The Intellectual and Developmental Disabilities Council of Tarrant County

Welcome

Barriers to Care for Black or Hispanic Girls and Women with Autism

Presented by Haylie L. Miller, Ph.D., Nicholas E. Fears, Ph.D., Annabel Y. Luna-Smith, B.A., with Autism & Developmental Disorders Research, School of Health Professions, UNT Health Science Center

Thursday, October 1, 2020

@IDDCouncil

/IDDCouncil

Intellectual and Developmental Disabilities Council of Tarrant County

PURPOSE

To transform the region into an inclusive community where individuals with intellectual and developmental disabilities (IDD) thrive.

MISSION

To bring stakeholders together to create an environment for the development of an efficient and accessible system of support for people with intellectual and developmental disabilities.

Tuesday's Caregiver Education ♦ Noon-1 pm

October 6 – No session

October 13 - Empowering Individuals to Rewrite Their Story

Monthly IDD Council Meeting
First Thursday of Each Month, 8:30 a.m. – 10 a.m.

Follow us on social media for upcoming topics, events and networking opportunities

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The Intellectual and Developmental Disabilities Council of Tarrant County

Intellectual and Developmental Disabilities Council of Tarrant County

Celebrating YOU

Annual Employer Recognition

Intellectual and Developmental Disabilities Council of Tarrant County

It's Santa! It's Santa!

Intellectual and Developmental Disabilities Council of Tarrant County

Membership Driven

Premier Partners:

Organizational Partners and many individual memberships

The Intellectual and Developmental Disabilities Council of Tarrant County

PLEASE JOIN US

to Celebrate

OUR NEW INCLUSIVE

Membership Menu

Intellectual and Developmental Disabilities Council of Tarrant County

Building Awareness and Inclusion in our Community!
IDD Council Membership Menu

We recognize and appreciate your support! The benefits and privileges described below are tokens of our appreciation and ways for you to be involved in building awareness and inclusion to our community. Your benefit year begins on the 1st day of the month in which your dues are received, and it continues for 12 consecutive months.

All IDD Council members have access to monthly meetings, job fairs, transition fairs, and access to information and resources via our monthly newsletter, social media, and IDD Council website.

Annual Benefits and Privileges to Members

$5000+ (All Benefits from $2500 level, plus ALL of the following):	$2500+ (All Benefits from $1000 level, plus choose 1):	$1000+ (All Benefits from $500 level, plus choose 2):
• Logo with link on website, ability to put our logo on their website with prior approval • Keynote speaker at Celebrating YOU Employer Recognition luncheon OR another premier event • Access to the benefits of the individual membership level for all families/employees affiliated with your organization • Guest feature (e.g., ad, article, profile) in an issue of the IDD Council newsletter	• Organization's name on IDD Council website • Tailored 1-hour training for your organization's staff or stakeholders (CEUs may be offered for an additional fee) • Present at a Caregiver Education session • Recognition in all IDD Council publications	• Monthly social media posts (1 image of your choice) • Speaker spot at a monthly membership meeting • Request of a custom topic for a Caregiver Education session; priority selection over non-member and non-custom requests • Recognition in select IDD Council publications

$500+ (All Benefits from $250 level, plus choose 2):	$250+ (All Benefits from $25 level, plus choose 2):	$25 Individual Member
• Banner with logo at all 4 Making Connections Disability Resource Fairs OR at April Cool's Day • Organizational info table at Sensory Santa • Permission to distribute information at events (e.g., in bags, or at the doorway)	• Organizational info table at one* of the following events: April Cool's Day, CapeAbilities Job Fair, a Caregiver Education session, OR a Making Connections event • Choose 1 topic for a monthly Caregiver Education session from a pre-set list of topics. Priority selection over non-member requests * May select two organizational table events as benefit option.	• Free training (non-CEU) • Collaboration and networking among agencies, caregivers, and other advocates • Recognition of membership on website and newsletter • Access to members-only portal with a resource directory and video/audio recordings of select presentations

...additional customized benefits available a-la-carte to meet your organization's needs!

CEUs may be offered for an additional fee at individual events.
Members at all levels will receive a discount on CEUs.

Barriers to Care for Black and Hispanic Women and Girls with Autism

Haylie L. Miller, Ph.D.

