are made.

**Declaration of conflicting interests**

The authors declare no conflicting interests.

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