Slide 1

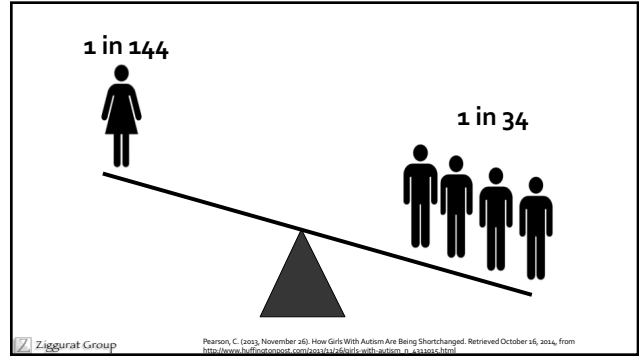**Demystifying Girls and Women on the Spectrum**
Ruth Aspy, Ph.D. & Barry G. Grossman, Ph.D.
Ziggurat Group
www.autismzig.com

1

Slide 2

1 in 144

1 in 34

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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

2

Slide 3

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)

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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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Slide 4

Male to Female Ratio

Autism 4 or 5:1	← Loomes et al, (2017)
Intellectual Disability and ASD 2:1	
Asperger's Disorder 9:1	
Happe's Hypothesis 2:1 (2018)	← **Hannah Devlin** *Science correspondent* @hannahdev Fri 14 Sep 2018 10.12 EDT

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(Fombonne, 2009), Attwood, T. (2006). The pattern of abilities and development of girls with Asperger's syndrome. Asperger's and girls. Arlington, TX: Future Horizons.; Devlin, (2018), Thousands of Autistic Girls and Women going undiagnosed due to gender bias, The Guardian.; Loomes, Hull, & Mandy (2017). J Am Acad Child Adolesc Psychiatry Jun 56(6).

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Slide 5

Self-Reinforcing Cycle

Fewer females with ASD are diagnosed → Data from males are used as the norm for ASD →

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Slide 6
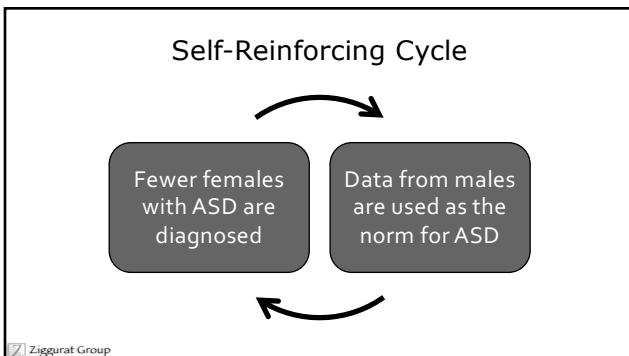
History and Research → Bias

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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Slide 7

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)

Hannah Devlin
Science correspondent
🐦 @hannahdev
Fri 14 Sep 2018 10.12 EDT

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Slide 8

It's Different for Girls: A Conversation with Four Women on the Spectrum

A panel discussion with four autistic women about their diagnosis, their work, their personal and professional relationships, and their communities. Moderated by Dr. Ruth Aspy and Dr. Barry Grossman, licensed psychologists specializing in assessment and intervention for people with ASD. Recorded live at OCALICON 2019.
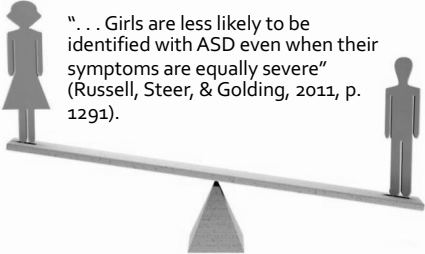
https://www.ocali.org/project/inspiring-change-podcast

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Slide 9

Gender Differences in Identification

". . . Girls are less likely to be identified with ASD even when their symptoms are equally severe" (Russell, Steer, & Golding, 2011, p. 1291).
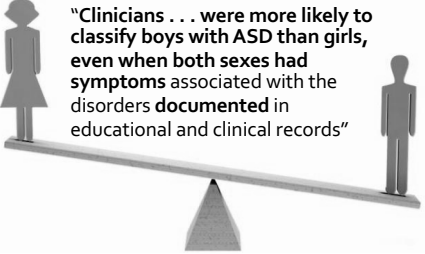
Ziggurat Group   Russell G, Steer C, Golding J. (2011). Social and demographic factors that influence the diagnosis of autistic spectrum disorders. Social Psychiatry and Psychiatric Epidemiology. 46,1283-1293.

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Slide 10

Gender Differences in Identification

"**Clinicians . . . were more likely to classify boys with ASD than girls, even when both sexes had symptoms** associated with the disorders **documented** in educational and clinical records"
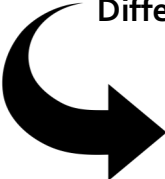
Ziggurat Group   Giarelli, et al. (2011). Sex differences in the evaluation and diagnosis of autism spectrum disorders among children. Disability and Health Journal, 3, 107-117.

