


# Autism in the African American Community

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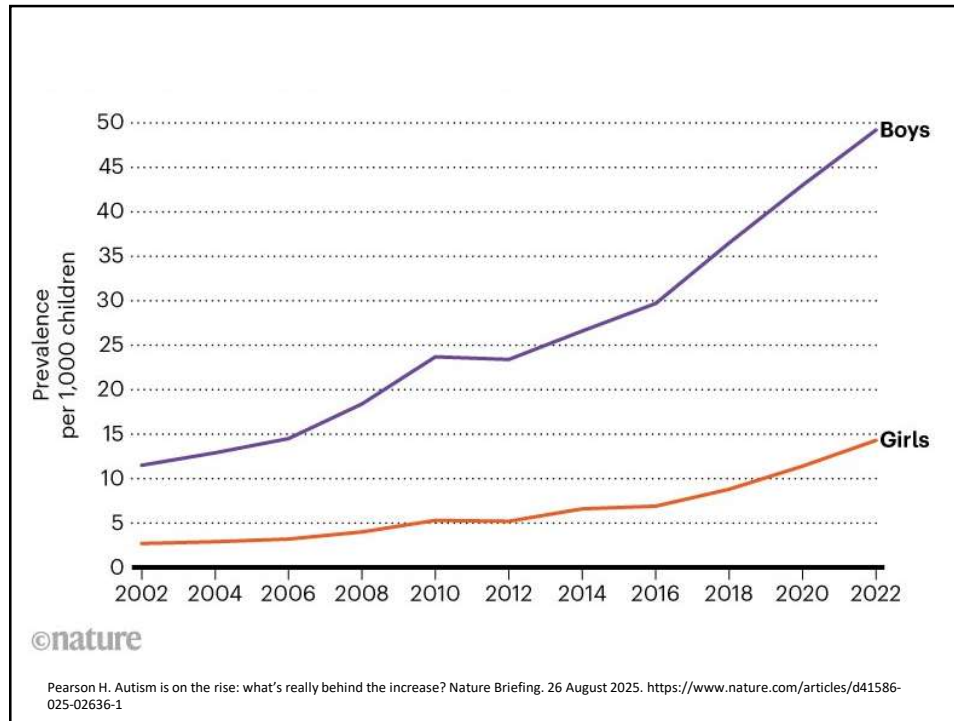
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## Autism Spectrum Disorder

- Complex neurodevelopmental disorder
- Manifests in infancy or early childhood
- Characterized as a pervasive developmental disorder that involves abnormalities in:
  - a) Social skills
  - b) Communication
  - c) Repetitive behaviors or restricted interests
- Etiology



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## Diagnosis

- Pediatric screening for typical development (9, 12, 18, and 24-30 months)
  - No babbling, pointing, or other gestures by 12 months
  - No single words by 16 months
  - No 2-word spontaneous phrases by 24 months, with the exception of repeated phrases (echolalia)
  - **ANY** loss of any language or social skills at **any** age
- ASD Screening at well-child visits (18 months and 24 months)
- **\*\*\***Observation by a trained clinician (clinical psychologist, neurologist, ect.)

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## Notable Symptoms

1. Potato sack babies
2. Too quiet
3. Looking through you
4. Fixation on objects
5. Low level babbling and slow/no word development
6. Toe walking
7. People as tools\*

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## Autism Spectrum Disorder in the Media



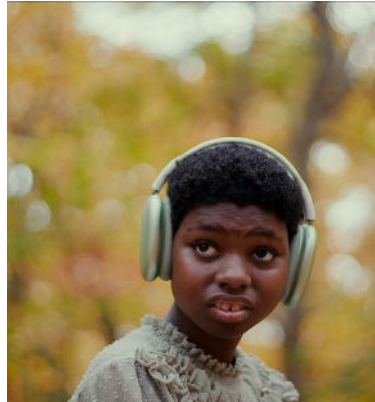
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## Autism Spectrum Disorder in the Media



Watson (CBS)



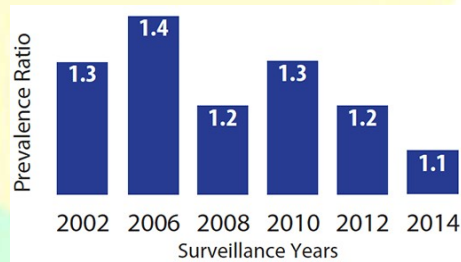
Makayla's Voice: A Letter to the World (Netflix)

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## ASD in African Americans

- Reported prevalence in Black children is now comparable to white children.
  - Previous reports indicated overall higher ASD prevalence in White children.
  - Rates still higher in AZ (40%), AR (40%), MO, NJ (30%), WI (20%)
  - Still lower in Hispanic children
  - **Why?**
- Age of diagnosis still 3 years later
  - More likely to get 'conduct disorder' Dx
  - Culturally competent assessment
    - What is culturally "normal"?
    - How does parent respond?
    - Racially biased practitioner beliefs
  - More often ascertained in school
- Access to Care



<https://www.cdc.gov/ncbddd/autism/addm-community-report/differences-in-children.html>

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- Established in 2000
- Biennial public health surveillance
- Ascertainment of ASD at age 8 years via records review

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## ADDM Sites in 2010



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## Ascertainment by census tracts (n=2489 tracts)

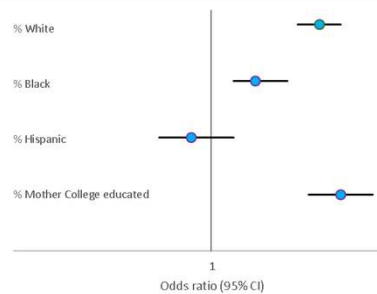
		Mean	SD
Case Ascertainment	% School only	10.3	24.9
	% Health only	44.5	41.0
	% Both School and Health	45.2	40.3



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## Personal

n = 2489 tracts	Both schools and healthcare	
	OR (95% CI)	aOR (95% CI) <sup>a</sup>
% White race	1.10 (1.08–1.12)*	1.04 (1.01–1.08)*
% Black race	1.04 (1.02–1.07)*	
% Hispanic ethnicity	0.98 (0.95–1.02)	0.99 (0.96–1.04)
% Mother college educated	1.12 (1.09–1.15)*	1.06 (1.02–1.09)*

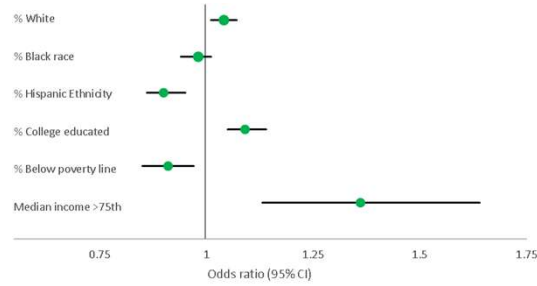


Dickerson AS et al. (2017) Autism Spectrum Disorder reporting in lower socioeconomic neighborhoods. *Autism*. 21(4): 470-480

