Females with Autism Spectrum Disorder: Assessment Considerations and New Mexico-Specific Data

Leadership Education in Neurodevelopmental Disabilities (LEND)
Capstone Project
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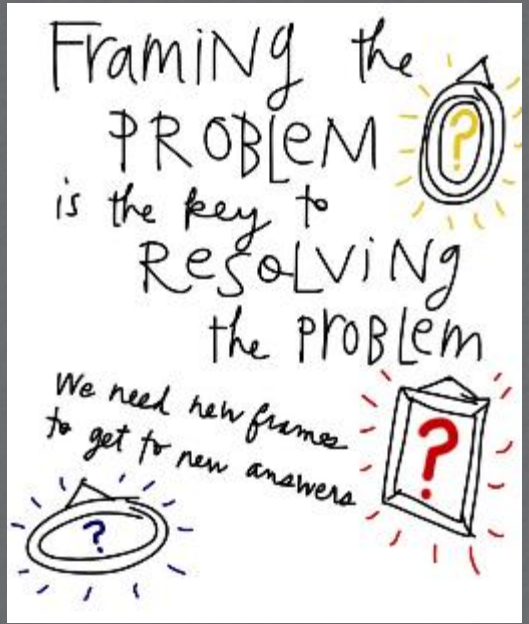
Agenda

- Problem Framing
- Research
- Product
- Dissemination
- Conclusions

LEND Competencies

- Competency 1: Family-Centered/ Culturally Competent Practice
- Competency 2: Interdisciplinary Practice
- Competence 3: Knowledge, Skills, and Attitudes
- Competency 4: Leadership
- Competency 5: Research and Critical Thinking

Problem Framing



Problem Framing: Females with ASD

Growing concern that females with autism are overlooked in both identification and research.

Prevalence Rates: USA

Identified Prevalence of Autism Spectrum Disorder

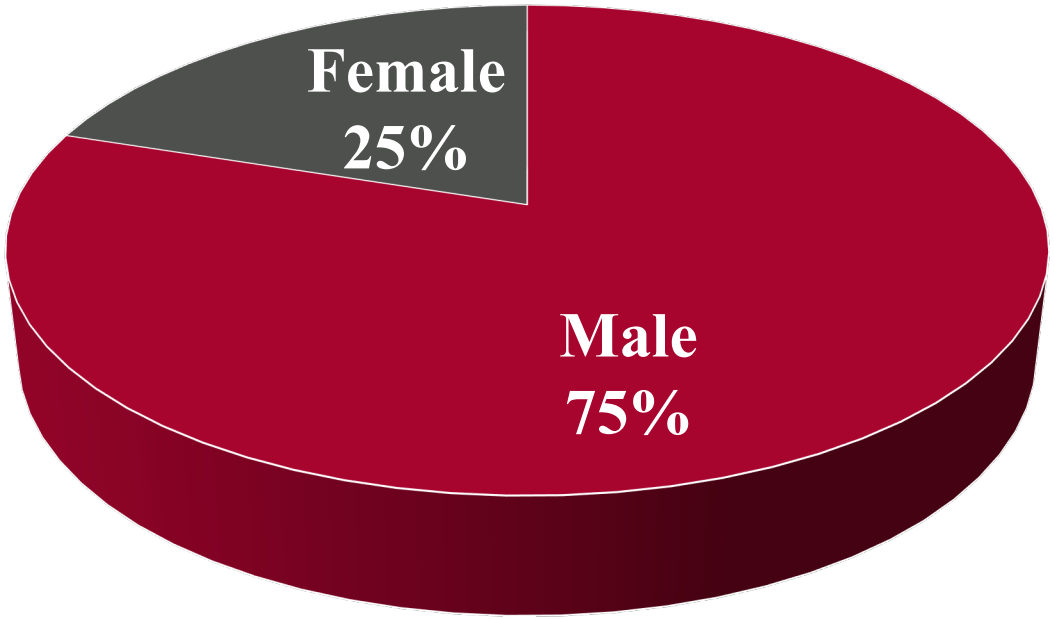
ADDM Network 2000-2016 Combining Data from All Sites

