

Foster care, maltreatment, and referral for ASD Evaluation: A retrospective chart review

Leni Swails, PhD
Krystal Vanderjagt, MA
Catherine Smith, PhD
Kansas LEND

University of Kansas Medical Center



No disclosures to report.

Objectives

- Review literature on the relationship of Autism Spectrum Disorder and related Developmental Disabilities (ASD/DD) to:
 - foster care
 - childhood maltreatment
- Results from an retrospective chart review
- Implications for practice and community training

Clinical Observation → Research Question

- Substantial waitlist for autism spectrum disorder (ASD) diagnostic services, similar to other diagnostic centers (Austin et al., 2016)
- Frequent evaluation referrals for children with complex mental or behavioral health needs, psychosocial stressors
- Pattern of children in foster care often not having ASD/DD
 - Occasional patients in foster care with significant symptoms of ASD/DD, but diagnosed very late

Literature: Foster Care and ASD/DD

- Foster care increased risk for:
 - Developmental delays & behavioral/mental health conditions (Simms, Dubowitz, & Szilagyi, 2000)
 - Over/underweight, need more subspecialty referrals, and have multiple chronic health conditions (Deutsch & Fortin, 2015)
- Neglect experienced prior to entering care may lead to a backlog of specialty referrals, including ASD/DD