University of North Texas Health Science Center

Redefining Autism Spectrum Disorder (ASD):

- Complex set of neurodevelopmental symptoms
- Not just social or psychological – “whole body”
- Not just a one-dimensional spectrum (low/high)

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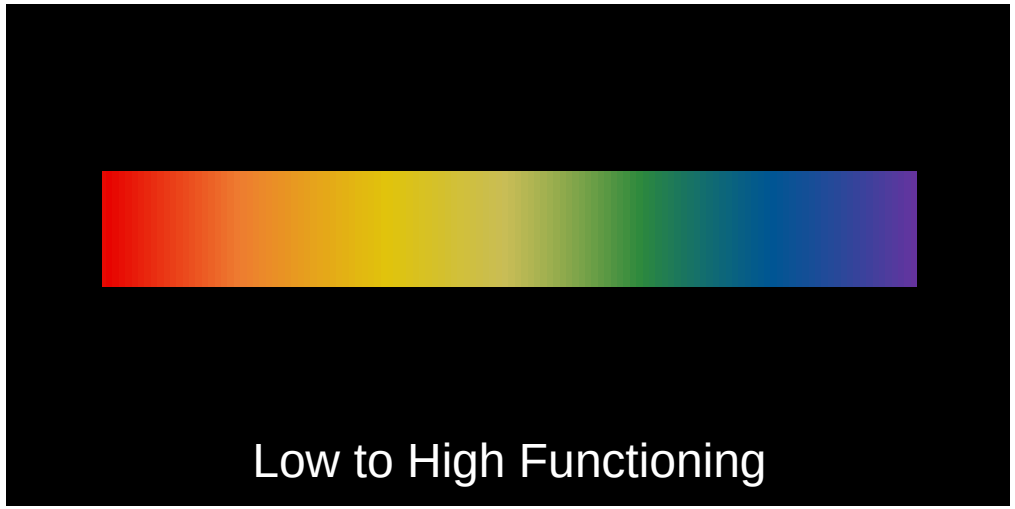

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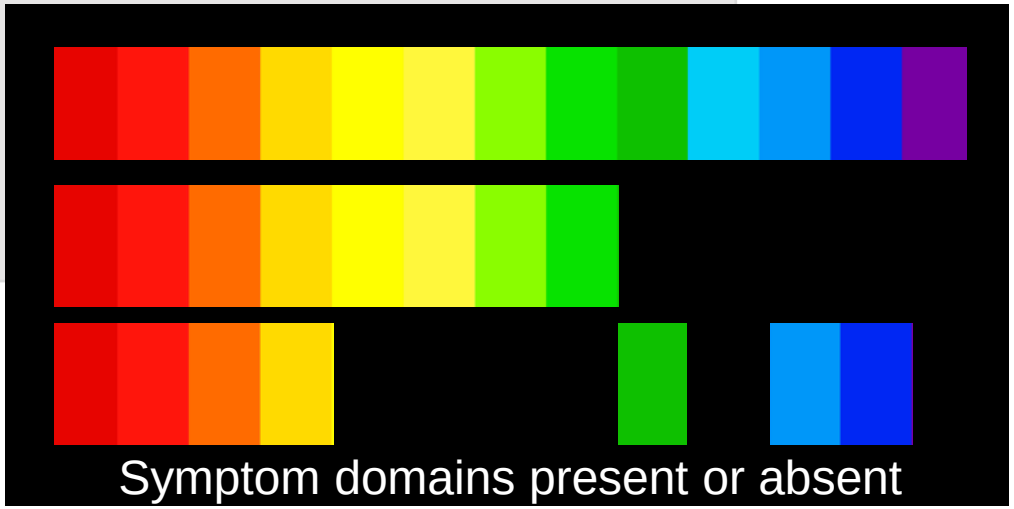

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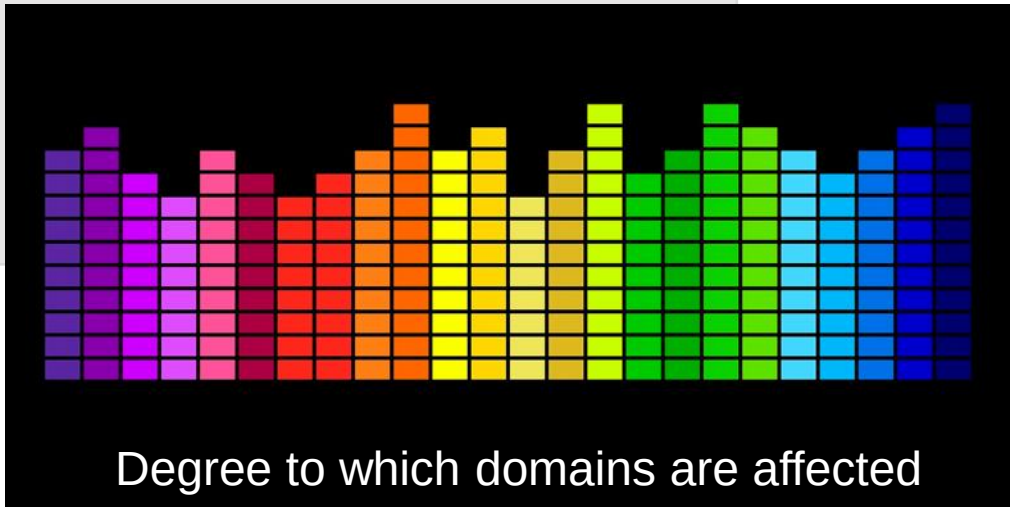