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# Neighborhood

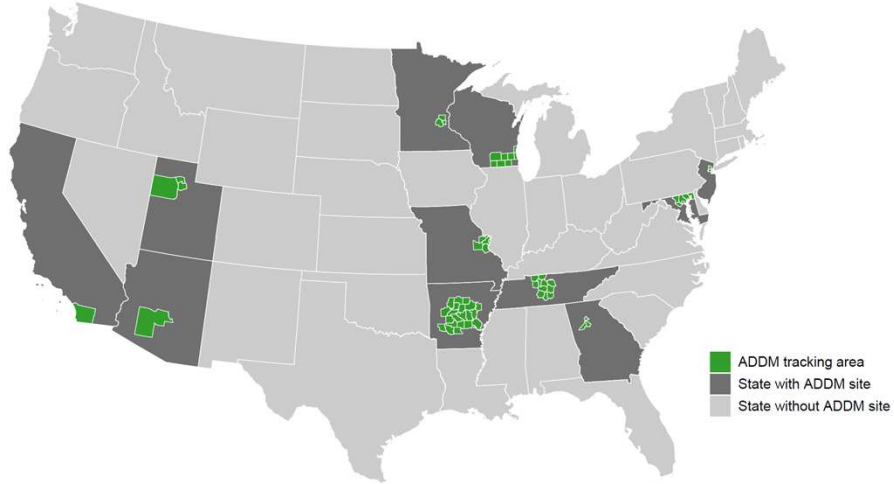
n = 2489 tracts	Both schools and healthcare	
	OR (95% CI)	aOR (95% CI) <sup>a</sup>
% White race	1.04 (1.01–1.07)*	1.01 (0.97–1.05)
% Black race	0.98 (0.94–1.01)	
% Hispanic ethnicity	0.90 (0.86–0.95)*	0.93 (0.88–0.99)*
% College educated	1.09 (1.05–1.14)*	1.06 (1.01–1.11)*
% Below poverty line	0.91 (0.85–0.97)*	0.99 (0.90–1.08)
Median income >75th	1.36 (1.13–1.64)*	



Dickerson AS et al. (2017) Autism Spectrum Disorder reporting in lower socioeconomic neighborhoods. *Autism*. 21(4): 470-480

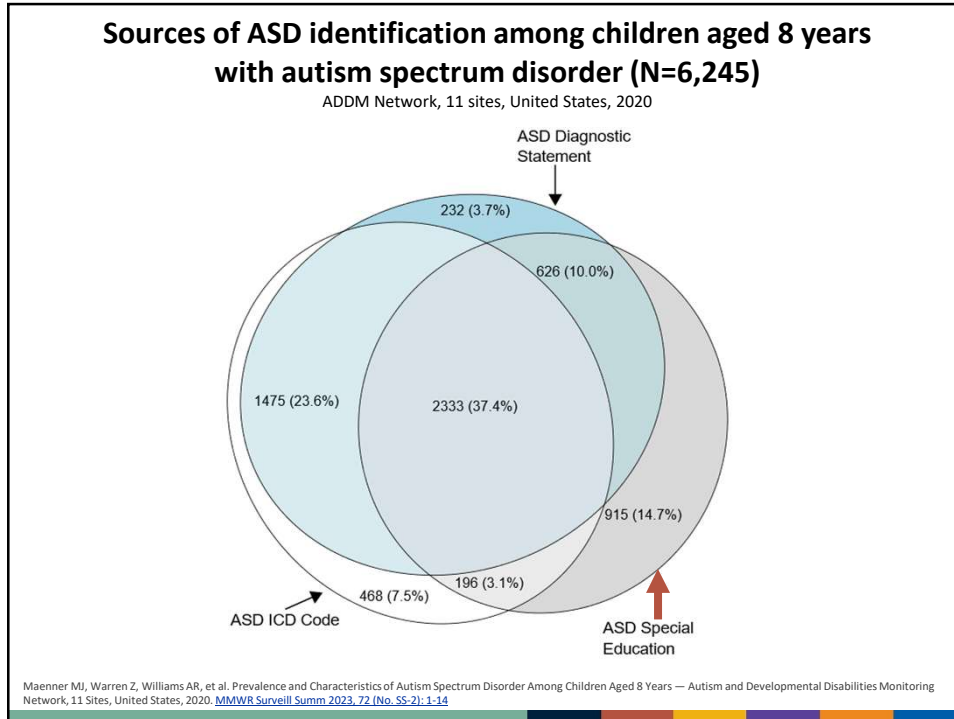
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## Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2020

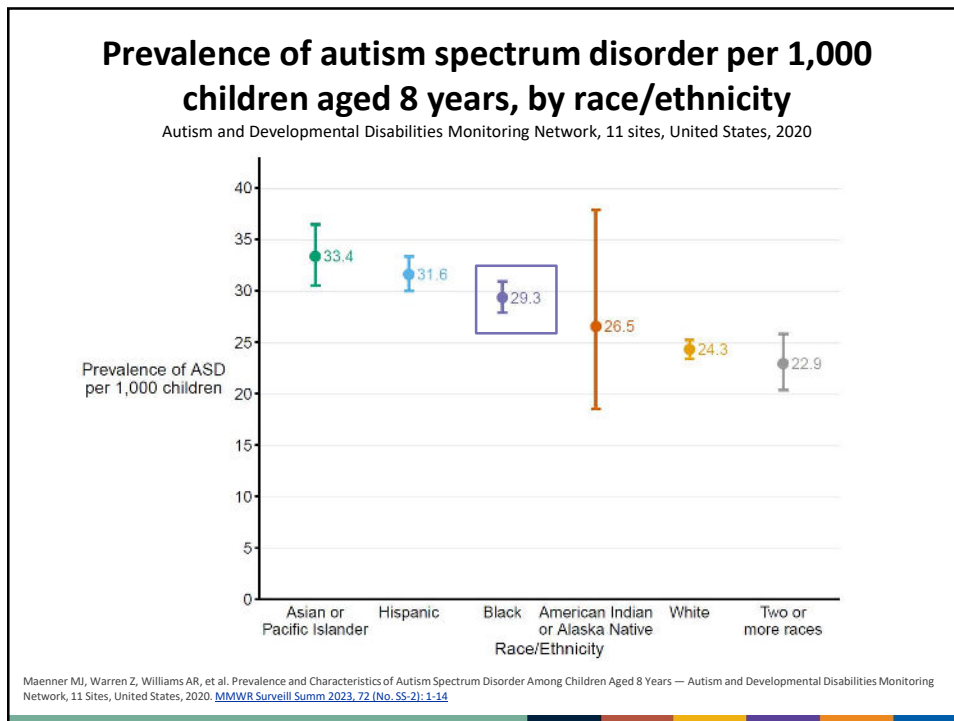


Maenner MJ, Warren Z, Williams AR, et al. Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2020. *MMWR Surveill Summ* 2023; 72 (No. SS-2): 1-14

