



# Misdiagnosis and under representation of females in autism data, and gender bias in autism assessment and support services

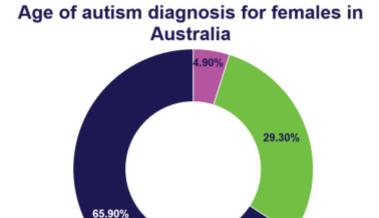
This short presentation is based on the Olga Tennison Autism Research Centre at La Trobe University's (OTARC) response to the Senate Select Committee on Autism, Term of Reference C (pg. 8). You can find a full copy of the submission <a href="https://example.com/here">here</a>.

# Gender and early diagnosis

<u>OTARC</u>'s research has found that autistic females tend to be diagnosed less often and later than males, leading to lost chances for females to gain early access to services. For every female diagnosed with autism there are roughly three to four males (Loomes et al 2017; Fombonne 2009).

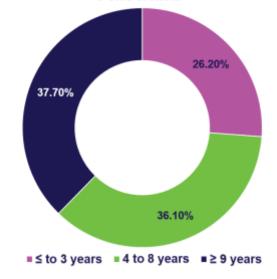
The Study of Australian School Leavers with Autism (<u>SASLA</u>; funded by the <u>Autism CRC</u>) found that males are more likely to be diagnosed at 3 years of age or under than females. SASLA study females (participants aged 15 to 25) were far more likely to be diagnosed at 9 years or older than were males.

You can compare the age of diagnosis for females and males in the SASLA study by using the sliding scale on the image below.





■≤ to 3 years ■ 4 to 8 years ■≥ 9 years



# Why are females less likely to be diagnosed?

- 1. Females may be more willing, able, or taught to mask\* their autism.
- 2. Females tend to want friendships and develop strategies like watching and imitating other girls.
- 3. The early social success that females have becomes harder to sustain as they age, due to the increased complexity of the social world.



4. The 'special interests' of females may be more 'gender typical' and so not stand out as being unusual (e.g., toy animals, Disney).



- 5. Females may cope with strong emotions by turning them inward (e.g. self-blame) rather than outward (e.g. observable challenging behaviours), making these signs less obvious.
- 6. Tools used to diagnose autism have a male bias and so are less effective at detecting autism in females.
- 7. Professionals who diagnose autism might not be aware of the different ways that autism can present in females.

\*Masking is replicating social behaviour that is more non-autistic or hiding behaviour that might be viewed as socially unacceptable (Lai et al, 2016). Note: the <u>Autism Aspect Masking</u> image has not been modified.

Opinions from our community on the reasons for gender differences in diagnosis:

"I think it is so important that diagnostic services and support services are aware that females may (sic) present differently and may have different support needs. I also think this message needs to get out to the general community as many families and individuals, still to this day, may not think their daughter/ themselves are autistic due to this misconception and this may prolong seeking a diagnosis and access to appropriate supports which can have detrimental effects on the individual. I think a big part of this would also need to include raising awareness among educators and GPs (who are usually the first point of contact regarding developmental concerns)."

(Individual who works with autistic people, SASIA community)

"We need to re-educate the medical and diagnosis profession on the myth that autism is primarily (a) male condition. Coupled with that is the need for a new set of criteria to readily diagnose females on the spectrum."

(Family member of an autistic individual and works with autistic people, SASLA community)

### Conclusions

- 1. Females are less likely to be referred for assessment than males because their autism symptoms may be less pronounced or overlooked in the absence of co-existing disabilities.
- 2. Referred females are less likely to get a diagnosis of autism than males because of a male bias in diagnostic tools and diagnostician's experience.

## Recommendations to the Select Committee

Thorough training of educational, medical, and allied health staff on the early presentation of the male and female autistic phenotype to reduce the age of diagnosis, particularly in girls.

# Acknowledgements

The Olga Tennison Autism Research Centre

The Olga Tennison Autism Research Centre (OTARC) is Australia's first centre dedicated to autism research. It has a strong focus on research translation through the development of evidence-based tools, and collaborates with other autism research centres and institutes both in Australia and internationally.

OTARC is situated in the School of Psychology and Public Health within the College of Science, Health and Engineering (SHE) at La Trobe University in Melbourne, Australia.

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#### The Cooperative Research Centre for Living with Autism (Autism CRC)

The Cooperative Research Centre for Living with Autism (Autism CRC) is the world's first national, cooperative research effort focused on autism. Taking a whole-of-life approach to autism focusing on diagnosis, education and adult life, Autism CRC researchers are working with end-users to provide evidence-based outcomes which can be translated into practical solutions for governments, service providers, education and health professionals, families and people on the autism spectrum. The Autism CRC funds the **SASLA** study.

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- Register to participate in research: sign up here.
- Donate to OTARC: tax-deductible donations gratefully received here.

This presentation was created by <u>Alex Haschek</u>.

## References

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