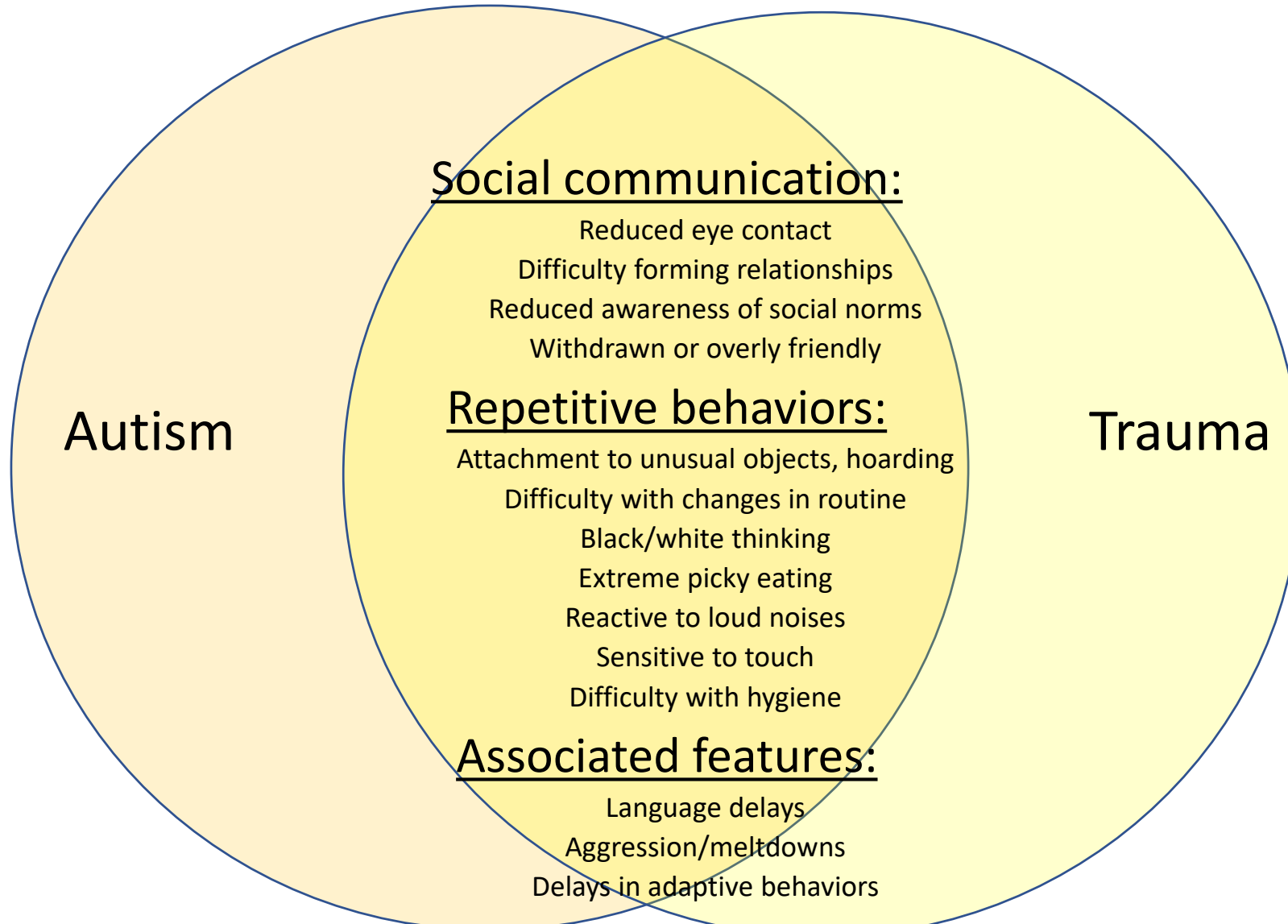
Literature: Foster Care and ASD/DD

- Children with disabilities increased risk for experiencing maltreatment:
 - Neurodevelopmental disability (Dinkler et al 2017)
 - Emotional disturbance and, to a lesser extent, intellectual, developmental, and learning disabilities (Lightfoot, Hill, & LaLiberte, 2011)
 - Children with disabilities 2x more likely to be placed out of home after maltreatment (Lightfoot, Hill, & LaLiberte, 2011)
- Children entering foster care twice as likely to have a diagnosis of ASD (Bilaver & Havlicek, 2013)

Literature: Foster care & ASD/DD

- *All of these studies are examining prevalence of ASD/DD within the foster care population, not looking at frequency of foster care/maltreatment referrals within an ASD/DD clinic*

ASD & Trauma Symptom Overlap



Current study

- Rate of foster care and reported abuse in a sample referred for evaluation of ASD/DD
- Comparative rate of ASD/DD diagnosis for those with/without:
 - Reported abuse history
 - Foster care involvement or placement in non-biologic home
- Clinical sample

Our Center

- Academic medical center interdisciplinary division for ASD/DD
- Primarily assessment focused
 - Regional location for ASD/DD evaluation
 - Serves patients from across the state of KS and well as parts of MO
- Approx. 650+ patients for diagnostic services/year
- Waitlist (length varies year-to-year):
 - Young child evaluation (under 4): 2-9 months
 - School age/adolescent evaluation (5-19): 3-12 months
 - Approx. 18 evaluations per week

Retrospective Chart Review

Information about children referred to an outpatient pediatric clinic for a new patient developmental evaluation

Inclusion criteria:

- Referred due to concerns about ASD/IDD diagnosis
- Completed online Patient Information Form
- Clinician completed summary page and indicated Yes or No for ASD/DD diagnosis
- n=1,238
- 2016-2019

Variables

- Household Type

- % of patients in foster care or likely history of foster care or removal from biologic home

- Abuse

- % of children referred for ASD/IDD evaluation with a history of likely physical/sexual abuse (abuse)

- Diagnostic Outcomes

- Relative rate of ASD/DD diagnosis by household type and abuse history
- ASD assessment measures (ADOS-2 comparison scores)

Patient Information Form: Household type

- Patient Information Form contains several questions related to household:
 - Child currently lives with:
 - Both biological parents
 - Biological mother
 - Biological father
 - Shared custody
 - Grandparent
 - Other relative
 - Adoptive parent
 - Foster parent
 - If nonbiological parent selected: How long has this child been in your care?
 - If adopted: At what age was this child adopted?