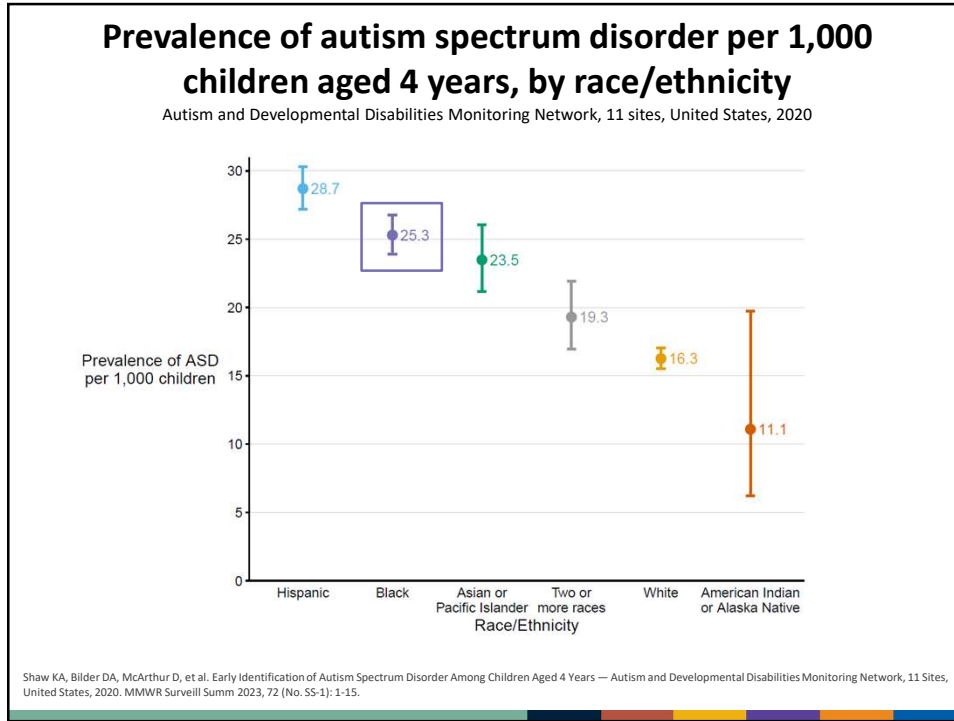
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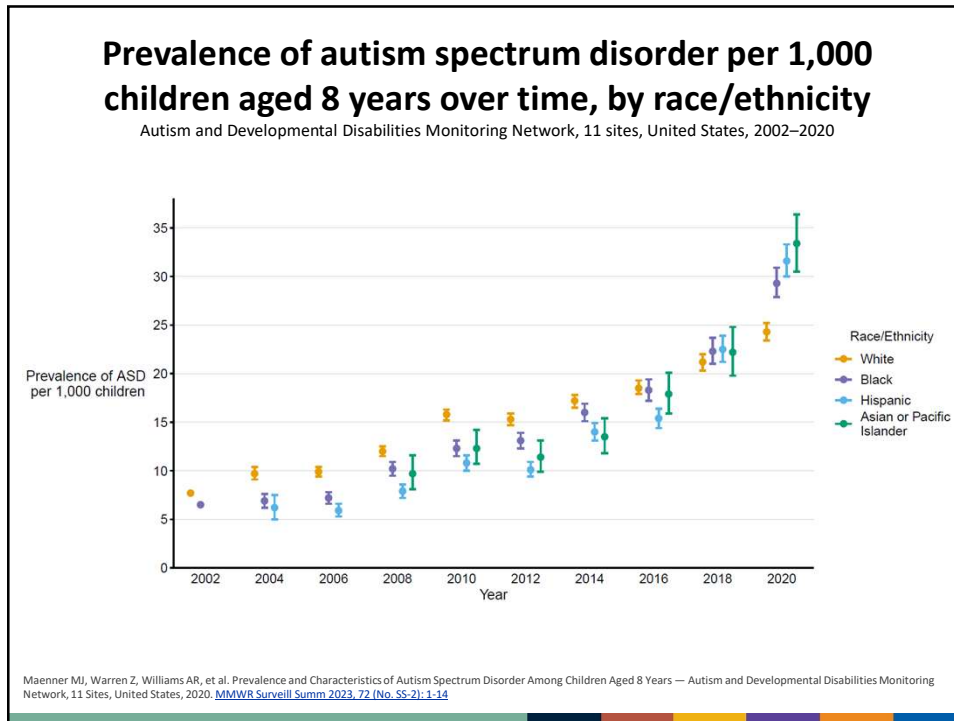
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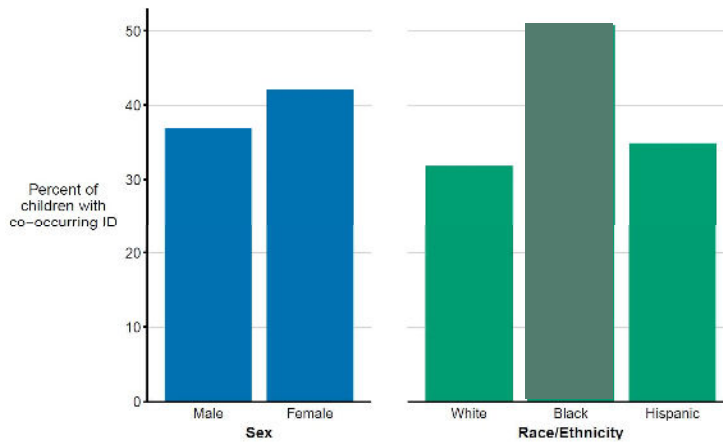
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### Percent of children aged 8 years with autism spectrum disorder with co-occurring intellectual disability\*, by sex and race/ethnicity

Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2020

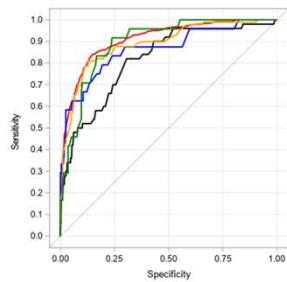


\* IQ score  $\leq$ 70 or examiner statement of intellectual disability in a comprehensive evaluation

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### ROC analysis of SRS predicting ASD diagnosis by maternal:

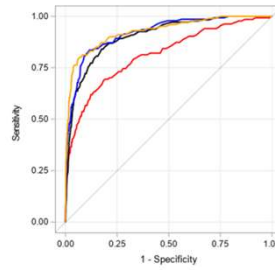
a) race and ethnicity groups



Maternal race/ethnicity  
 Non-Hispanic White, Non-Hispanic Black, Non-Hispanic Asian, Non-Hispanic Other, Hispanic

AUC values:  
 White: 0.92, Black: 0.84, Asian: 0.89,  
 Hispanic: 0.87, Other race groups: 0.88

b) education level



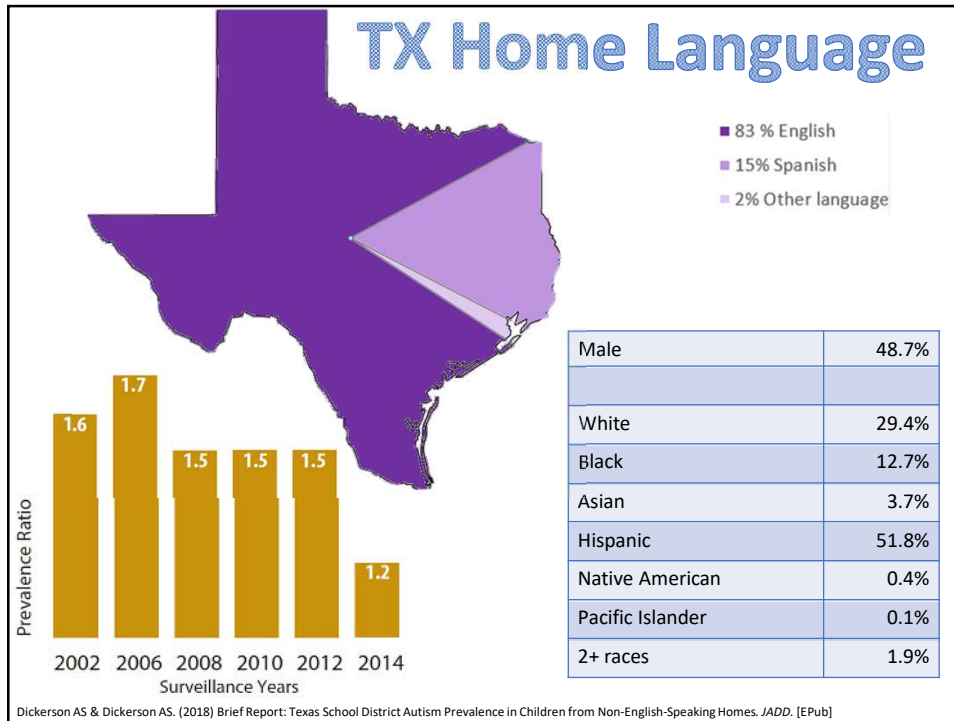
Maternal Education  
 < HS, HS degree, GED or equivalent, Some college, no degree, Assoc/Trade, Bachelor degree (BA, BS), Master's, Prof or Doctorate Degree