Surveillance Year	Birth Year	Number of ADDM Sites Reporting	Combined Prevalence per 1,000 Children (Range Across ADDM Sites)	This is about 1 in X children...
2000	1992	6	6.7 (4.5-9.9)	1 in 150
2002	1994	14	6.6 (3.3-10.6)	1 in 150
2004	1996	8	8.0 (4.6-9.8)	1 in 125
2006	1998	11	9.0 (4.2-12.1)	1 in 110
2008	2000	14	11.3 (4.8-21.2)	1 in 88
2010	2002	11	14.7 (5.7-21.9)	1 in 68
2012	2004	11	14.5 (8.2-24.6)	1 in 69
2014	2006	11	16.8 (13.1-29.3)	1 in 59
2016	2008	11	18.5 (18.0-19.1)	1 in 54

https://www.cdc.gov/ncbddd/autism/data.html

Prevalence Rates: USA, 2016 Data

3.4-4.1:1



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https://www.cdc.gov/ncbddd/autism/data.html

Problem Framing: Females with ASD

- A predictive model (USA) indicated up to 39% more females should be diagnosed with ASD
- Ratio should be about 28% female and 72% male
- Leaky assessment pipeline

(Barnard-Brak, Richman, & Almekdash, 2019)

Barriers to diagnosis (Lockwood Estrin et. al., 2020)

- See: Lockwood Estrin, G., Milner, V., Spain, D., Happe, F., & Colvert, E. (2020). Barriers to Autism Spectrum Disorder diagnosis for young women and girls: A systematic review. *Review Journal of Autism and Developmental Disorders,* . https://doi.org/10.1007/s40489-020-00225-8 for more information and graphic.

Problem Framing: Females with ASD

Under- or late-identification is problematic because (Begeer et al., 2013):

- Delays intervention that might have otherwise helped address unique behavioral health and social needs
- More likely to experience bullying or coercion/manipulation
- Increased chance of mental health challenges (Hirvikoski et al., 2020; Kovacs & Devlin, 1998):

Anxiety

Depression

Increased risk for suicide

Eating disorders

Self-harm

Challenges with mis-diagnosis

What can we do?

- If early and accurate identification is important, then what can we do to help this process?
  - Imagine Conference Presentation
    - Assessment considerations
    - Panel
  - How are we doing in NM?
    - Data collection

Research

Process

1. Literature review
2. NM-specific data
3. Imagine Conference Presentation Preparation

Literature Review

1. Literature review
   - ASD, females
   - Best practices for evaluation
   - New evaluation measures/tools
   - National prevalence rates
   - Resources

New Mexico Data Gathering Steps

NM-specific data

- IRB Approval: CDD Database
- Database training
- Access and understand database independently
- Review and analyze demographic data

CDD Clinical Database: Background

- Developed by Dr. Courtney Burnette with a UNM Clinical & Translational Science Center (CTSC) grant
- Starting in 2015, the database has collected demographic and evaluation data from clients of the CDD's Autism Spectrum Evaluation Clinic (ASEC)
- Current PI: Brandon Rennie, PhD
- Data on Redcap

CDD Clinical Database: Data Types

Following evaluation, the following de-identified information is collected:

- Demographic:
  - Age, sex, race/ethnicity, IDEA eligibility, zip code
- Evaluation data:
  - Scores on evaluation instruments used within the clinic.