Patient information form: abuse/trauma history

- The child has a history of trauma or abuse:
 - No
 - Yes (choose all that apply):
 - Sexual abuse
 - Physical abuse
 - Unknown

Types of appointments- mostly interdisciplinary

Clinic Type	N	Percent
Interdisciplinary evaluation	1,121	90.5%
Single Discipline Screening/Triage	33	2.7%
Single Discipline Psychology Evaluation	15	1.2%
Missing	69	5.6%

Most clinics were interdisciplinary:

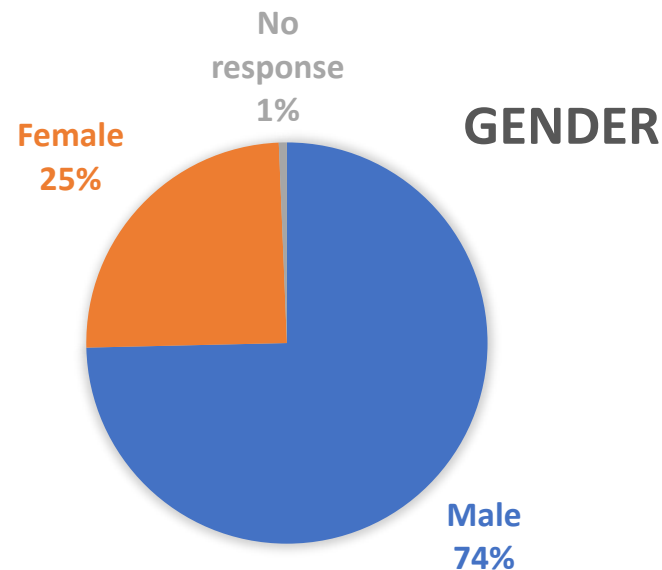
- Psychology
- Speech language pathology and/or developmental-behavioral pediatrics, nursing

A handful of single discipline clinics- usually for more clear-cut diagnoses

Basic demographics and sample statistics

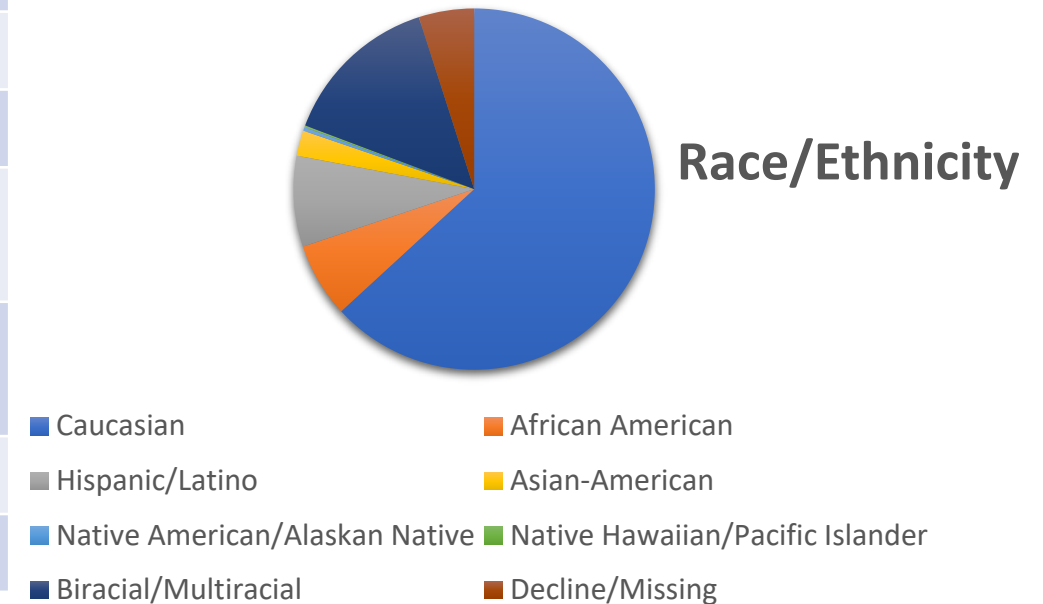
Age		
Average: 6.5 years	Standard Deviation: 4 years	Range: 1-19 years

Gender		
Male: n= 924; 74.6%	Female: n= 306; 24.7%	No response/missing: n= 8; 0.6%



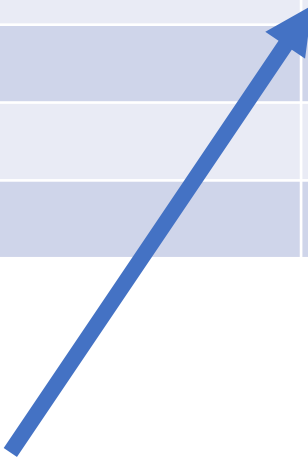
Basic demographics and sample statistics