AUC values:  
 White: 0.92, Black: 0.84, Asian: 0.89,  
 Hispanic: 0.87, Other race groups: 0.88

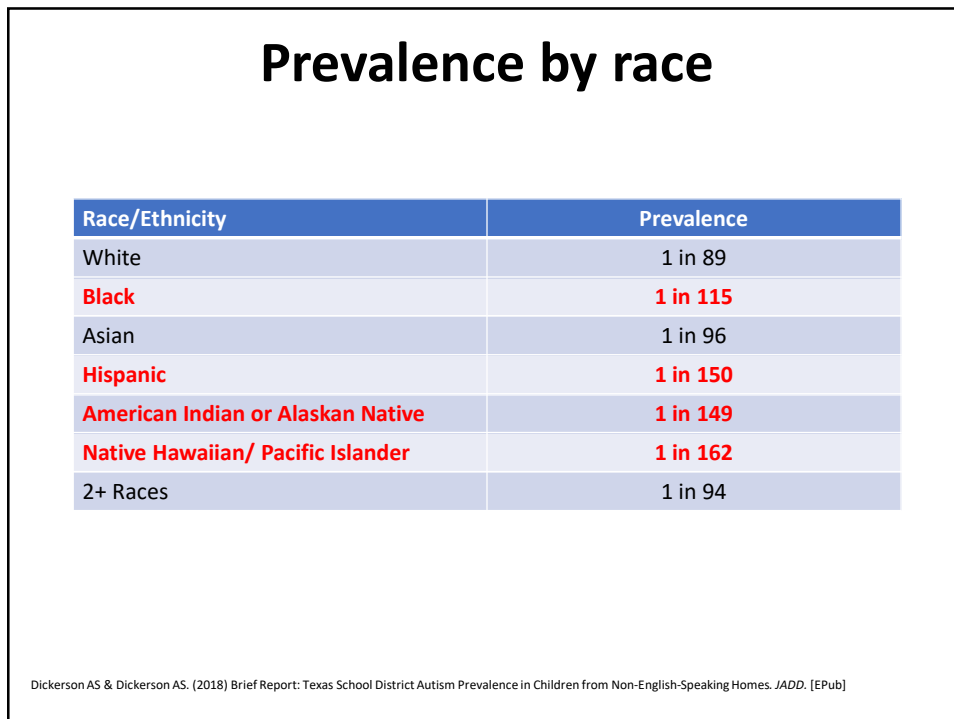
**Strong predictive ability of SRS across demographic groups, but poorer agreement with diagnosis in Black children and among those with low education**

Lyall K, Dickerson AS, et al. Demographic correlates of autism: How do associations compare between diagnosis and a quantitative trait measure. *Under review for AJE*

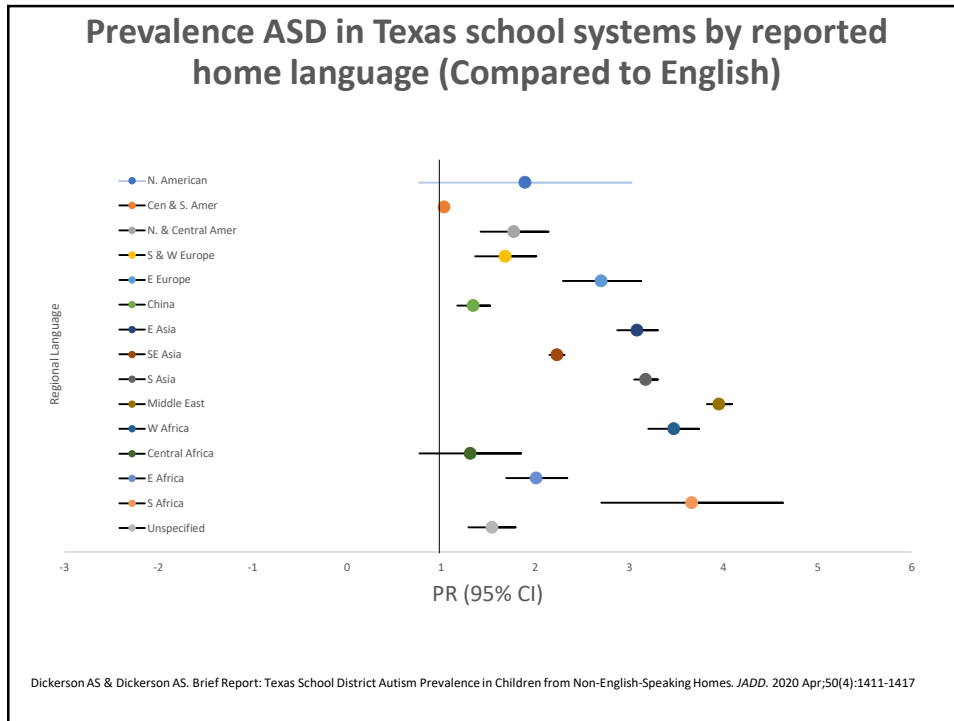
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# ECHO

Environmental influences  
on Child Health Outcomes

A program supported by the NIH

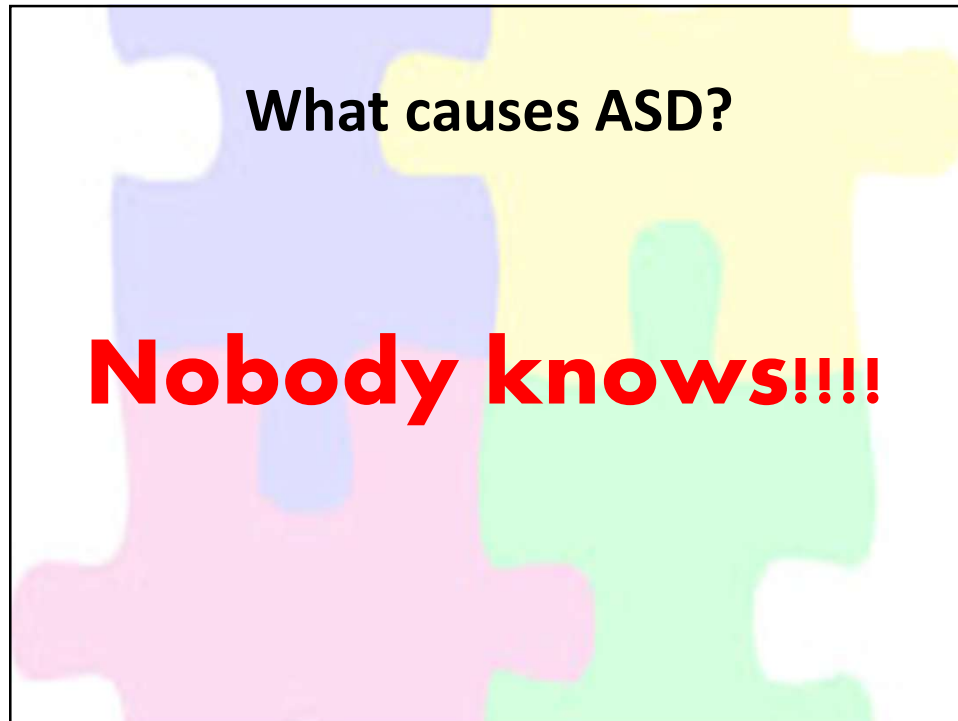
## Subclinical Outcomes

- Behavior problems
- Learning deficits
- Missed school days
- Underperformance in school

