

Girls and Women on the Spectrum: Closing the Gender Gap

RUTH ASPY, PH.D.

The Ziggurat Group
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Gender

1 in 144



1 in 34



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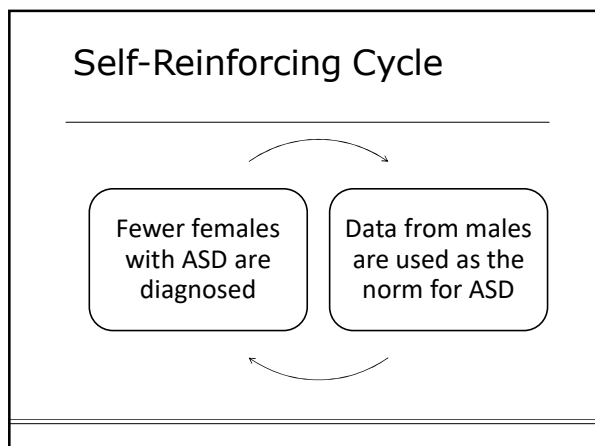
Gender Gap

One in 34 boys in the U.S. has been diagnosed with autism, compared to just **1 in 144 girls**.

But a growing body of research hints that the significant sex-based differences in autism diagnoses are a result not just of biological differences, but of a **failure to recognize ASD in girls**. (Pearson, 2013)

Pearson, C. (2013, November 26). How Girls With Autism Are Being Shortchanged. Retrieved October 16, 2014, from http://www.huffingtonpost.com/2013/11/26/girls-with-autism_n_4311015.html

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History and Research
➔
Bias

Early descriptions based on boys

Girls and Women outnumbered in Research

- Research studies have often used male-only participants.
- Eight to one male to female participants in brain imaging studies

Hannah Devlin
Science correspondent
 @hannahdev
 Fri 14 Sep 2018 10:12 EDT

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History and Research
➔
Bias

“This means that what we think we know about autism from research is actually just what we know about male autism.” (Happe, 2018)

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Level of Functioning and Identification

Two groups:

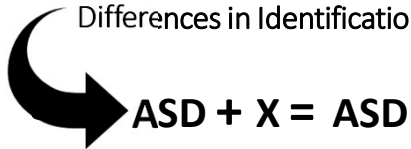
1. Severely impaired girls – readily diagnosed
2. High functioning girls – not diagnosed or late diagnosis. (Van Wijngaarden-Cremers et al., 2014)

Average or above average IQ decreased the chance of an ASD diagnosis **more** in girls than boys. (Giarelli et al., 2010)

Van Wijngaarden-Cremers et al. (2014). Gender and age differences in the core triad of impairments in autism spectrum disorders: A systematic review and meta-analysis. *Journal of Autism and Developmental Disorders*, 44-627-635.

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Differences in Identification



Dworzynski, K., Ronald, A., Bolton, P., & Happe, F. (2012). How different are girls and boys above and below the diagnostic threshold for autism spectrum disorders? *Journal of the American Academy of Child and Adolescent Psychiatry*, 51(8), 788--

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Age of Diagnosis

- On average, ASD diagnosis in females occurred **2 years after caregivers expressed concerns**.
- The average time between first symptoms and diagnosis was **longer for females** than for males.
- Girls with Asperger's are identified **later** than boys (average of 2 years)
- In **adults**, females with autistic disorder were diagnosed **later** than males

Begeer, Mandell, Wijnker-Holmes, Venderbosch, Rem, Stekelenburg, & Koort (2013). Sex differences in the timing of identification among children and adults with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 43, 1151-1156.

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The consequences of a missed or late diagnosis

- social isolation
- peer rejection
- lowered grades
- greater risk for mental health and behavioral distress such as anxiety and depression during adolescence and adulthood

(Wilkinson, 2008, p.3)

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There is a growing awareness of an increased risk for anorexia nervosa among women on the spectrum.

Some believe that the **delay may be a contributing factor in diagnosis or total failure to recognize autism in girls to the development, continuation, and/or severity of anorexia nervosa in autism.**

One researcher found that 23% of women hospitalized for anorexia met the diagnostic criteria for autism (Devlin, 2018).

Another found a rate of 35% of women with anorexia who went to clinics also have autism (Ray, 2019).

OICALI AIM Module

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There is a growing awareness of an increased risk for anorexia nervosa among women on the spectrum.

These research estimates may be inflated because ASD traits sometimes emerge as a result of anorexia nervosa, but without actually having autism. Effects of malnutrition can resemble ASD, but when nutritional status is gained those traits diminish. **It is important to be aware of the relationship between autism and eating disorders because when the two disorders co-occur the recovery rate is low and the mortality rate is higher.** These clients tend to have the **worst outcomes**, so that becomes an important reason to identify them (Clairy, 2020).