Race/Ethnicity		
	N	Percent of total sample
Caucasian	777	62.8%
African American	82	6.6%
Hispanic/Latino	100	8.1%
Asian American	28	2.3%
Native American/American Indian/Alaskan Native	4	0.3%
Native Hawaiian/Pacific Islander	2	0.2%
Biracial or Multiracial	176	14.2%
Declined or Missing Data	61	16.9%



Household type- Rates of foster care higher than national/state average

	Number	Percent
Biologic parent household	1101	88.9%
Adopted <u>after</u> birth	464	3.7%
Adopted <u>at</u> birth	18	1.5%
Foster care (current)	31	2.5%
Lives with relative (grandparent, aunt, uncle)	34	2.7%
Missing	8	0.6%
TOTAL	1238	100%



National foster care rate 6: 1,000
Kansas foster care rate: 11: 1,000
ASD Referred sample: 25: 1,000

*National and state foster care
data from: Kids Count, 2018*

Children living in their biologic home or with adopted parents since birth were significantly younger

	Biologic home or adopted at birth	Foster care, relative care, or adopted after birth
Number of people	1119	111
Average Age	6.4 years	8.1 years



T=-4.109
P<.01

Low reported rates of physical/sexual abuse

	Yes	No
Physical/sexual abuse	68 (5.5%)	1162 (93.9%)

*No option for neglect or emotional abuse on the questionnaire

	Unknown
History of trauma or abuse	69 (5.6%)

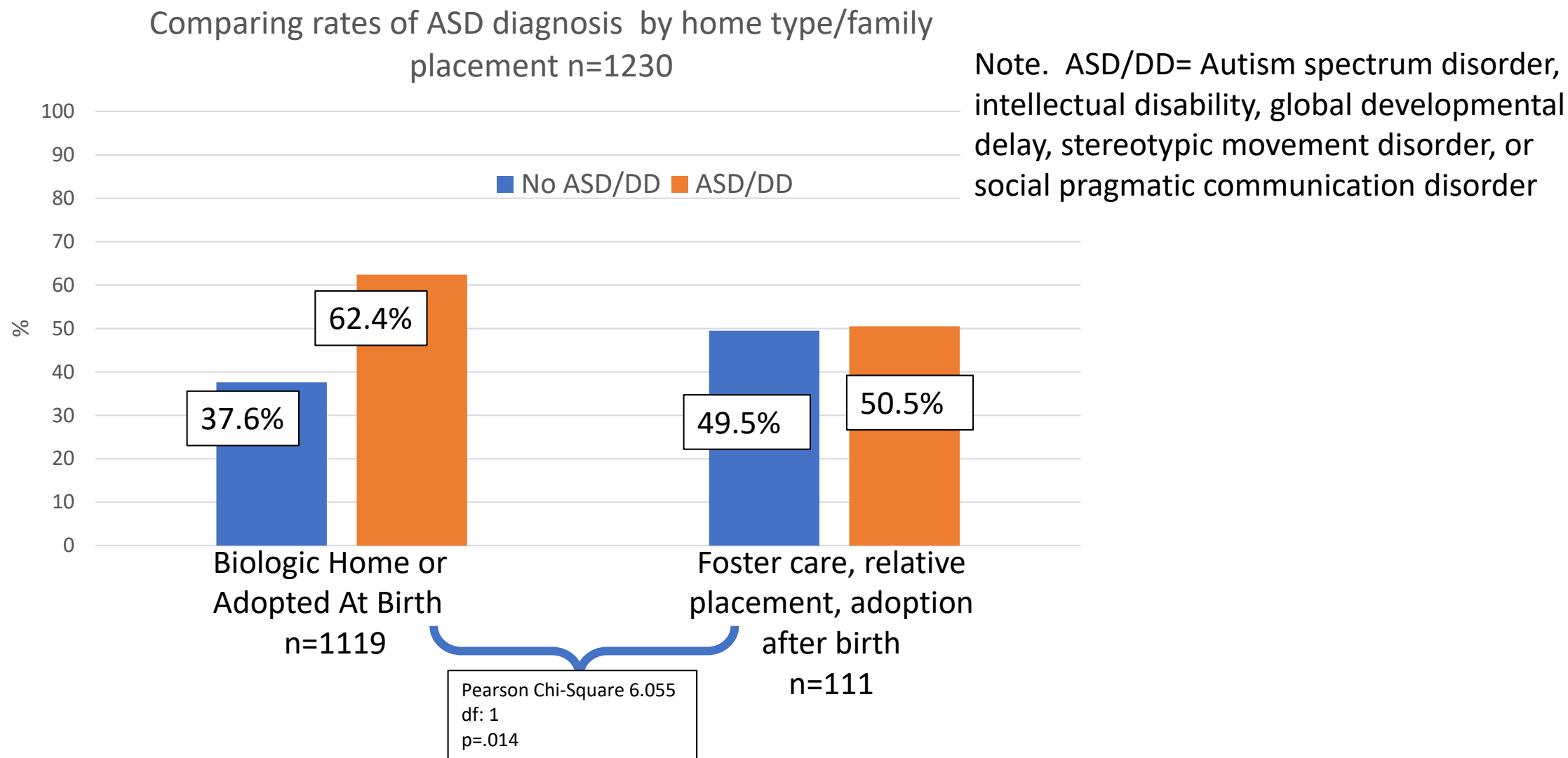
ASD and Related Diagnoses: relatively high rate of *new* ASD diagnoses