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Slide 11

Differences in Identification

ASD + X = ASD

Ziggurat Group   Dworzynski, K., Ronald, A., Bolton, P., & Happe, F. (2012). How different are girls above and below the diagnostic threshold for autism spectrum disorders? Journal of the American Academy of Child and Adolescent Psychiatry, 51(8), 788-797.
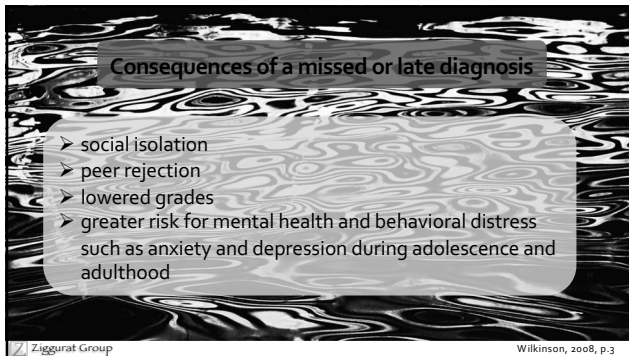
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Slide 12

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

Ziggurat Group   Begeer, Mandell, Wijnker-Holmes, Venderbosch, Rem, Stekelenburg, & Koot (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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Slide 13

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

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Wilkinson, 2008, p.3

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Slide 14

Sex Differences in Mental Health

Females with ASD are more likely to be depressed and anxious than than males with ASD (Lai et al., 2019)

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Lai MC, Kassee C, Besney R, Bonato S, Hull L, Mandy W, Szatmari P, Ameis SH (2019). Prevalence of co-occurring mental health diagnoses in the autism population: a systematic review and meta-analysis. Lancet Psychiatry. Oct;6(10):819-829.

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Slide 15

Suicide Risk in Autistic Females 2013-2017

- The cumulative suicide rate was **significantly higher for those with ASD** than those without ASD

- 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**

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Kirby, A. V., Bakian, A. V., Zhang, Y., Bilder, D. A., Keeshin, B. R., & Coon, H. (2019). A 20-year study of suicide death in a statewide autism population. *Autism Research*, 12(4), 658-666.

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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, or total failure to recognize autism in girls**, may be a contributing factor **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).

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AIM Module   https://autisminternetmodules.org

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Slide 17

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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AIM Module   https://autisminternetmodules.org

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Slide 18

The failure to identify girls with ASD has cumulative repercussions.

At the **individual** level, without identification, a girl continues her course of development without critical interventions and becomes increasingly at risk for depression, anxiety, and victimization.

At the **system** level, the failure to identify girls perpetuates this failure for future generations.

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Everything Else But ASD

Mental health dx → For SOME, diagnosis of ASD.

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Reasons for Underidentification of Females with ASD

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Slide 21

Referral Bias

Girls with ASD show different and less severe communication and social challenges. Families and professionals often attribute girls' challenges to **shyness or anxiety**. This **can** lead to fewer refe**rrals** and misdiagnosis.

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Kopp, Gillberg, & Fernell (2002). Autism spectrum disorders: sex differences in autistic behaviour domains and coexisting psychopathology. Developmental Medicine & Child Neurology, 49, 361-366.

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Slide 22

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

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(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**.

▪ Starting at age 6, females had fewer restricted interests and stereotyped behaviors than males

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

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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Slide 24

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* (p.8)

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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
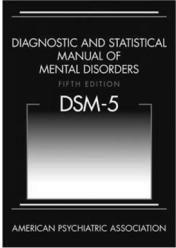
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Slide 25

Poll #2

?

Have you encountered anyone diagnosed with Social Pragmatics Disorder?

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Slide 26

Empirical evidence is NOT in support of Social Pragmatic Disorder

DIAGNOSTIC AND STATISTICAL MANUAL OF MENTAL DISORDERS
FIFTH EDITION
DSM-5
AMERICAN PSYCHIATRIC ASSOCIATION

- Autism Spectrum Disorder
- Social Communication Disorder

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https://spectrumnews.org/features/special-report/live-dsm-5-discussion/

SFARI SIMONS FOUNDATION AUTISM RESEARCH INITIATIVE

LIVE DSM-5 DISCUSSION
a virtual roundtable featuring:

Thomas Insel
Director,
National Institute
of Mental Health

Catherine Lord
Director,
Center for Autism
and the Developing Brain

Helen Tager-Flusberg
Director,
Research on Autism
& Developmental Disorders

LIVE CHAT IN PROGRESS

Submit your question now using the chat window to the left

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Intensity

Special Interests

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Slide 29

Intense Narrow Interests

"A girl with autism may be fascinated by horses or by a particular pop star," This isn't unusual among girls, and may not stand out as much as a boy who is obsessed with the Latin names of plants, for example. **"But the _intensity and narrowness_ of [her] interest is unusual."** Happé

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Slide 30

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

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Slide 32

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.

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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.
Constantio, 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).