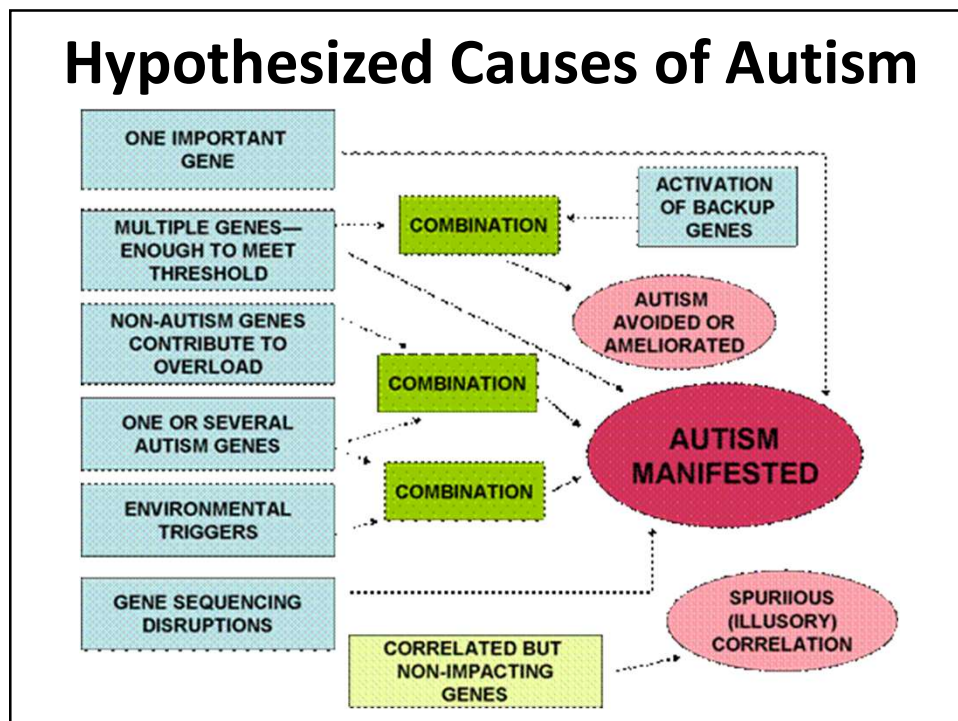


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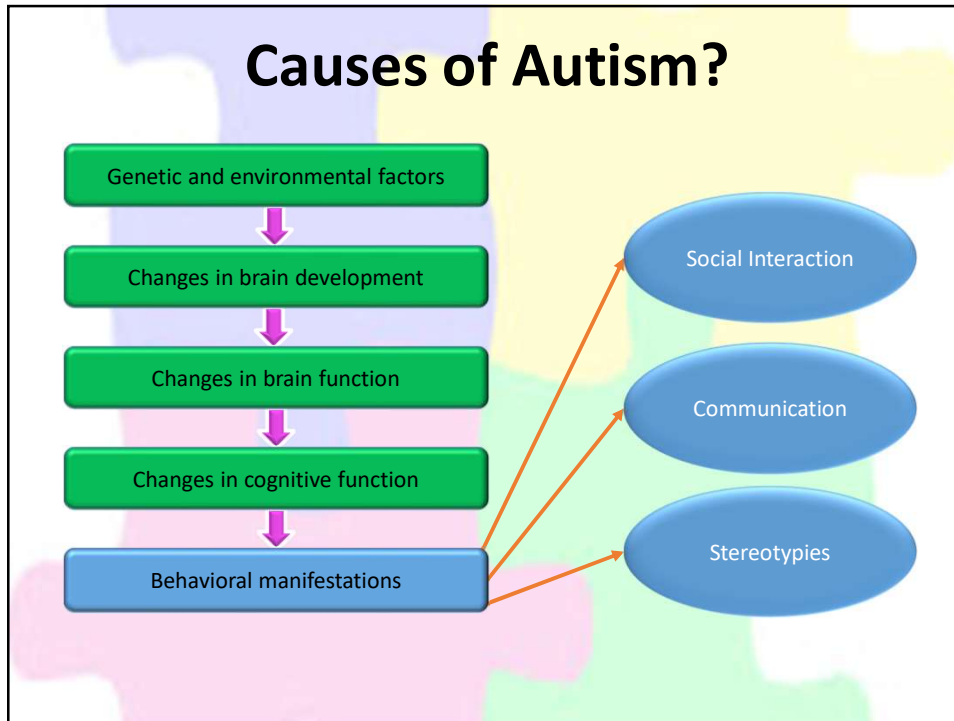
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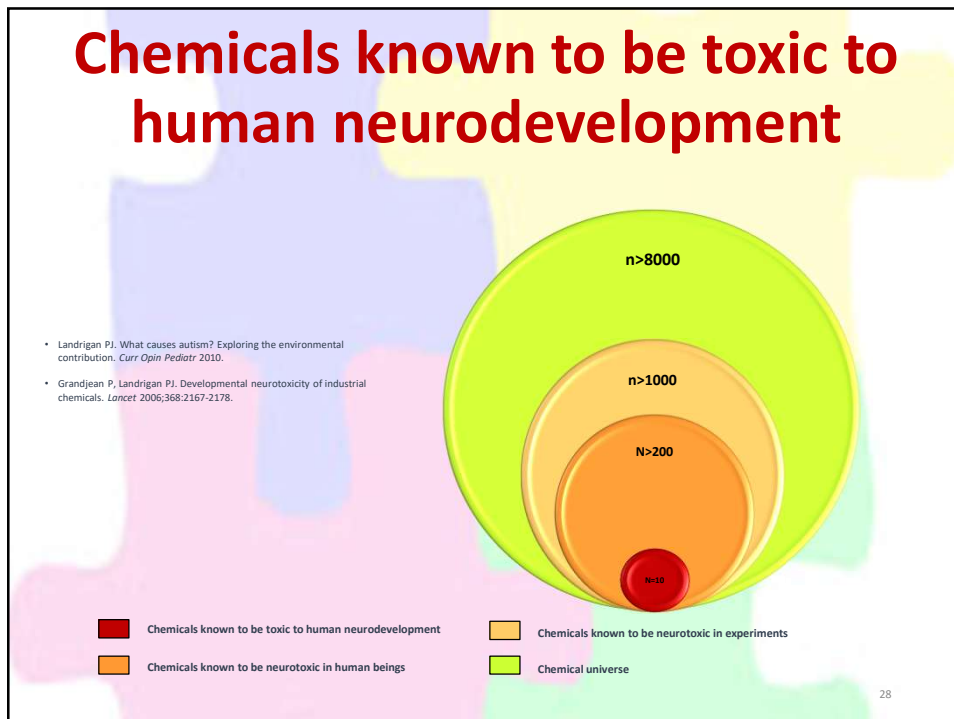