Diagnosis	Yes	No
Autism Spectrum Disorder	680 (54.9%)	550 (44.7%)
Global Developmental Delay	220 (17.8%)	1010 (81.6%)
Intellectual Disability	25 (2%)	1205 (97.3%)
Stereotypic Movement Disorder	5 (0.4%)	1225 (98.9%)
Social Pragmatic Communication Disorder	8 (0.6%)	1222 (98.7%)

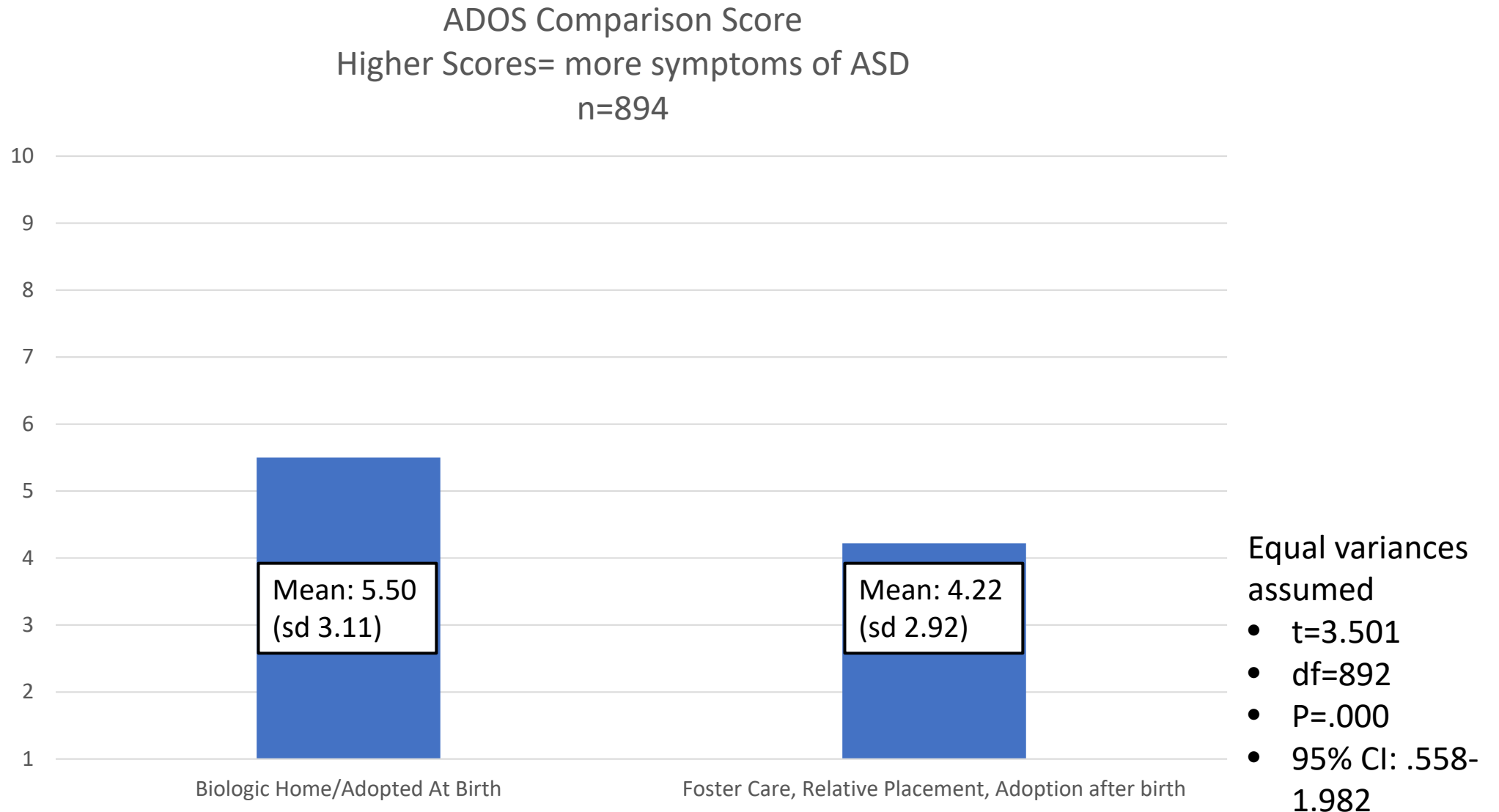
Note: Some children had more than one diagnosis