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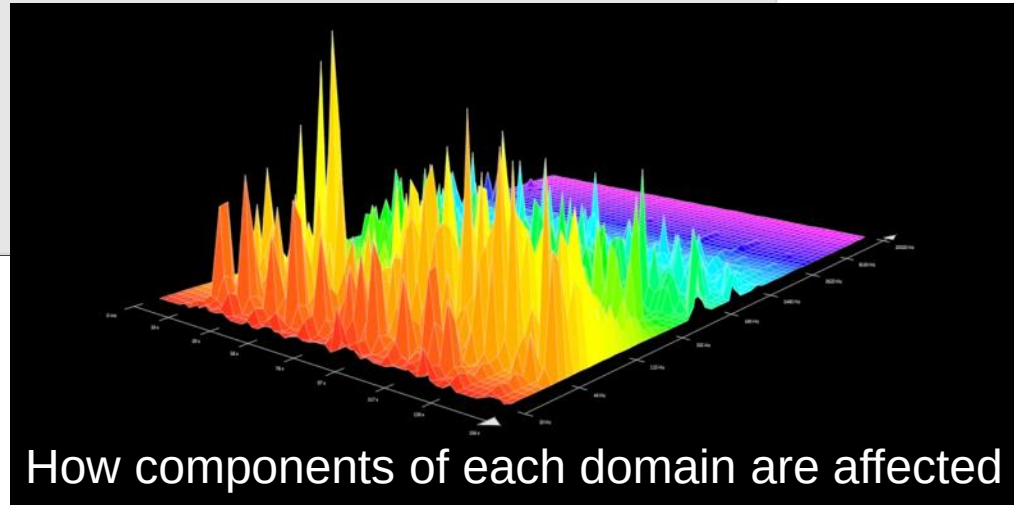

How components of each domain are affected

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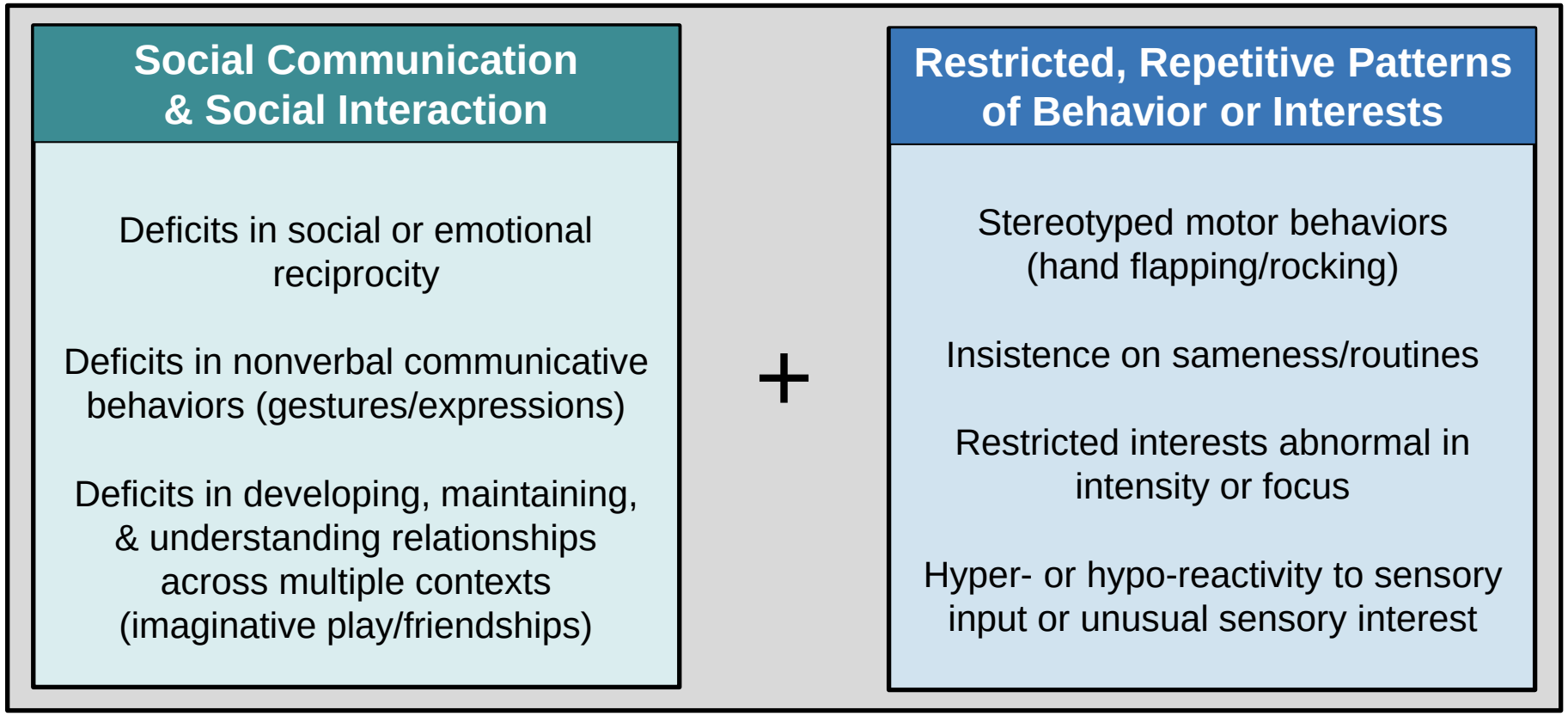
ASD Diagnostic Criteria



