The merging of Asperger’s with autism in the DSM-5: Exploring the impact on those previously diagnosed

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Decision to merge four previously separate categories into autism spectrum disorder in the DSM-5
Designed to improve diagnosis reliability
Claim won't change diagnosis rates (American Psychiatric Association, 2013)
Concerns will reduce number diagnosed (Wakefield, 2013), lead to less services (Vivanti et al., 2013) and more stigma (Ohan, Ellefson, & Corrigan, 2015)
May have impact on identity of those previously diagnosed (Singh, 2011)
Previous studies have focused on professionals, general public or used online data
Asperger's vs Autism

- Both pervasive developmental disorders which affect social interaction and patterns of behaviour and interests
- Asperger's doesn’t have associated language and cognitive deficits (Colman, 2014)
- Growth in rates of diagnosis (Halfon & Kuo, 2013)
- Appears to be different public perceptions (Carmack, 2014, Vroom, 2013)
The decision to change the criteria

- Driven by poor inter-rater reliability in diagnosis (Buxbaum & Baron-Cohen, 2013)
- Other changes in criteria
- Impact on professionals, researchers and those previously diagnosed
- Diversity in response from Asperger's community (Singh, 2011)
Theme 1: Asperger's as a social or health identity

- Distinguishing between normality and disease (Barker & Galardi, 2015)
- Trivialisation of more severe autism (Kenny et al., 2016; Kite, Gullifer, & Tyson, 2013)
- Greater recognition of all on spectrum (Fusco, 2014; Kite et al., 2013; Parsloe & Babrow, 2016)
- Labels not helpful (Kenny et al., 2016; Parsloe & Babrow, 2016)
Theme 2: Changes to diagnosis

- Diagnosis now simpler (Fusco, 2014; Kite et al., 2013)
- Criteria more imprecise (Parsloe & Babrow, 2016)
- Fears of losing diagnosis (Fusco, 2014; Linton, Krcek, Sensui, & Spillers, 2014; Parsloe & Babrow, 2016) and hence losing services (Fusco, 2014; Giles, 2014; Parsloe & Babrow, 2016; Spillers et al., 2014) and understanding from the general public (Giles, 2014; Kenny et al., 2016)
Theme 3: Changes to identity

- Loss of identity and differentiation from autism (Fusco, 2014; Kenny et al., 2016; Parsloe & Babrow, 2016; Spillers et al., 2014)
- Will face more stigma (Fusco, 2014; Kite et al., 2013; Linton, 2014; Parsloe & Babrow, 2016)
- The two aren't qualitatively different (Giles, 2014; Linton et al., 2014)
- New criteria are more inclusive (Giles, 2014; Kenny et al., 2016; Linton et al., 2014; Parsloe & Babrow, 2016)
Theme 4: Neutrality about the change

- Not that important (Giles, 2014; Parsloe & Babrow, 2016; Spillers et al., 2014).
- Some professionals will continue to use term descriptively (Fusco, 2014)
- Rejection of psychiatry and the DSM (Giles, 2014; Kenny et al., 2016; Spillers et al., 2014).
- Conspiracy, corruption and incompetence (Parsloe & Babrow, 2016)
Opinions are varied and qualitative research can document and synthesise this diversity.
Still relatively recent research.
Need to emphasise voices of those previously diagnosed.
Existing research based on international online forums (Giles, 2014; Linton, 2014; Linton et al., 2014; Parsloe & Babrow, 2016; Spillers et al., 2014), limits in generalisability and elaboration of responses. May also have bigger impact on those living in Australia (Amaze, 2012).
Seek to overcome past shortcomings with face-to-face interviews with those previously diagnosed with Asperger’s regarding the DSM change, its impact and concerns about its impact in the future.
Qualitative research design, series of semi-structured interviews (aiming for 6-10 adult participants)

Will recruit participants through social networks/snowballing, and if needed through existing networks. Option of attending in friendship pairs for social support (Highet, 2003)

Expect 80% male and 20% female

Interview guide with open-ended questions and probes will be piloted on volunteer and refined (Bourgeault et al., 2010).

2 consent forms: one for sharing in network and one for participation

Will be audio recorded and given reimbursement for their time, expected to be 30 mins-1 hour in duration

Data will then be transcribed and analysed (using thematic analysis)
Ethical Considerations

- Minor risk may experience some mild emotional discomfort.
- Will be minimised by use of friendship pairs, by experience of research supervisor, by consulting/piloting interview guide and by participants electing to present and reflecting on their opinions.
- Participants will be provided with details of support services if required.


References