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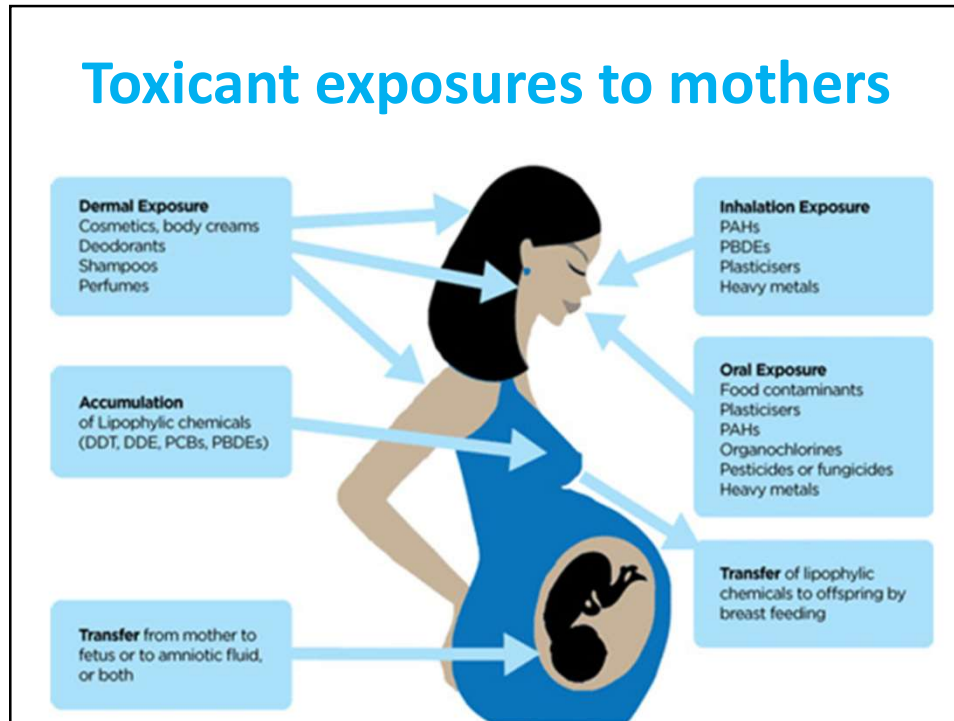
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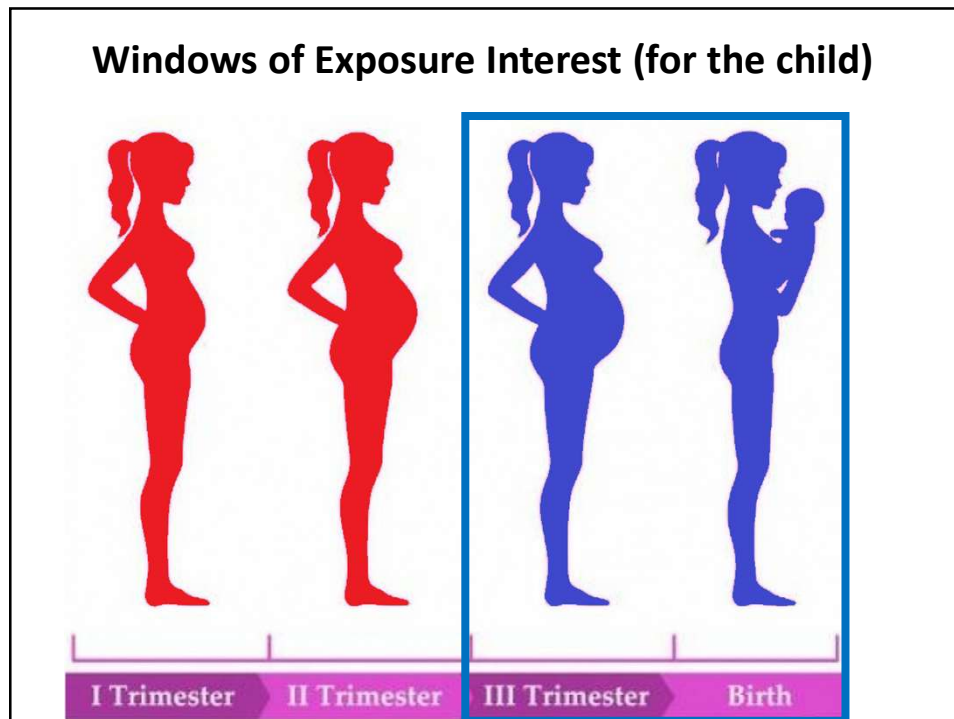
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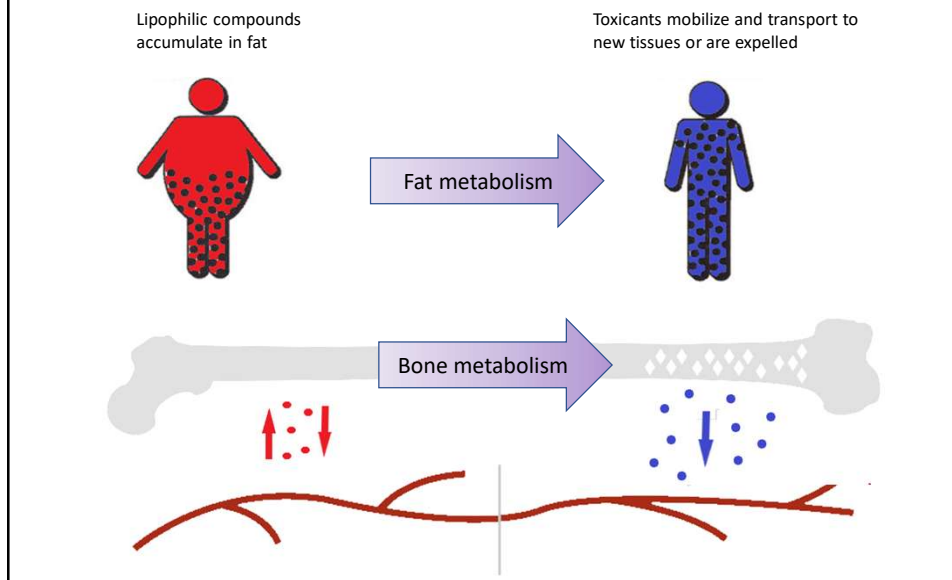