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Suicide risk in Autistic Females

Between 2013 and 2017, the cumulative incidence of suicide in the ASD population was 0.17%, which was **significantly higher than in the non-ASD population** (0.11%; $P < 0.05$). During this period, this **difference was driven by suicide among females with ASD**; suicide risk in females with ASD was **over three times higher than in females without ASD** (relative risk (RR): 3.42; $P < 0.01$).



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Reasons for Underidentification of Females with ASD

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Gender Differences

Girls on the higher end of the spectrum also have

- fewer special interests
- better superficial social skills
- better language and communication skills and
- less hyperactivity and aggression

(Gillberg & Coleman, 2000)

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Lower Levels of Restricted Interests

Research of equivalence of autism symptoms domains in males and females with ASD using the Social Responsiveness Scale (SRS) and the Autism Diagnostic Interview – Revised (ADI-R) found that cognitively able females with ASD had **substantially lower levels of restricted interests, this difference could not be accounted for by measurement bias.**

Frazier and Hardan. Equivalence of symptom dimensions in females and males with autism. Autism, 2016, Aug 7.

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Less prominent restrictive /repetitive → misclassified

Our findings raise the possibility that girls with less prominent [restricted/repetitive behaviors] may **miss being tested for ASD or get misclassified** as having **social communication disorder** . . . Regardless of the potential impact on diagnosis, our findings point to a need for further research on the development of clinical instruments that are better tailored towards autism in females.

Supekar & Menon (2015). Sex differences in structural organization of motor systems and their dissociable links with repetitive/restricted behaviors in children with autism. Molecular Autism ,6:50.

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Intensity
Special Interests

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Special Interests

Circumscribed interests may be more **social in nature** in girls

- Animals
- Dolls
- Pop-groups
- Classic literature
- Imaginary friends
- Fantasy Kingdoms
- Princesses

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Instruments

possible gender bias

Example - the RBS-R (The Repetitive Behavior Scale-Revised) **restricted interests** subscale refers to objects such as trains, dinosaurs, and toy cars—traditionally male interests.

Solomon, M., Miller, M., Taylor, S. L., Hinshaw, S. P., & Carter, C. S. (2012). Autism symptoms and internalizing psychopathology in girls and boys with autism spectrum disorders. *Journal of autism and developmental disorders*, 42(1), 48-59.

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Instrument Limitations

Standardization samples for most instruments include more boys than girls.

Lack of gender norms may lead to gender bias when “cutoff” scores are used.

Screening instruments are not designed to assess for different manifestations of symptoms (e.g., females).



Koenig, K., & Tsatsanis, K. D. (2005). Pervasive developmental disorders in girls. In D. J. Bell, S. L. Foster, & E. J. Mash (Eds.), *Handbook of behavioral and emotional problems in girls* (pp. 211–237). New York, NY, US: Kluwer Academic/Plenum Publishers.

Constantino, J.N. & Charman, T. (2012). Gender bias, female resilience, and the sex ratio. *Journal of the American Academy of Child & Adolescent Psychiatry*, 51(8), 756-758.

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Diagnostic Criteria



“It should be borne in mind that the diagnostic criteria were formulated on basis of behaviors and features found in boys” (p.633).

ASD looks different in females but the diagnostic criteria are based on boys and men.

Van Wijngaarden-Cremers et al. (2014). Gender and age differences in the core triad of impairments in autism spectrum disorders: A systematic review and meta-analysis. *Journal of Autism and Developmental Disorders*, 44-627-635.

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Gender Differences

In contrast to the camouflaging hypothesis, “affected females may present with an altered phenotype against the established diagnostic criteria” (Kirkovski, Enticott, & Fitzgerald, 2013, p. 2586).

Kirkovski, M., Enticott, P. G., & Fitzgerald, P. B. (2013). A review of the role of female gender in autism spectrum disorders. *Journal of autism and developmental disorders*, 43(11), 2584-2603.

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What is camouflaging?

- Strategies used by autistic people to minimize the visibility of their autism during social situations (Lai et al. 2011).
- Conscious or unconscious techniques which result in a less autistic behavioral presentation
- Driven by the desire to ‘fit in’ in order to appear non-autistic, and to form relationships with others (Hull et al. 2019)

Hull, L., Mandy, W., Lai, M.-C., Baron-Cohen, S., Allison, C., Smith, P., & Petrides, K.V. (2019). Development and Validation of the Camouflaging Autistic Traits Questionnaire (CAT-Q). *Journal of Autism and Developmental Disorders*, 49:819–833