CDD Database Data

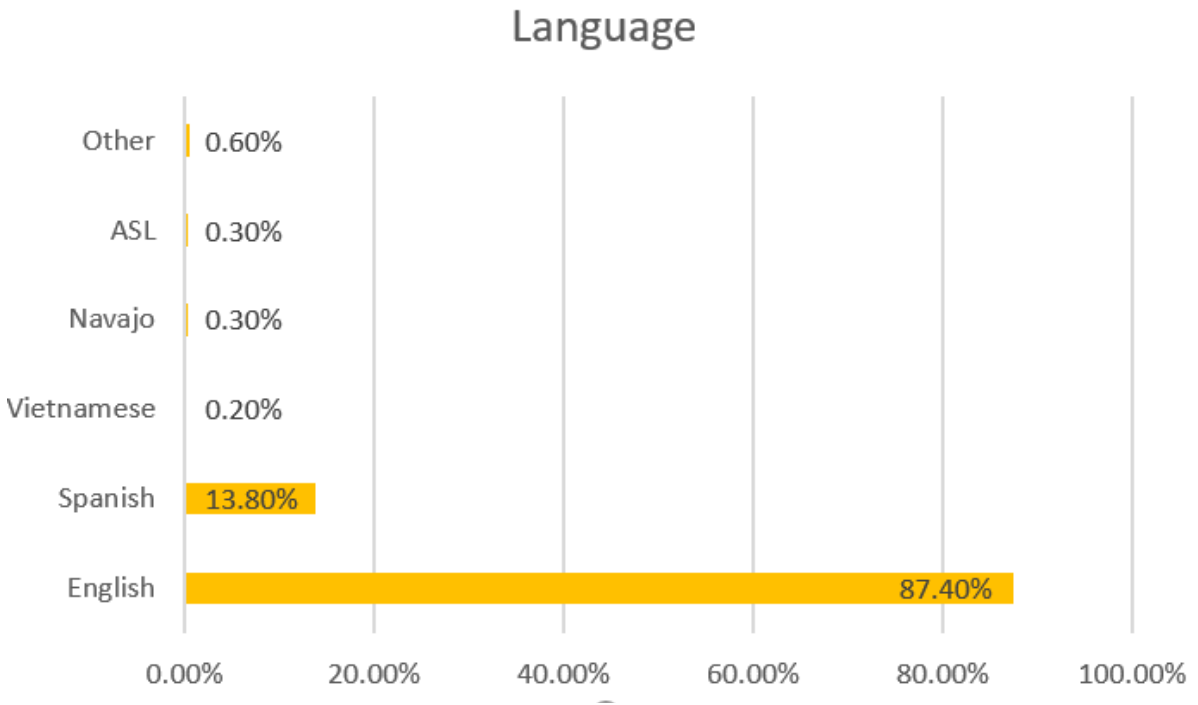
- Downloaded data from Redcap on March 29, 2021
- Data from August 2014 to January 2019
- *N* = 1,066
- SPSS v. 27

CDD Database Results

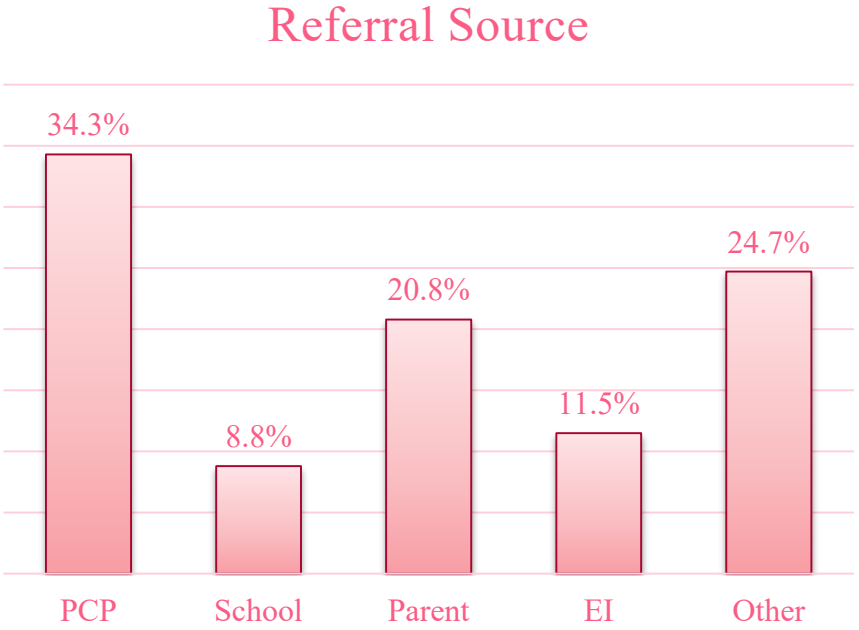
1. General findings
2. Delineated female/male

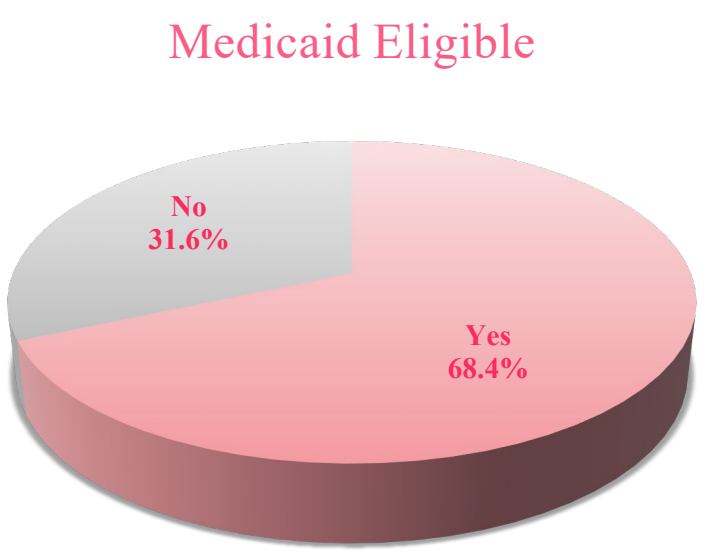
Language

Males and Females
($N = 1{,}056$)



