The misdiagnosis and mental health consequences of late diagnosed autistic women:

The importance of early support

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My Story…

Dropped out of school at 14

Developed severe agoraphobia, anxiety and depression

Was given a cocktail of medications

Finally received therapy after several years

Multiple mental health 'crises'

Labelled 'avoidant' and 'borderline' personality

Diagnosed with Asperger's Syndrome at 23

Post Diagnosis Support

Pros:

- Learnt more about my needs

- Better able to communicate these

- Helped mental health professionals adapt my care

Cons:

- No longer qualify for some mental health services

- Professionals continue to misdiagnose and not adapt

Why do mental health professionals miss autistic women?

Research Background

- Autistic females tend to get diagnosed later than males - many not until adulthood (Begeer, et al., 2013)

- Could be due to masking autistic traits (Hull et al., 2019)

- Also due to professionals misdiagnosing with other psychiatric conditions (Bancroft, et al., 2012)

Autistic women discussed how pre-diagnosis their concerns were often dismissed by their GPs, some reported misdiagnosis:

"You go to your doctor...and you get diagnosed with multiple personality disorder which is completely opposite to what you are."

Bargiela, Steward, Mandy (2016)

" Autistic and possibly autistic participants were more likely to report receiving mental health diagnoses compared to non-autistic participants, but were less likely to agree with those diagnoses."

- Autistic charactistics confused with mental health symptoms

- Mental health issues perceived as being caused by ASC

- Healthcare professionals' lack of autism awareness

Au-Yeung et al (2018)

My PhD Research

Phase 1

Are there any differences in the mental health of autistic women with a diagnosis, those without, and autistic men?

- More other psychiatric diagnoses in undiagnosed autistic women?

- Higher rates of anxiety and depression in women without diagnoses?

- More other psychiatric diagnoses before autism diagnoses are made in women?

Phase 1 findings

Survey 1:

Sample: 153 diagnosed autistic women vs 690 potentially undiagnosed autistic women

Method: AQ, EQ, ASC status, and declaration of other psychiatric diagnoses

Key findings:

- Diagnosed autistic women 1.6 x more likely to have other diagnoses

- Potentially autistic women 1.3 x more likely to be diagnosed with BPD

Survey 2:

Sample: 90 diagnosed autistic women vs 77 potentially undiagnosed autistic women vs 27 diagnosed autistic men

Method: Additionally - Social functioning measure, GAD-7 and PHQ-9

Key findings:

- Equally high anxiety and depression in both groups of women

- More mental health conditions in diagnosed autistic women than men & ASC more likely to be diagnosed last (57% vs 26%)

Clinicians confuse autistic traits in women with other conditions that have overlapping features

Many undiagnosed autistic adults are struggling with their mental health without the appropriate support

My PhD Research

Phase 2

Are autistic women perceived differently to autistic men on their social behaviours?

- Do non-autistic peers form better first impressions of autistic women than autistic men?

- Is this related to higher levels of camouflaging for autistic traits?

- Does this correlate with a later age of autism diagnosis?

Phase 1 findings

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Sample: 40 autistic women, 40 autistic men, 40 non-autistic women, and 40 non-autistic men

Method: Filmed having a casual conversation with a research assistant. and given the Camouflaging Autistic Traits Questionnaire. Rated by 127 non-autistic peers using the first-impressions scale.