Lai, M.-C., Lombardo, M. V., Pasco, G., Ruigrok, A. N. V., Wheelwright, S. J., Sadek, S. A., ... Baron-Cohen, S. (2011). A behavioral comparison of male and female adults with high functioning autism spectrum conditions. *PLoS ONE*, 6(6), e20835. <https://doi.org/10.1371/journal.pone.0020835>

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Sex differences in camouflaging behavior

- No sex difference in reporting whether one engages in camouflaging behavior
- In comparison to autistic males, **autistic females** tended to report that they camouflaged
 - **across more situations**
 - **more frequently**
 - **more of the time**

Cassidy et al. *Molecular Autism* (2018) 9:42



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Examples of camouflage

- forcing oneself to make eye contact during a social interaction
- pretending to make eye contact by looking at the space between someone's eyes or at the tip of their nose
- using working memory strategies to develop a list of appropriate topics for conversation.

Lai, M.-C., Lombardo, M. V., Pasco, G., Ruigrok, A. N. V., Wheelwright, S. J., Sadek, S. A., ... Baron-Cohen, S. (2011). A behavioral comparison of male and female adults with high-functioning autism spectrum conditions. *PLoS ONE*, 6(6), e20835. <https://doi.org/10.1371/journal.pone.0020835>

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Journal of Autism and Developmental Disorders (2019) 49:819–833
<https://doi.org/10.1007/s10803-018-3792-6>

ORIGINAL PAPER



Development and Validation of the Camouflaging Autistic Traits Questionnaire (CAT-Q)

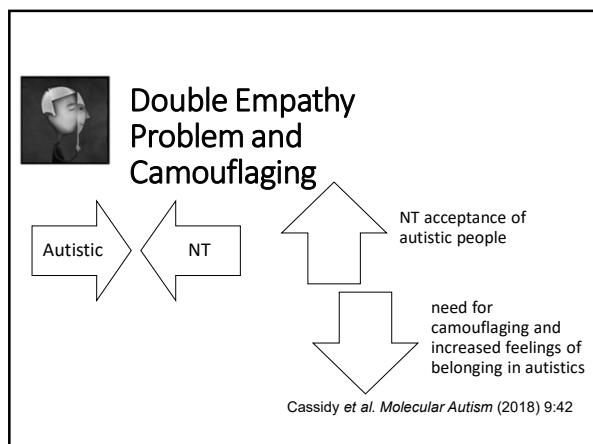
Laura Hull^{1,2} · William Mandy¹ · Meng-Chuan Lai^{2,3,4} · Simon Baron-Cohen¹ · Carrie Allison¹ · Paula Smith¹ · K. V. Petrides¹

Published online: 25 October 2018
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Abstract

There currently exist no self-report measures of social camouflaging behaviours (strategies used to compensate for or mask autistic characteristics during social interactions). The Camouflaging Autistic Traits Questionnaire (CAT-Q) was developed from autistic adults' experiences of camouflaging, and was administered online to 354 autistic and 478 non-autistic adults. Exploratory factor analysis suggested three factors, comprising of 25 items in total. Good model fit was demonstrated through confirmatory factor analysis, with measurement invariance analyses demonstrating equivalent factor structures across gender and diagnostic group. Internal consistency ($\alpha=0.94$) and preliminary test-retest reliability ($r=0.77$) were acceptable. Convergent validity was demonstrated through comparison with measures of autistic traits, wellbeing, anxiety, and depression. The present study provides robust psychometric support for the CAT-Q.

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Camouflage results in discrepancies between measures of autistic characteristics

Discrepancy research methods measure camouflaging by identifying discrepancies between different measures of social ability or autistic characteristics, such that individuals (especially females) **appear less autistic in some settings yet still meet autism diagnostic criteria in others.**

Hull, L., Mandy, W., Lai, M.-C., Baron-Cohen, S., Allison, C., Smith, P. & Petrides, K.V. (2019). Development and Validation of the Camouflaging Autistic Traits Questionnaire (CAT-Q). *Journal of Autism and Developmental Disorders*, 49:819–833

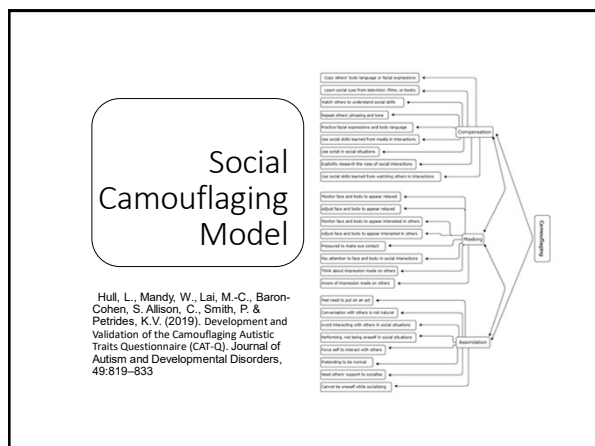
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Self-reported measurement of camouflaging