Other (Males and Females, *N* = 1,038)





Ethnicity

Hispanic or Latino	All (*N* = 955)	Females (*N* = 228)	Males (*N* = 727)
Yes	57.2%	53.9%	58.3%
No	42.8%	46.1%	41.7%

Race

Race	All (*N* = 749)	Females (*N* = 182)	Males (*N* = 567)
American Indian/Alaska Native	14.0%	18.7%	12.5%
Asian	2.4%	4.4%	1.8%
Black or African American	2.8%	4.9%	2.1%
Native Hawaiian or other Pacific Islander	0.7%	1.1%	.5%
White (including Hispanic/Latino)	80.20%	70.9%	83.1%

School Eligibilities Prior to Eval

Educational Eligibility	All (*N* = 1,063)	Females (*N* = 245)	Males (*N* = 818)
Autism	21.9%	17.1%	23.3%
Developmental Delay (DD)	20.7%	19.2%	21.1%
Unknown	16.3%	18.0%	15.9%
Speech Language Impairment (SLI)	12.4%	11.0%	12.8%
Other Health Impairment (OHI)	4.2%	2.9%	4.6%
Learning Disability (LD)	3.0%	1.6%	3.4%
Intellectual Disability (ID)	2.5%	4.1%	2.1%
Emotional Disability (ED)	1.9%	3.3%	1.5%

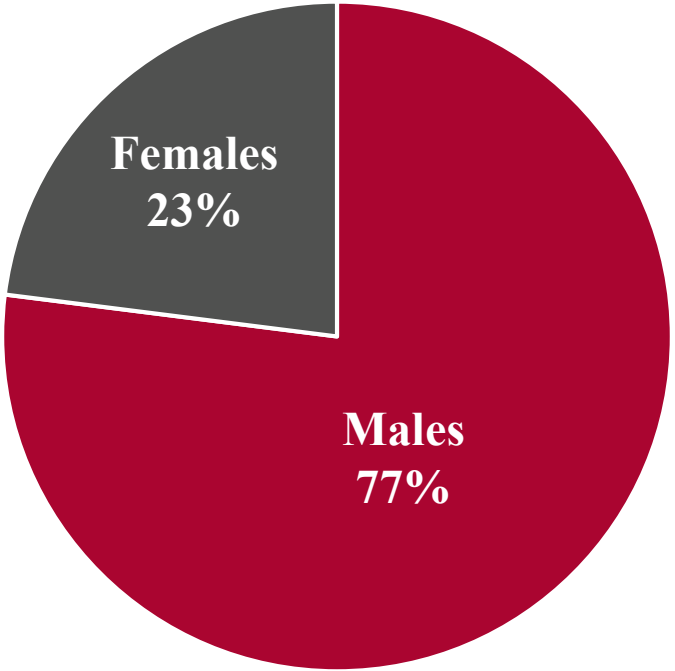
School Eligibilities Prior to Eval

Educational Eligibility	All (*N* = 1,063)	Females (*N* = 245)	Males (*N* = 818)
Gifted/Talented (GT)	1.4%	1.6%	1.3%
Deaf	0.1%	0	0.1%
Hearing Impairment (HI)	0.1%	0	0.1%
Deaf/Blind	0.2%	0	0.2%
Multiple Disabilities (MD)	1.5%	4.1%	0.7%
Vision Impairment (VI)	0.1%	0	0.1%
Traumatic Brain Injury (TBI)	0.4%	0	0.5%

Most Prevalent Diagnoses Given

Diagnosis	All (N = 1,063)	Females (N = 245)	Males (N = 818)
ASD Statistically significant (*p* = .003)	59.0%	53.5%	60.6%
Language Disorder	34.2%	31.8%	34.8%
Speech Sound Disorder	23.5%	22.4%	23.8%
Global Developmental Delay (GDD)	19.7%	16.7%	20.7%
Other	18.1%	18.0%	18.1%
ADHD	15.2%	9.8%	16.9%
Anxiety (Unspecified, Generalized)	13.0%	13.2%	12.9%
Intellectual Disability	9.8%	16.7%	7.7%