AND…

Symptoms present in early development, cause clinically significant impairment, and are not better explained by intellectual disability or global developmental delay.

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ASD Diagnostic Criteria

The problem is…

- Criteria were created around boys
- Assessments were tailored to boys
- Studies include mostly boys
- …so how are we supposed to find the girls?

The Big Questions…

Does ASD look different in women/girls? Minorities?

Do we need new/better assessment tools?

What kinds of barriers do women/girls face in getting a diagnosis?

How does this impact outcomes?

What can professionals and policy-makers do?

Gender and race/ethnicity in ASD

Gender differences in prevalence likely reflect disparities, not biological differences (Constantino & Charman, 2012; Loomes et al., 2017)

- 1 in 151 girls compared to 1 in 37 boys

Race/ethnicity differences in prevalence also likely reflect disparities, not biological differences (Mandell et al., 2009)

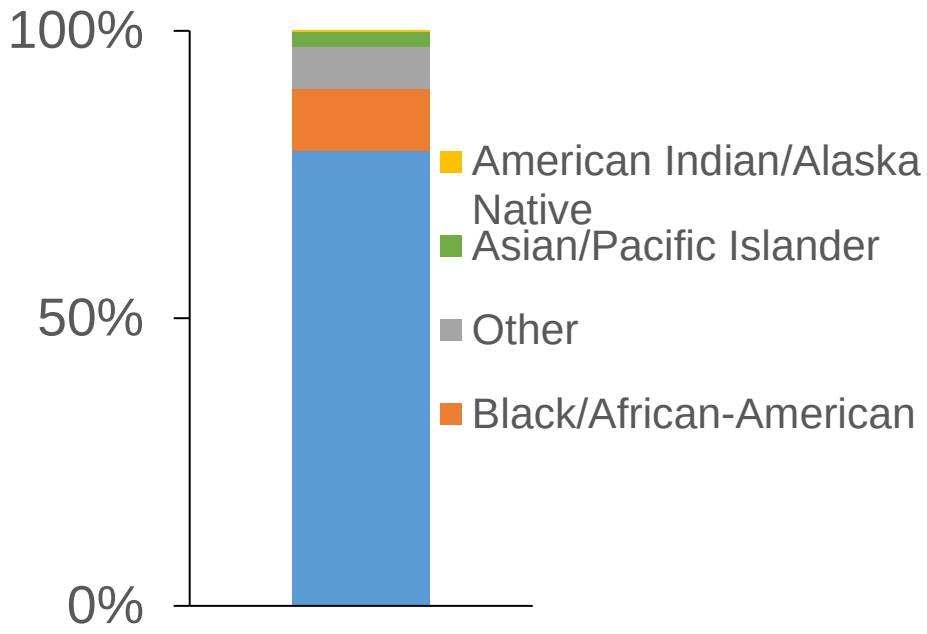
- White non-Hispanic children more likely to be diagnosed than Black or Hispanic children