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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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Gender Related Diagnostic Issues
Statement from DSM-5

"*In clinic samples females tend to be more likely to show accompanying intellectual disability, which suggests that girls without accompanying intellectual disability or language delays may go **unrecognized**, perhaps because of **subtler** manifestation of social and communication difficulties.*"

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To make matters worse
Masking, blending, acting, pretending, mimicking, camouflaging

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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., Wheel- wright, 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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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

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Lai, M-C., Lombardo, M. V., Pasco, G., Ruigrok, A. N. V., Wheel- wright, 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**

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CASSIDY ET AL. *MOLECULAR AUTISM* (2018) 9:42

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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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Negative Consequences of Camouflaging

- Heightened stress or mental health conditions such as depression
- Reduced access to clinical support and services as a result of difficulties being hidden (Cage et al. 2017; Head et al. 2014).
- Less frequent diagnosis of females than males with the same autistic characteristics
- Women who try to hide or "camouflage" their autistic traits are likely to report that they feel distressed, think of suicide, and/or struggle to function in everyday life.(Beck et al. 2020)

Beck JS, Lundwall RA, Gabrielsen T, Cox JC, South M. Looking good but feeling bad: "Camouflaging" behaviors and mental health in women with autistic traits. Autism. 2020 May;24(4):809-821.
Cage, E., Di Monaco, J., & Newell, V. (2017). Experiences of autism acceptance and mental health in autistic adults. *Journal of Autism and Developmental Disorders*, 48, 473–484.
Head, A. M., McGillivray, J. A., & Stokes, M. A. (2014). Gender differences in emotionality and sociability in children with autism spectrum disorders. *Molecular Autism*, 5(1), 19.

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Negative Consequences of Camouflaging: Autistic Burnout

- Mental and physical overwhelm associated with a loss of functioning
- Increased sensory sensitivity or overload
- Chronic exhaustion
- Frequent meltdowns
- Loss of skills such as speech and executive functioning

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Dewendt, S. (2020, April 09). Autistic burnout, explained. Retrieved December 14, 2020, from https://www.spectrumnews.org/news/autistic-burnout-explained/

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Burnout

Autistic burnout is the emotional, physical and mental exhaustion caused by the cumulative effect of excessive and prolonged stress from having to consciously think through every life process. After years of performing at a high level, women can suddenly hit a wall. Due to interoception difficulties, they might miss cues of fatigue, hunger or negative emotion until the issues are severe. **Feelings of inadequacy** push them to work their hardest to prove their worth. They become profoundly drained and fatigued and can no longer function. This experience is often first identified as severe depression, but then a thorough history can reveal underlying sensory, social and behavioral challenges. It can take years to fully recover from burnout, and most people never return to the level of activity and performance they previously sustained.

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Dori Zener, Journey to diagnosis for women with autism; Advances in Autism, Volume 5 NO. 1 2019. pp2-13

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Camouflage

"In order to engage in camouflaging, one must have insight into one's own difficulties, how these may be negatively perceived by others, and have a strong motivation to adapt one's social behavior to be accepted."

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

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Shunning

Neurotypical people tend to be reluctant to interact with their autistic peers, shunning them.

Sasson, N. J. et al. (2017). Neurotypical peers are less willing to interact with those with autism based on thin slice judgments. *Scientific Reports 6,* 40700.

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Learning Acceptance (not who you think)

Some training programs have tried to teach autistic people to act more like non-autistic people to help them gain acceptance. Fewer have focused on teaching non-autistic people how to be more autism friendly. In this study, we used a short training video that teaches people about autism.
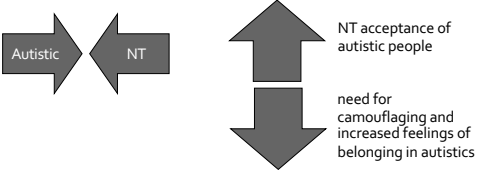
Non-autistic people who watched this video
- had better knowledge about autism
- showed more autism-friendly attitudes
- were more open to having a relationship with an autistic person
- had more positive beliefs about autism
- connected autism with unpleasant traits, even if they had watched the autism training video.

This suggests that teaching non-autistic people about autism may promote more autism-friendly attitudes, but some beliefs may be harder to change.

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Jones DR, DeBrabander KM, Sasson NJ. Effects of autism acceptance training on explicit and implicit biases toward autism. Autism. January 2021.

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Double Empathy Problem and Camouflaging

Autistic ⟷ NT

NT acceptance of autistic people

need for camouflaging and increased feelings of belonging in autistics

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

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ORIGINAL PAPER

CrossMark

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

Laura Hull[1,6] · William Mandy[1] · Meng-Chuan Lai[2,3,4] · Simon Baron-Cohen[3] · Carrie Allison[3] · Paula Smith[3] · K. V. Petrides[5]

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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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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Social Camouflaging Model

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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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

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

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Contact Us

Ruth Aspy, Ph.D.
aspy@texasautism.com
214-227-7741
www.texasautism.com
www.autismzig.com

Barry G. Grossman, Ph.D.
grossman@texasautism.com
214-227-7741
www.texasautism.com
www.autismzig.com

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