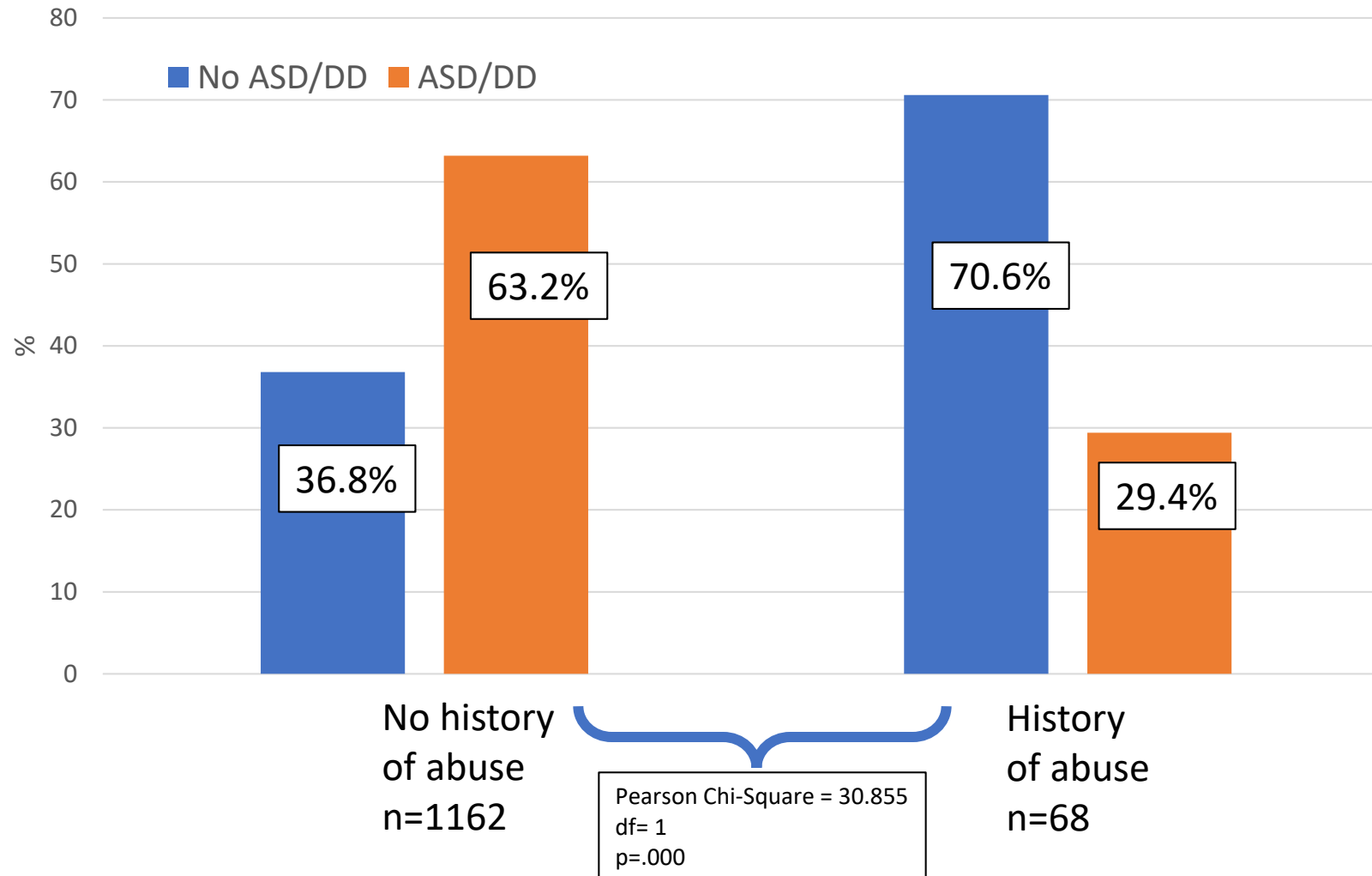
Children in foster care *less* likely to receive a *new* diagnosis of ASD/DD