Local & National Prevalence

United States: 1 in 59 children
(CDC, 2018)

Hispanic children 50% less likely to be diagnosed than WNH children

Black children 30% less likely to be diagnosed than WNH children(CDC, 2018)



Local children's hospital EMR review:

All autism charts from 2007-2018, age 0-21

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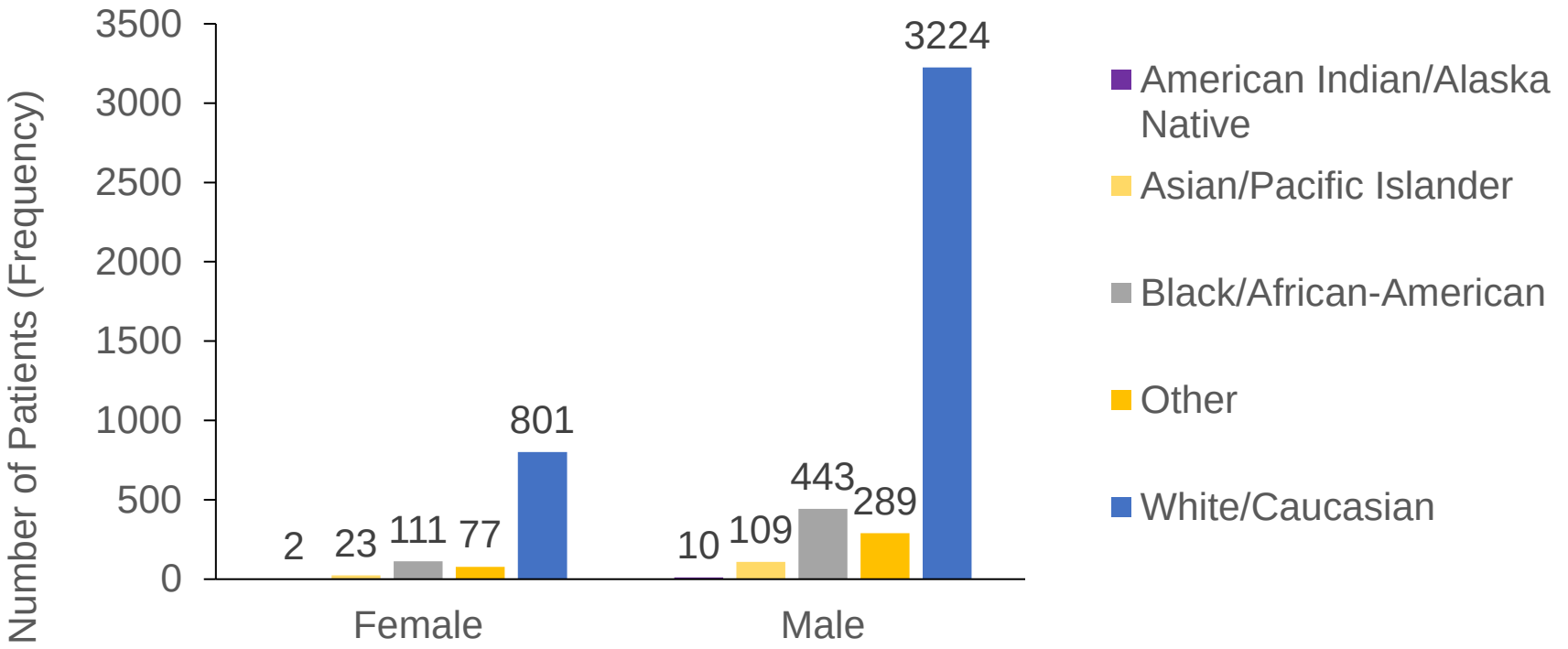
Local Prevalence

Kata, Bowman, Mauk, & Miller (under review)