CDD Prevalence Rates (*N* = 1,064)



Age of Diagnosis

Males and Females (N = 1,063)

Mean: 6.50 years
Standard Deviation 4.21

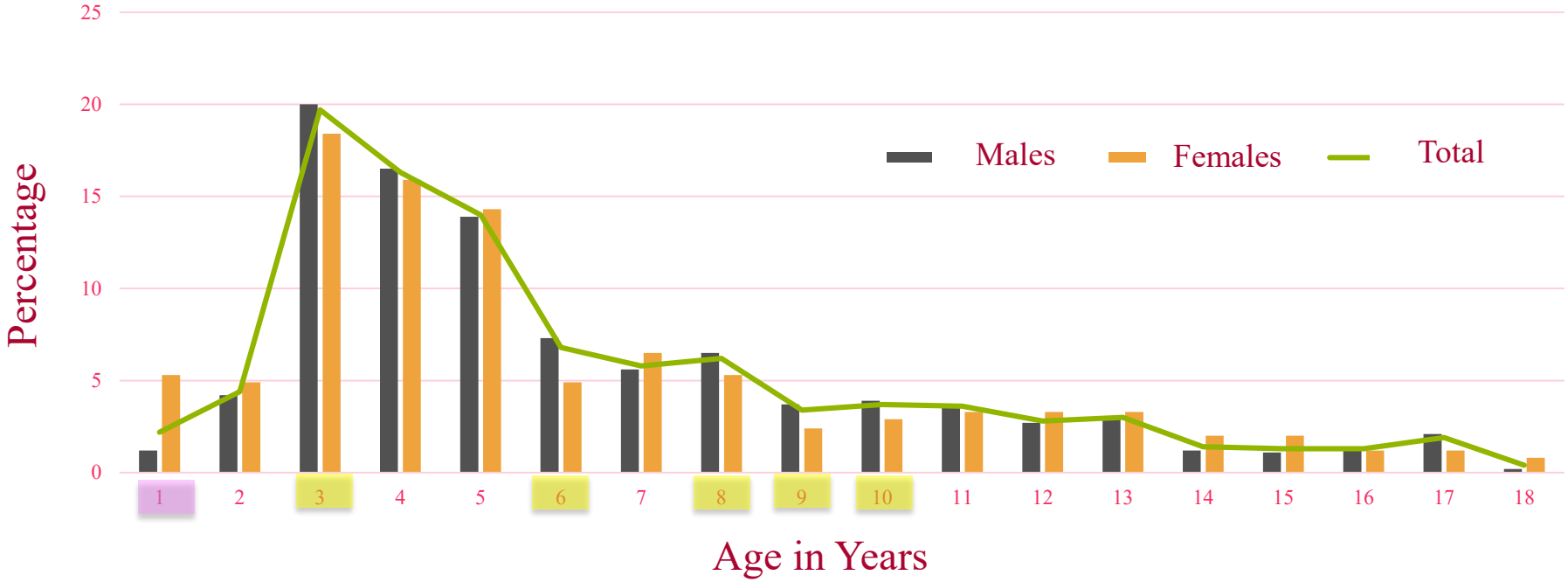
National average:
approximately
4.3 years

https://www.cdc.gov/ncbddd/autism/data.html

Age of Diagnosis (females, males)

Full Age Range	School-Age Range
Males (N = 815) Mean: 6.51 years Standard Deviation: 4.13 Range: **1-28** years	Males (N = 803) Mean: 6.3 years Standard Deviation: 3.77 Range: **1-18** years
Females (N = 245) Mean: 6.47 years Standard Deviation: 4.46 Range: **1-21** years No statistically significant difference (*p* = .892)	Females (N = 240) Mean: 6.2 years Standard Deviation: 4.04 Range: **1-18** years No statistically significant difference (*p* = .209)

Age of Diagnosis



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To Summarize: NM Data

- Slightly above USA trend with male/female ratio
- Males more likely to receive ASD diagnosis
- Females we see are more likely to be non-White than males
- Age of diagnoses overall not significantly different (but some variance across ages)
- Female symptom presentation more likely to include ID/MD

Presentation Preparation

- Prepare presentation
- Panel
  - Learn about hosting a panel
  - Find panel members
  - Meet to brainstorm topics

Product

Product

- 2021 Imagine Conference Presentation
  - Including updated, New Mexico specific data related to females evaluated for Autism Spectrum Disorder by the CDD.