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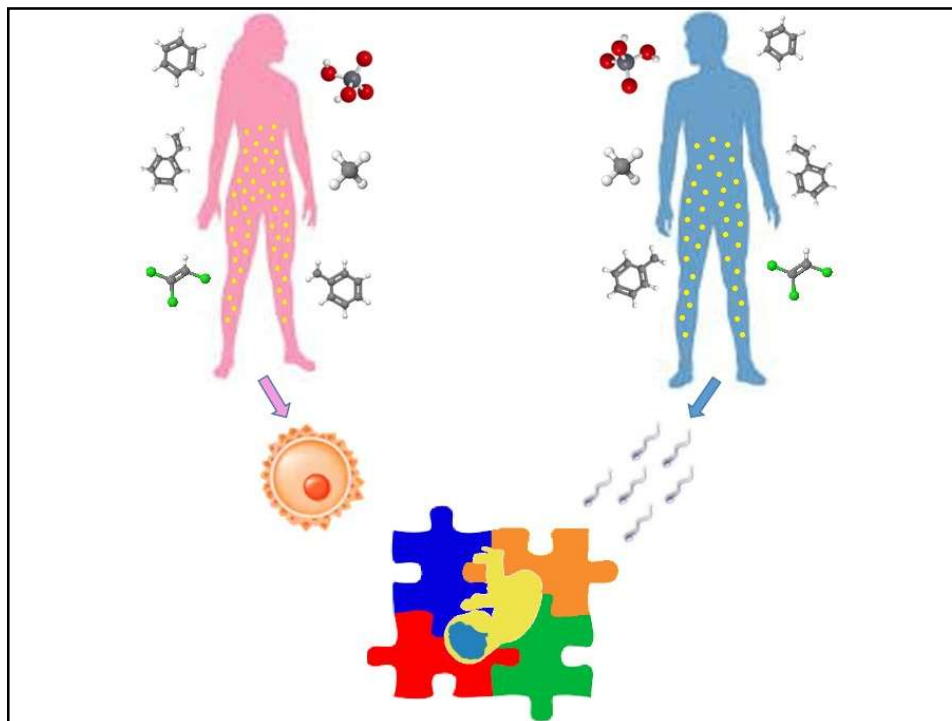


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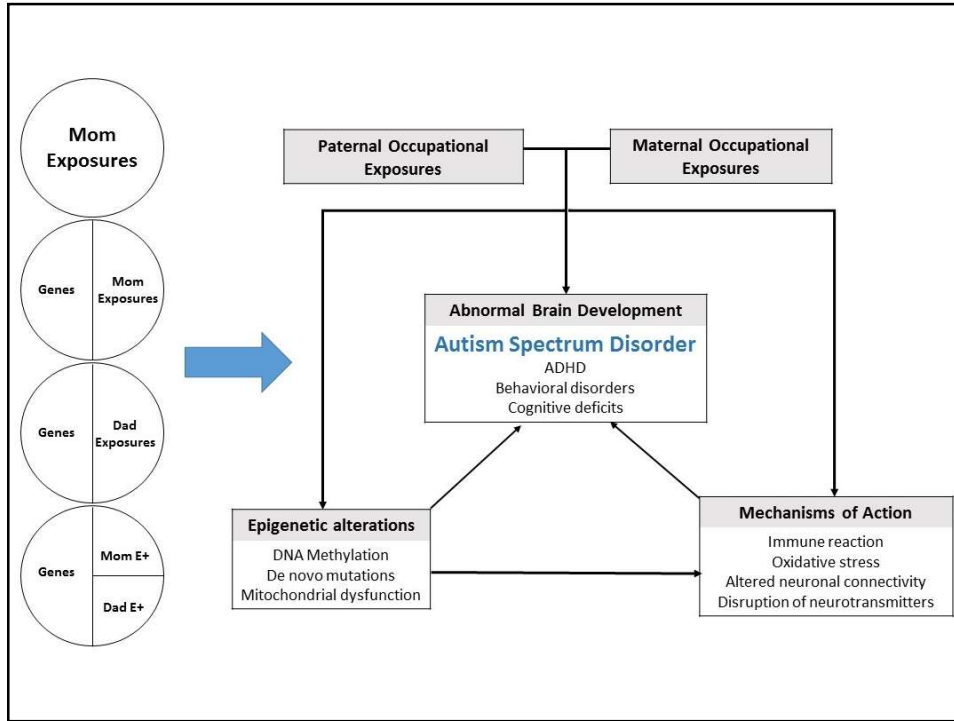
## Accumulation of persistent pollutants in fat and bone