Key findings:
- Autistic women were rated more positive than autistic men, but both were rated more negatively than non-autistic people

- Camouflaging did not correlate with these impressions

- Better first-impressions was associated with a later age of autism diagnosis

The cycle
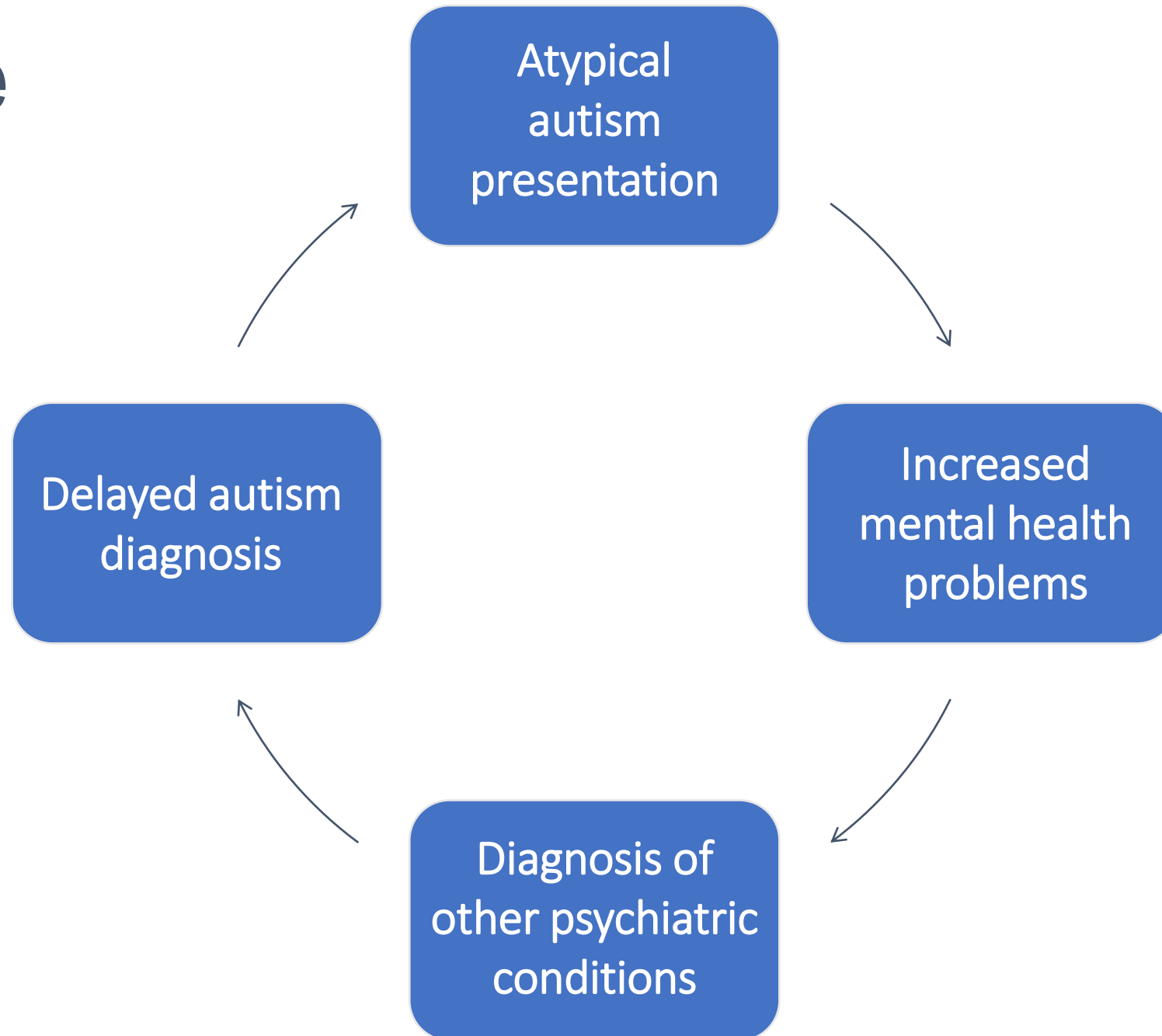
What needs to change?

Earlier identification of autism:

- Fewer misdiagnoses and incorrect treatments

- Better adaptations to current mental health treatments

- Facilitates the creation of a more autism-friendly environment (Fernell et al. (2013)

- More time to find a place in a community of autistic individuals who understand and support one another (Kapp, 2020)