Dissemination

Dissemination

1. May 27th, 3:30-5:00 Imagine Conference Presentation
2. Provide information for clinic leadership about types of clients that are served in New Mexico and how this compares to national trends.

Conclusions

Lessons Learned

- Literature review
  - Gender identity/expression
  - Camouflaging/masking (across genders)
  - Evaluation tools
- Panel Hosting

- Imagine Conference panel members: Gillian Kocur, Elisheva Levins, and Rachel Pretlo
- Brandon Rennie, research mentor
- Sylvia Acosta, LEND mentor
- Debra Sugar and Marci Laurel with panel recruitment and help with planning
- Monica Florella Asendo Pimentel, CDD Database Data Manager

References

Barnard-Brak, L., Richman, D. and Almekdash, M.H. (2019), How many girls are we missing in ASD? An examination from a clinic- and community-based sample., *Advances in Autism*, 5(*3),* 214-224. https://doi.org/10.1108/AIA-11-2018-0048

Begeer, S., Mandell, D., Wijnker-Holmes, B., Venderbosch, S., Rem, D., Stekelenburg, F., & Koot, H. M. (2013). Sex differences in the timing of identification among children and adults with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, *43*(5), 1151–1156. https://doi.org/10.1007/s10803-012-1656-z

Hirvikoski, T., Boman, M., Chen, Q., D'Onofrio, B. M., Mittendorfer-Rutz, E., Lichtenstein, P., Bölte, S., & Larsson, H. (2020). Individual risk and familial liability for suicide attempt and suicide in autism: A population-based study. *Psychological Medicine*, *50*(9), 1463–1474. https://doi.org/10.1017/S0033291719001405

Hull, L., Lai, M.-C., Baron-Cohen, S., Allison, C., Smith, P., Petrides, K., & Mandy, W. (2020). Gender differences in self-reported camouflaging in autistic and non-autistic adults. *Autism*, *24*(2), 352–363. https://doi.org/10.1177/1362361319864804

Hull, L., Petrides, K. V., Allison, C., Smith, P., Baron-Cohen, S., Lai, M. C., & Mandy, W. (2017). "Putting on my best normal": Social camouflaging in adults with autism spectrum conditions. *Journal of Autism and Developmental Disorders*, *47*(8), 2519–2534. https://doi.org/10.1007/s10803-017-3166-5

References

Kovacs, M. & Devlin, B. (1998), Internalizing disorders in childhood. *Journal of Child Psychology and Psychiatry, 39*: 47-63. https://doi.org/10.1111/1469-7610.00303

Lai, M.C. & Szatmari, P. (2019). Sex and gender impacts on the behavioural presentation and recognition of autism. *Current Opinion in Psychiatry 33* (1). https://doi.org/10.1097/YCO.0000000000000575.

Livingston, L.A., Shah, P., Milner, V. & Happe, F. (2020). Quantifying compensatory strategies in adults with and without diagnosed autism. *Molecular Autism 11*(15). https://doi.org/10.1186/s13229-019-0308-y

Lockwood Estrin, G., Milner, V., Spain, D., Happe, F., & Colvert, E. (2020). Barriers to Autism Spectrum Disorder diagnosis for young women and girls: A systematic review. *Review Journal of Autism and Developmental Disorders,* . https://doi.org/10.1007/s40489-020-00225-8

Loomes, R., Hull, L., & Mandy, W. (2017). What is the male-to-female ratio in autism spectrum disorder? A systematic review and meta-analysis. *Journal of the American Academy of Child and Adolescent Psychiatry*, *56*(6), 466–474.

Maenner MJ, Shaw KA, Baio J, et al. Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2016. MMWR Surveill Summ 2020;69(No. SS-4):1–12. DOI: http://dx.doi.org/10.15585/mmwr.ss6904a1

Russell, G., Golding, J., Norwich, B., Emond, A., Ford, T., & Steer, C. (2012). Social and behavioural outcomes in children diagnosed with autism spectrum disorders: A longitudinal cohort study. *Journal of Child Psychology and Psychiatry, and Allied Disciplines*, *53*(7), 735–744. https://doi.org/10.1111/j.1469-7610.2011.02490.x

Questions or Comments