1:4 ratio of females to males

1:4 ratio of non-white children to white children

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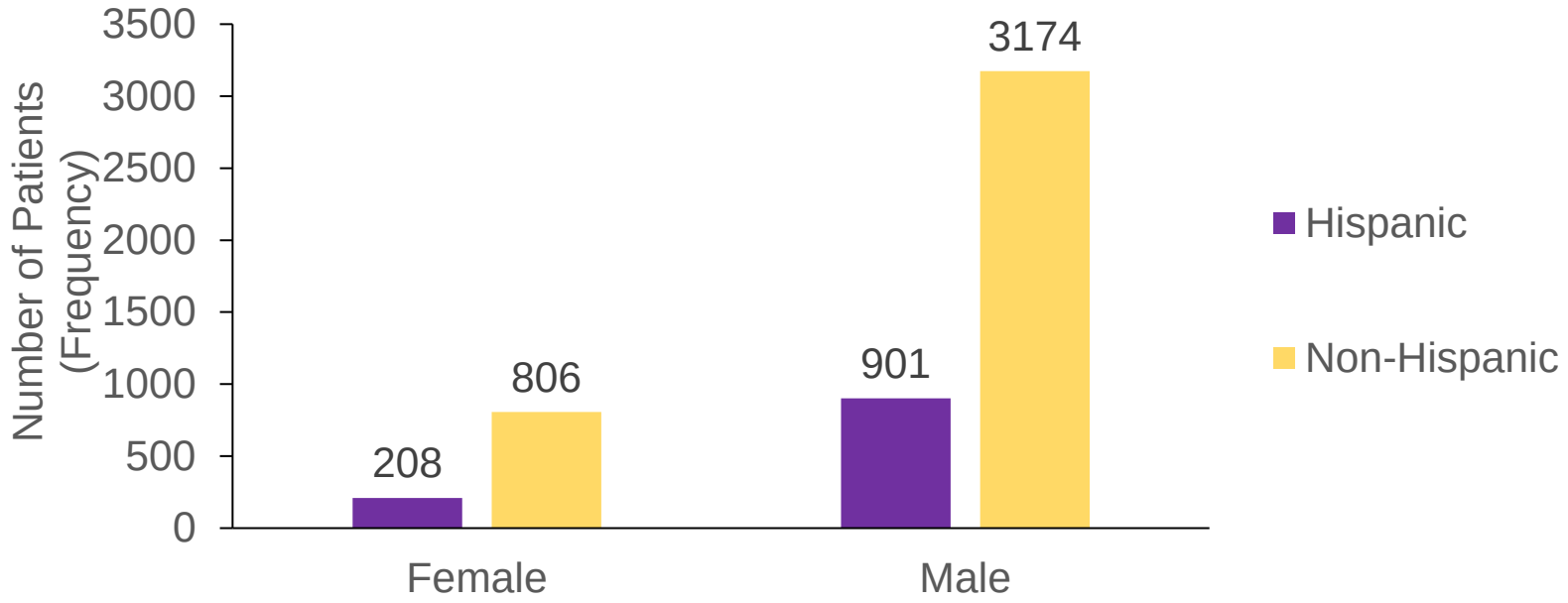
Local Prevalence

Kata, Bowman, Mauk, & Miller (under review)



1:4 ratio of Hispanic to white non-Hispanic females
1:3.5 ratio of Hispanic to white non-Hispanic males
1:15 ratio of Hispanic females to white non-Hispanic males

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Disparities in Diagnosis and Care

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Disparities in Age of Diagnosis

7.6 yrs in girls, 7.1 yrs in boys when symptoms are mild, despite equivalency when symptoms are severe *(Chen, Marvin, & Lipkin, 2015)*

8.8 yrs among Hispanic children, 6.3 yrs among white non-Hispanic children *(Mandell et al., 2002)*

Providers more likely to delay diagnosis for Black children (Shevell et al., 2001)

Delayed diagnosis → later intervention → worse outcomes

Disparities in Type of Diagnosis

Black and Hispanic children are more likely to receive an intellectual disability diagnosis (36-47%) compared to WNH children (27%) *(Maenner et al., 2020)*

> Also more likely to get “bad child” or “problem behavior” diagnoses like conduct disorder or adjustment disorder *(Mandell et al., 2009)*

Girls more likely to be overlooked, or receive incomplete diagnoses of anxiety/depression first.

Wrong diagnosis → wrong services → worse outcomes

Disparities in Type of Diagnosis

Minority girls at greatest risk for missed or delayed diagnosis *(Slopen et al., 2016; Alegria, Vallas, & Pumariega, 2011)*

Black and Hispanic children less likely to have their first evaluation by 36 months than WNH children *(CDC, 2016).*

Still **screening based on social symptoms** (e.g., poor eye contact)

This leaves room for biases rooted in social norms

Few objective, sensitive, specific tools available to characterize non-social symptoms

Let's talk about ***intersectionality***…

For a deeper dive on this topic, see Lopez & Gadsden (2016):

https://nam.edu/wp-content/uploads/2016/12/Health-Inequities-Social-Determinants-and-Intersectionality.pdf

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Who is most vulnerable?

