

# Barriers to ASD Diagnosis for Girls

A REVIEW OF THE LITERATURE



This brief is based on several recent reviews and empirical articles. **The excerpts and quotes on page 2 are taken directly from a mixed-methods systematic review by Lockwood Estrin and colleagues (2020).**

## BACKGROUND

Autism Spectrum Disorder (ASD) is sometimes considered a 'male disorder' with a male:female ratio of about 4:1. There are increasing concerns that autistic girls and women are being missed, diagnosed later than males, or misdiagnosed.

## GENDERED SYMPTOMS AS BARRIERS

### • BEHAVIORAL PROBLEMS

- Girls tend to need to exhibit more behavioral problems (e.g. **hyperactivity**) than their male counterparts and/or have an **intellectual disability** in order to receive an ASD diagnosis
- When comparing males and females without a diagnosis but with high-ASD traits, females were more likely to display **staring and seizure-like activities**

### • SOCIAL COMMUNICATION ABILITIES

- Girls may be more likely to **camouflage/mask** symptomatic behaviors

### • LANGUAGE

- Verbally-fluent girls were diagnosed at a later age than boys (by 1.8 years). That's 2 years of missed opportunities for supports and services.
  - supports the suggestion that **girls often need to display more disabling difficulties with spoken language to receive a formal diagnosis**

### • RESTRICTED AND REPETITIVE BEHAVIORS AND INTERESTS (RRBIS) AND SENSORY ACTIVITIES

- Parent-reported sensory symptoms significantly predicted ASD diagnosis irrespective of gender
- Younger **boys have more RRBIs** but they fluctuate over time whereas **girls may have fewer RRBIs and they seem to remain more consistent** over time
- RRBIs may be both qualitatively and quantitatively different in females and correlated with different brain regions than males

## PERCEIVED BARRIERS TO DIAGNOSIS

### • COMPENSATORY BEHAVIORS

- **Camouflaging** techniques to mask social difficulties and RRBs
- **Gendered social expectations and play behaviors** may make autistic girls stand out less to teachers in a school setting
- **'Social Echolalia'**, the act of **mimicking socially skilled peers** might obscure the difficulties girls experience with flexible and spontaneous social interactions

### • PARENTAL CONCERNS

- **Parents of boys were 2.43 times more likely than parents of girls to label ASD itself as a concern** for their toddlers who screened positive on ASD questionnaires

### • CLINICIAN BIAS

- When clinicians evaluate girls, compared to boys, with a complex developmental profile, they may be **more likely to exclude a classification of ASD if other conditions are present.**



**"AUTISM IS NOT A 'BOY'S DISORDER', NOR IS IT A DISORDER. RATHER, IT IS A WAY OF BEING THAT IS DISABLED AND LARGELY MISUNDERSTOOD BY SOCIETY."**

When parents express concerns to primary grade teachers, they may be met with invalidation

*"She's fine", "You're expecting too much, she's fine"*

Parents of girls less are likely to express concerns about social interactions prior to diagnosis. This could be because social demands have not yet outgrown the girl's compensatory (e.g. masking) behaviors.

*"She would just say how she hated school and how she hated visiting my parents and how loud everything is..."*

Parents often found that their concerns were met with skepticism

*"...autism is sort of a boy kind of issue. And my daughter was so sweet, and people would just say, 'What's your problem?' 'Why are you labeling her?'"*

**Parents expressed frustration knowing their daughter was developing atypically, yet not receiving validation from medical professionals about their concerns.**

*"She is a late bloomer", "This is usually a boys thing"*

Parents are forced to exaggerate impairment to receive an adequate evaluation

*"I needed to make my daughter look more impaired than she actually was in order to get a diagnosis and needed services"*