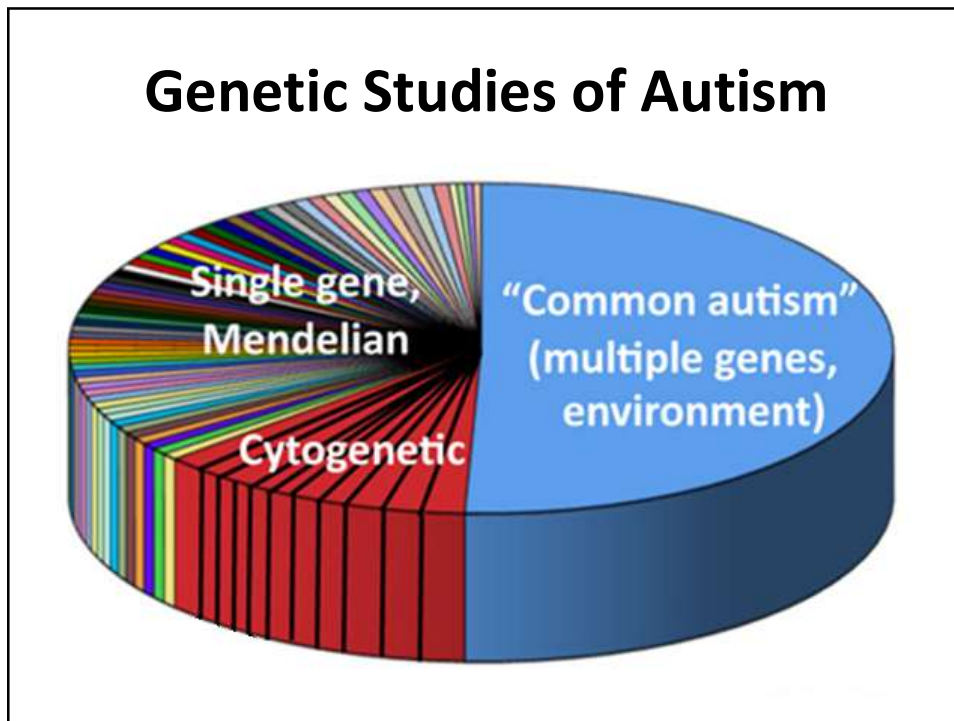
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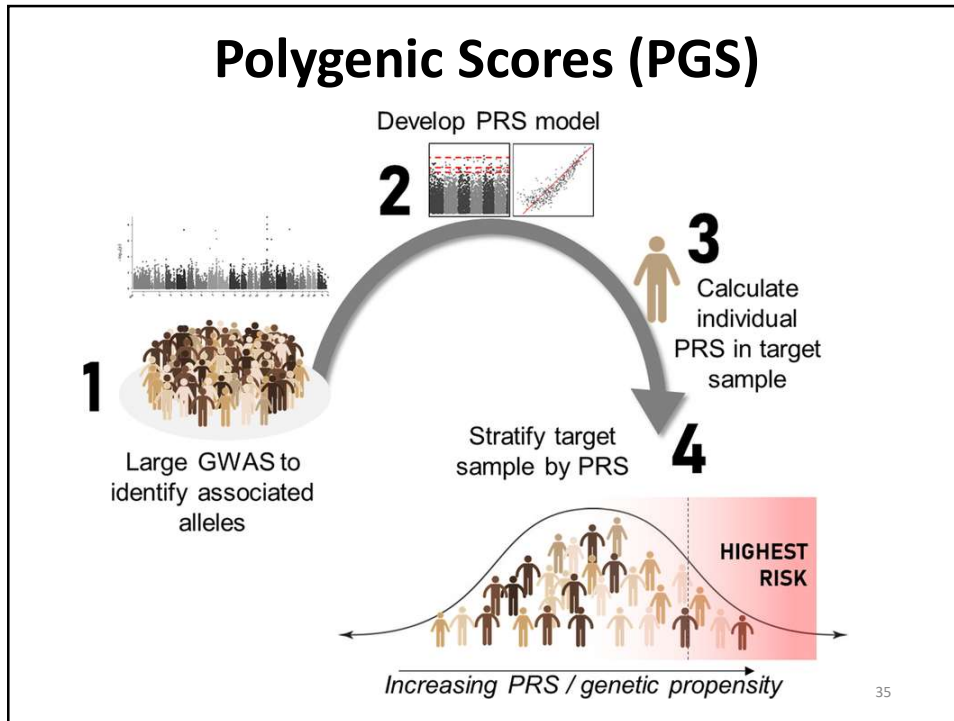
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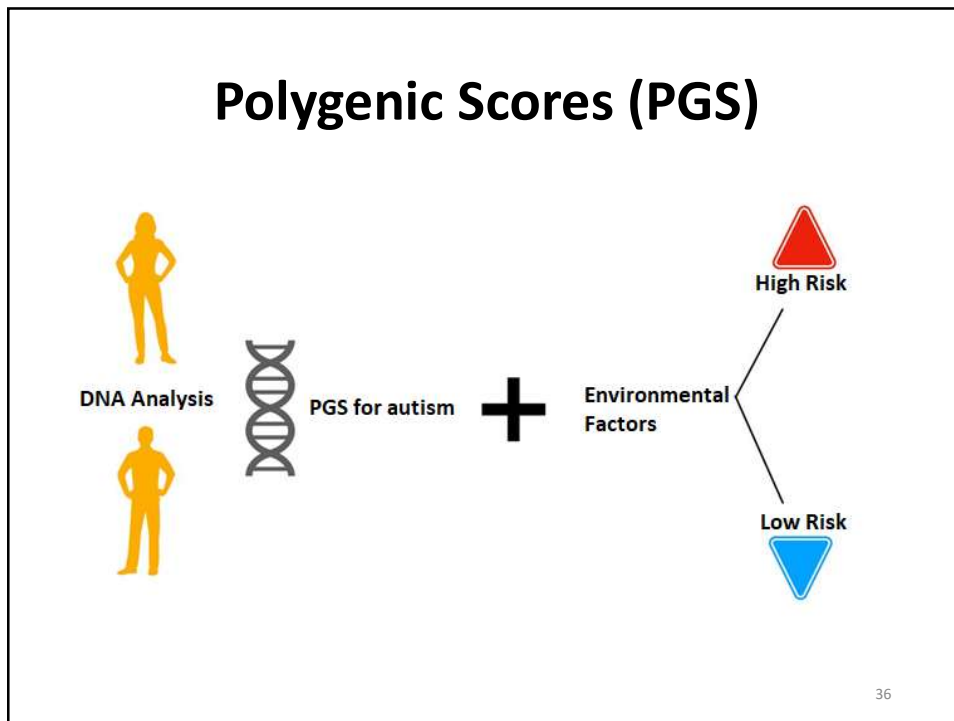
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## Community Based Participatory Research

**OBSERVATION:**  
Understand what influences children's health as they grow and develop.



**INTERVENTION:**  
Test whether making changes in children's lives will enhance their health.







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## Adults with Autism



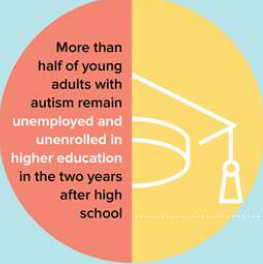
An estimated 5 percent of adults with autism have ever been married



Many young adults with autism don't receive any health care for years after they stop seeing a pediatrician


Depression affects an estimated 26 percent of adults with autism


3 times the U.S. average



More than half of young adults with autism remain unemployed and unenrolled in higher education in the two years after high school

As many as **one-third** have epilepsy





Most young adults with ASD live with their parents

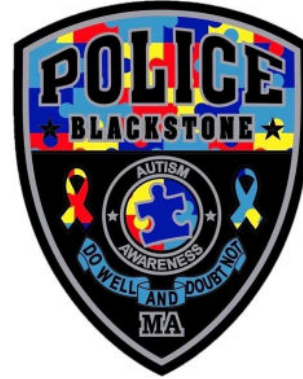
more than double that of young adults without special needs

<https://health.ucdavis.edu/health-magazine/issues/summer2019/features/autism/helping-adults-with-ASD-live-better-lives.html>

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# Police Interactions



By age 21, ~20% of youth autistic youth had been stopped and questioned by police. Almost 5% had been arrested.

Rava, J. et al. The Prevalence and Correlates of Involvement in the Criminal Justice System Among Youth on the Autism Spectrum. J Autism Dev Disord 47, 340-346 (2017).



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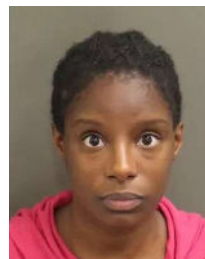
# Having Autism...While Black



**Brandon Davis**  
Detained for walking home



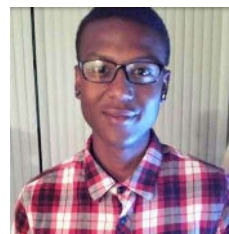
**Kayleb Moon-Robinson**  
Charged with felony for outburst



**Imarah Aaliyah Bryan**  
Arrested for petty theft & failure to appear



**Neli Lawson**  
Sentenced to 10 years in prison after sitting outside at a library



**Elijah McClain**  
Died after being detained for walking home

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## Services for Adults with ASD

- Yes, adults with ASD can have fulfilling lives!
- Prepare in advance...
- School until 21: **Job Training and Daily Living Skills!!**
- Get on waiting lists for Medicaid and Day Programs
- Start transitions to new situations early (in-home care or day centers)
- Non-profits have respite care
- Work with Health and Human Services to plan for long-term care (insurance)

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## Resources

- Fannin DK, Williams EG, Fuller M, Pearson JN, Boyd BA, Drame ER, Taylor J, Dickerson AS, Spinks-Franklin A, Coles-White J. Unpacking the prevalence: A warning against overstating the recently narrowed gap for Black autistic youth. *Autism Res.* 2024 Jun;17(6):1072-1082. doi: 10.1002/aur.3168. Epub 2024 May 28. PMID: 38804591; PMCID: PMC11186720.
- Yates Flanagan, A., Cola, M., Yu, N., Peele, H., Dicette, K., Hicks, G., Pelella, M. R., King-Pointer, A., Owens, J., Truong, D. M., Hauptmann, A., Pacheco, J., Russell, A., Lee, A., Schillinger, S., Covello, M., Lyons, M., Solórzano, R., Turnacioglu, S., ... Parish-Morris, J. (2024). Policing Black autistic children: A qualitative approach to understanding Black caregivers' concerns. *Autism*, 29(5), 1303-1317. <https://doi.org/10.1177/13623613241303549> (Original work published 2025)

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