People whose identities include 2+ groups “at risk” for being overlooked or misdiagnosed

For example:

Black Hispanic girls with autism

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How does intersectionality impact people?

Knowledge & surveillance

Time from first concern to diagnosis

Access to care

Agency & ability to advocate effectively

Communication with provider (including being taken seriously)

Ability to coordinate care team/navigate systems

Resources to maintain care

Access to social support from family/community

Symptom differences for girls/women?

Difficult to tell whether there are differences in *symptoms* between girls/boys, or whether our *societal expectations* are just different

Quiet and solitary little girls fit a “good girl”/”easy child” stereotype

Girls are expected to be more relational as they get older, so social communication symptoms are more obvious/problematic, especially after childhood

Specific problems for girls/women

Girls with ASD more often attempt to mask their symptoms as they get older

- Masking is commonly reported among women with ASD as being effortful and exhausting

Depression (34%) and anxiety (36%) are common among women with ASD *(Croen et al., 2015)*

Eating disorders are also common *(Brede et al., 2020)*

High risk (3x that of typical development) of being coerced into sexual victimization *(Gotby et al., 2018)*

Implications for Policy & Practice

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Addressing biases/disparities

Intellectual Humility

I might be wrong about a symptom or diagnosis.

I do not have expertise in this area.

Someone else might know more about this than me.

This is outside the scope of my practice.

I need to refer this person to someone for additional/alternative care.

Cultural Humility

I might not understand this person's background.

I might need to ask some questions that make me feel/seem ignorant.

I do not have to agree with this person's perspective to respect them.

I might make assumptions based on how someone looks, speaks, or acts.

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Each stage in the care trajectory is vulnerable:

- **Surveillance** – overlooking someone, ignoring signs
- **Screening** – relying too much on subjective judgments or trying to work around algorithms deemed "overly conservative"
- **Referral** – deciding a family "won't follow through" or can't afford it, so "why bother?"; trying not to "waste their time"
- **Assessment** – lack of training/reliability, insufficient test battery
- **Diagnosis** – "bad child" diagnoses for some groups
- **Intervention** – prescribing without attention to feasibility/access
- **Monitoring Outcomes** – only monitoring proactive/convenient patients, or only monitoring a restricted range of outcomes

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To reduce negative effects of intersectionality, we need to advocate for policy changes with…

Legislators to adopt policies that promote *universal access* to **early identification and intervention**;

Schools and public agencies to educate their staff on **surveillance, inclusion, disparities, and bias/stereotype reduction**;

Public investment in initiatives that **reduce wait times and barriers to assessment/diagnosis/services**;

Insurers to **close loopholes that allow exclusions** for ASD services;

Employers, clinics, and insurers to provide **patient navigators** who can help families coordinate care and be a source of continuity.

+

Acknowledge that implicit biases are a normal part of the human experience, and then work to overcome them.

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Beware **potential sources of bias** or **harmful stereotypes** that might lead to disparities at some stage in the trajectory, like…

- Autism is less common in minorities/females
- Parents who question practitioners are ignorant/difficult
- Minority children are more disruptive/misbehave often
- Children from low-resource communities are often just not "raised right"
- Some parents want their child to have a diagnosis to get free services they don't need

Ready to tackle your own implicit biases?

1

Take the Implicit Attitudes Test!

*It's not just for assessing racial biases! There are versions for assessing biases based on size, religion, **ability**, sexuality, age…*

2

Watch Vernā Myers' TED Talk on acknowledging and working to overcome your own biases through intentional, mindful action

https://implicit.harvard.edu/implicit/selectatest.html
https://www.ted.com/talks/verna_myers_how_to_overcome_our_biases_walk_boldly_toward_them

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The Remaining Problems…

Major disparities exist in who gets diagnosed, and when.

Women and girls struggle with **unique problems across the lifespan**, especially because of societal expectations.

Provider knowledge plays a big role – need to assess and educate primary-care physicians and educators, and improve implicit bias training and detection efforts in clinics and schools

Patient-blaming and culture-blaming is still rampant

ASD is a **complex condition** with a wide range of **variability** in symptom profiles.

Women and girls may learn to **mask the presentation of ASD symptoms**.

Risk for **disparities in care** can be driven by the interaction between race/ethnicity or gender identity.

Changes must occur in both **policy & practice**.

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Autism does not discriminate.

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How Can You Help?

- Counteract **stereotypes** of ASD by providing information about how boys and girls may differ

- Raise awareness of **disparities** faced by vulnerable groups in your community

- Encourage families to **participate in research**, so that underrepresented communities are represented equally in the literature!

