

## Whither Asperger's Syndrome? Revisiting the DSM-5 Diagnostic Revision

Archana Bharadwaj MD, MPH, CHES<sup>1,2</sup>, M. Ariel Cascio PhD<sup>1</sup>

- 1. Central Michigan University College of Medicine
- 2. Washington University in St. Louis Department of Anesthesiology



Anesthesiology

#### Introduction

- The Diagnostic and Statistical Manual (DSM) has served as the gold standard for diagnosis and management of mental health and developmental disorders.
  - Diagnoses have shaped lived experiences and access to care.
- In the DSM-5, Asperger's and autism were grouped under the term Autism Spectrum Disorder (ASD).
  - Change due to inconsistent application of diagnostic criteria.
- Concerns voiced by the Asperger's community in response to the proposed changes included:



Inability to access support services.



Heightened stigma related to the term autism.



Loss of identity associated with the Asperger's terminology.

• In 2013, Cascio posited that three theories may explain the fate of Asperger's after its reclassification under the *DSM-5*:

## Transient Mental IIIness (Nadesan)

 Diagnosis that may have had temporary meaning that has now been lost.

# Diagnosis You Have to Fight to Get (Dumit)

 People identify with Asperger's as a diagnosis, but its meaning is no longer recognized by clinical professionals.

## Demedicalization (Conrad)

 Asperger's is no longer thought to be a disorder, but a personality trait that does not need to be treated or cured.

## Objective

• To identify which theory best captures what we see in the literature with respect to the fate of Asperger's syndrome after its removal from the DSM-5.

### Methods

 Non-scoping literature review, including peer reviewed articles, theses, and dissertations.

## Inclusion Criteria

- Empirical Research
  - Perspectives on individuals on the spectrumInvolves
- perceptions of Asperger's •Addresses DSM-5 change

## Search Methods

 Books on Autism, Neurodiversity, and Social Sciences
Search Terms: ("DSM- 5" OR "DSM V" OR identity) AND (Asperger\*)

### Results

## Eligible Articles

- Six peer-reviewed articles.
- One book chapter.
- One indexed doctoral dissertation.

## Demedicalization

"Describing oneself as autistic is an extremely important and positive assertion about oneself, it means that one feels complete and whole as one is."

#### A Diagnosis You Have to Fight to Get

 Concerns about losing services and some children lost access:

"They said he was too high functioning. That even though we have had a couple of episodes where my son had gotten out of control and had physically attacked me...they didn't think he needed [Therapeutic Support Staff] TSS on a long-term basis or even a short-term basis."

Lack of school system understanding and knowledge leading to struggles with the school system to obtain services.

#### **Conclusions**

- Few publications addressed change despite fears.
- Most publications focused on impacts on diagnostic rates with fewer ASD diagnosis under the new criteria.
- Many pieces support the demedicalization theory while some support the diagnosis you have to fight to get theory.
- Majority of works explicitly or implicitly rejected the idea that Asperger's is "transient"; it remained meaningful as a separate concept from autism, at least in early publications.
- More research should explicitly investigate identification with the Asperger's label, especially in light of the growing infamy of the eponymous doctor.

# Explanations for a mixed pattern in data:

Asperger became a term of identity prior to the *DSM-5* change.

Restrictive DSM-5 criteria may be a barrier entry into the medical system.

Limited publications restricts conclusions about diagnostic trends.

Intentional distancing from label due to Hans Asperger's connection to the Nazi movement.

## References

- 1. American Psychiatric Association., and American Psychiatric Association. DSM-5 Task Force. 2013. *Diagnostic and statistical manual of mental disorders : DSM-5*. 5th ed. Washington, D.C.: American Psychiatric Association.
- 2. American Psychiatric Association., and American Psychiatric Association. Task Force on DSM-IV. 1994. *Diagnostic and statistical manual of mental disorders : DSM-IV*. 4th ed. Washington, DC: American Psychiatric Association.
- 3. Cascio, Ariel. 2013. "Is Asperger's Syndrome a Transient Mental Illness? Encountering the DSM -5." EASA Medical Anthropology Network / AAA Society for Medical Anthropology / Universitat Rovira i Virgili Joint International Conference, Tarragona, Spain.
- 4. Conrad, Peter, and Alison Angell. 2004. "Homosexuality and remedicalization." Society 41 (5): 32-39.
- 5. Dumit, J. 2006. "Illnesses you have to fight to get: facts as forces in uncertain, emergent illnesses." Social Science & Medicine 62 (3): 577-90. https://doi.org/10.1016/j.socscimed.2005.06.018.
- 6. Kenny, Lorcan, Caroline Hattersley, Bonnie Molins, Carole Buckley, Carol Povey, and Elizabeth Pellicano. 2015. "Which terms should be used to describe autism? Perspectives from the UK autism community." *Autism: the international journal of research and practice* 20. <a href="https://doi.org/10.1177/1362361315588200">https://doi.org/10.1177/1362361315588200</a>.
- 7. Nadesan, Majia. 2013. "Constructing Autism: Unravelling the "Truth" and Understanding the Social." Constructing Autism: Unravelling the 'Truth' and Understanding the Social: 1-248. <a href="https://doi.org/10.4324/9780203299500">https://doi.org/10.4324/9780203299500</a>.
- 8. Riley, Pamela. 2019. "DSM-5, Asperger's Syndrome Diagnosis, and Mothers' Experiences with Mental Health Services DSM-5, Asperger's Syndrome Diagnosis, and Mothers' Experiences with Mental Health Services." Doctorate., College of Counselor Education & Supervision, Walden University.