ADOS-2 Scores between home types



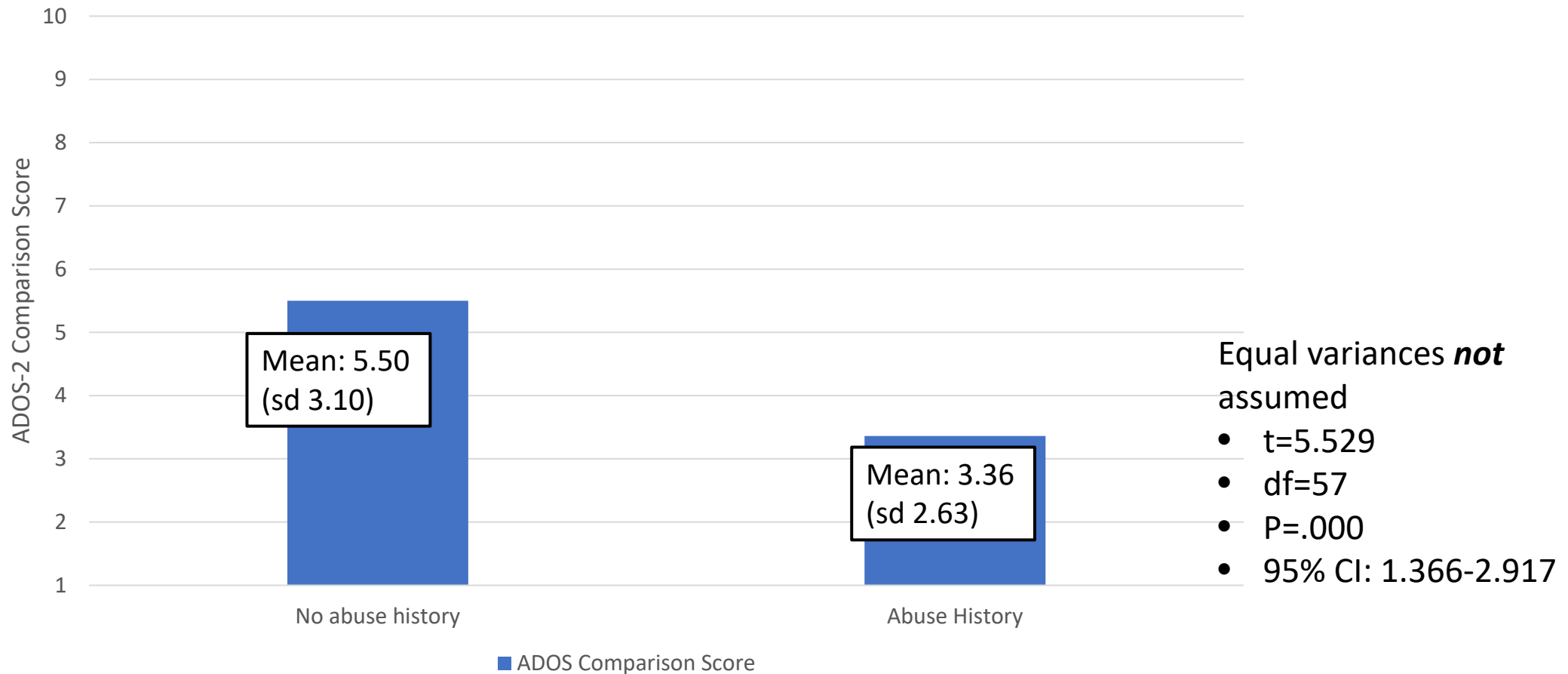
Children with abuse history *less* likely to receive a *new* diagnosis of ASD/DD