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Want to get involved?

- Our lab is currently doing several different research studies, and for many of them, we pay participants for their time.

- We especially need women/girls, and Black and Hispanic families, in order to make sure those communities are well-represented in the scientific literature, and well-understood by the community!

- Contact us for more information at autism@unthsc.edu or 817-735-2312!

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Acknowledgments

- **Mentors & Collaborators**
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UT SOUTHWESTERN MEDICAL CENTER

NIH NSF

AUTISM SPEAKS

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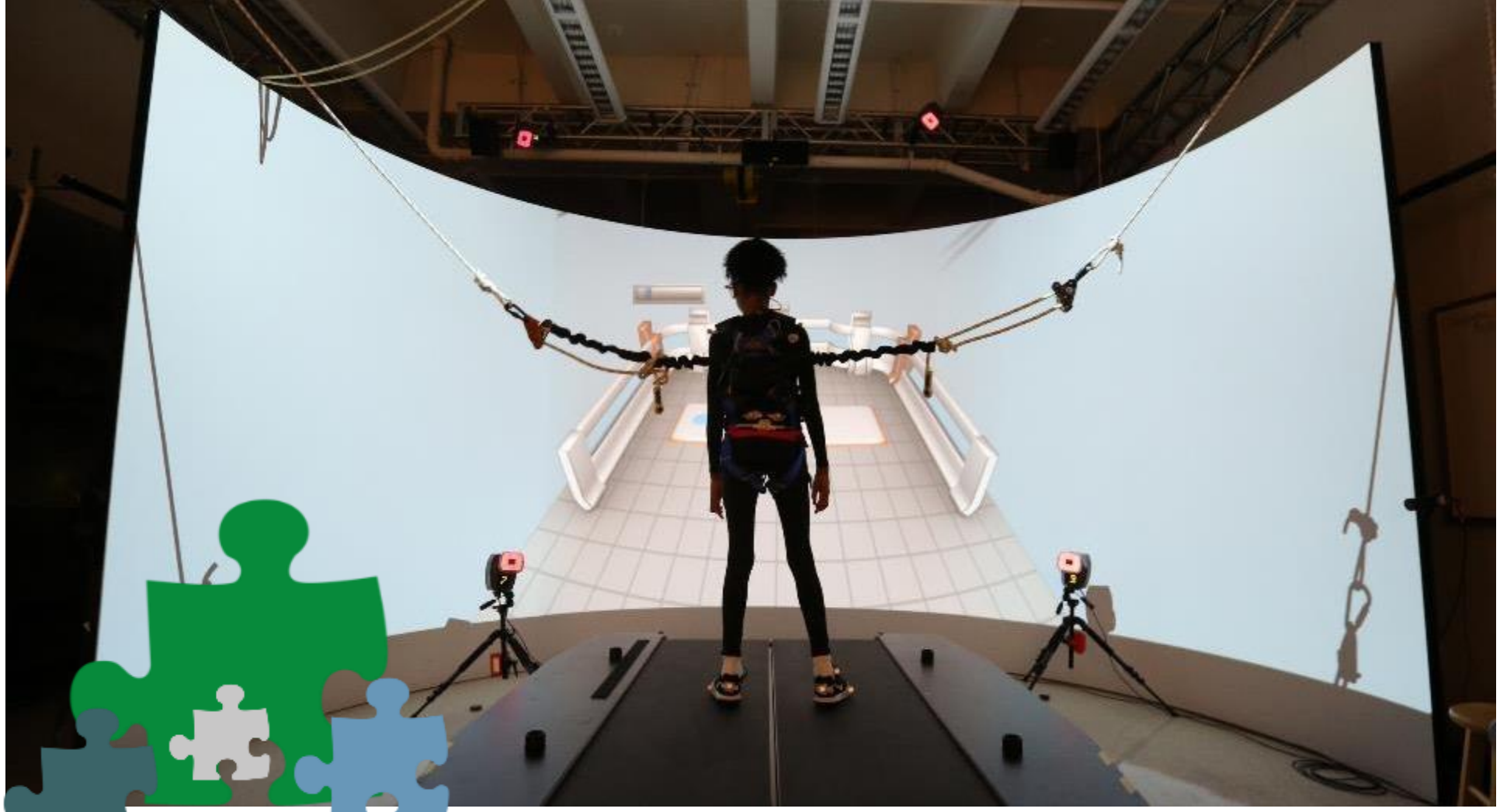
Most importantly, our thanks to the amazing families who give time & effort so generously to advance our understanding of ASD!



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Thank you!

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