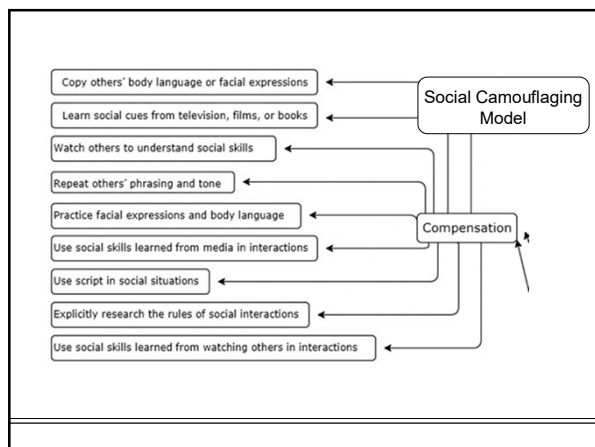
Autistic individuals can report directly on their own camouflaging behaviours, identifying strategies and intentions that might not be visible to an observer without in-depth discussion with the autistic person themselves.

Hull, L., Mandy, W., Lai, M.-C., Baron-Cohen, S., Allison, C., Smith, P. & Petrides, K.V. (2019). Development and Validation of the Camouflaging Autistic Traits Questionnaire (CAT-Q). *Journal of Autism and Developmental Disorders*, 49:819–833

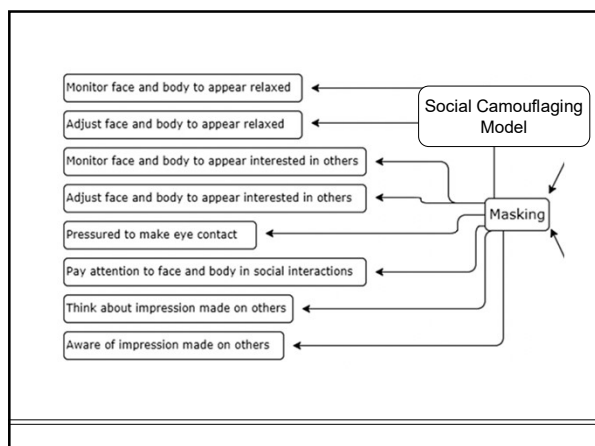
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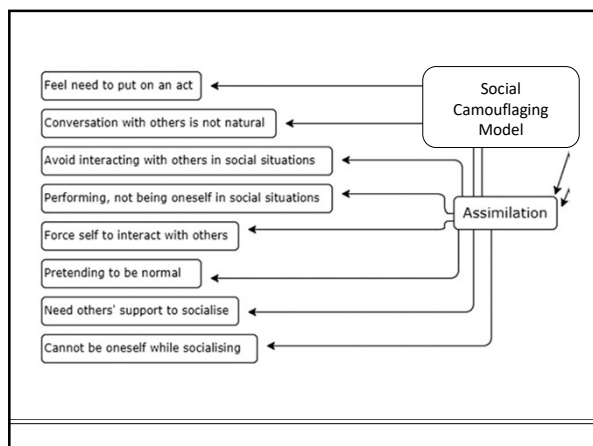
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<https://embraceasd.com/cat-q/>

The Camouflaging Autistic Traits Questionnaire (CAT-Q) is a self-report measure of social camouflaging behaviours in adults. It may be used to identify individuals considered at-risk for autism, but who do not currently meet diagnostic criteria.

- Statements: 25
- Duration: 5–10 minutes
- Type: screening tool
- Authors: Laura Hull et al.
- Publishing year: 2018
- Seminal Paper: Development and Validation of the Camouflaging Autistic Traits Questionnaire (CAT-Q) (Hull et al., 2018)

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The CAT-Q

Please read each statement below and choose the answer that best fits your experiences during social interactions. Please note that you have to score this test yourself; the radio buttons are included so you can keep track of your answers. Statements with an asterisk (*) should be reverse-scored, which we will explain in the Results section after the test.

1. When I am interacting with someone, I deliberately copy their body language or facial expressions.

1. ☐ Strongly Disagree
2. ☐ Disagree
3. ☐ Somewhat Disagree
4. ☐ Neither Agree nor Disagree
5. ☐ Somewhat Agree
6. ☐ Agree
7. ☐ Strongly Agree

2. I monitor my body language or facial expressions so that I appear relaxed.

1. ☐ Strongly Disagree
2. ☐ Disagree
3. ☐ Somewhat Disagree
4. ☐ Neither Agree nor Disagree
5. ☐ Somewhat Agree
6. ☐ Agree
7. ☐ Strongly Agree

<https://embraceasd.com/cat-q/>

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