Note. ASD/DD= Autism spectrum disorder, intellectual disability, global developmental delay, stereotypic movement disorder, or social pragmatic communication disorder

ADOS Scores by Reported Abuse History

ADOS Comparison Score by abuse history
Higher Scores= more symptoms of ASD
n=894



Interpretation of Results

- Children in foster care are referred for autism evaluation at a higher rate
 - 2.5% of our sample in foster care, compared to 0.6% nationally
- Children with a history of reported abuse or changes in family placement:
 - Are less likely to have ASD/DD after being referred for evaluation
 - Have lower ADOS scores

Interpretation of Results

- Possible explanations:
 - Over-referral for services
 - Important to address due to long waitlists
 - Our clinic- ranged from 2-12months over the study period
 - Lack of consistent developmental monitoring leads to over-referral for ASD
 - Symptoms of trauma may overlap with ASD symptoms, complicating referrals
 - Symptoms of ASD overattributed to trauma?
 - Diagnostic “overshadowing”

Additional Questions and Next Steps

- Is not ASD/DD, what were children diagnosed with?
- Would results be the same if including neglect as well as physical/sexual abuse?
- Do these findings “hold” if accounting for child age?

Future Directions

- Partner with foster care agencies and case workers to provide education and access to screening tools
- Developmental monitoring in “red book”
- Symptoms that distinguish children with :
 - Trauma + ASD from Trauma + No ASD/DD
- Develop improved screening tools for ASD/DD in older children

Acknowledgements

- Rene Jamison, PhD, KS LEND
 - Alice Zhang, PhD, BCBA, KS LEND
 - Sean Swindler, Med, KS LEND
-
- Families who provided data and clinicians who maintained meticulous records!



References

- Austin, J., Manning-Courtney, P., Johnson, M. L., Weber, R., Johnson, H., Murray, D., ... & Murray, M. (2016). Improving access to care at autism treatment centers: a system analysis approach. *Pediatrics*, 137(Supplement 2), S149-S157.
- Bilaver, L.A. & Havlicek, J. (2013). Foster children with Autism Spectrum disorder: Prevalence, length of stay, and placement patterns. *Journal of Public Child Welfare*, 7(5):496-519
- Deutsch, S. A., & Fortin, K. (2015). Physical health problems and barriers to optimal health care among children in foster care. *Current problems in pediatric and adolescent health care*, 45(10), 286-291.
- Dinkler, L., Lundström, S., Gajwani, R., Lichtenstein, P., Gillberg, C., & Minnis, H. (2017). Maltreatment-associated neurodevelopmental disorders: a co-twin control analysis. *Journal of Child Psychology & Psychiatry*, 58(6), 691-701
- Kids Count (2018). <https://kac.org/data-and-research/kidscount/>
- Lightfoot, E., Hill, K., & LaLiberte, T. (2011). Prevalence of children with disabilities in the child welfare system and out of home placement: An examination of administrative records. *Children and Youth Services Review*, 33(11), 2069-2075
- Simms, M. D., Dubowitz, H., & Szilagyi, M. A. (2000). Health care needs of children in the foster care system. *Pediatrics*, 106(Supplement 3), 909-918.