A ROADMAP FOR EQUITY IN AUTISM IDENTIFICATION AND CARE

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I have no financial disclosures.

LAND ACKNOWLEDGEMENT

https://nativegov.org/a-guide-to-indigenous-land-acknowledgment/

Photo by **Anway Pawar** on **Unsplash**

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OBJECTIVES

- Quantify disparities in autism diagnosis and interventions by race and ethnicity, sex, socio-economic status and cognitive ability, based on published studies.

- Identify potential mechanisms through which disparities in autism diagnosis and care are perpetuated.

- List potential solutions to improve equity in autism identification and care.

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1. AN OVERVIEW OF AUTISM INEQUITIES

2. Foundational Concepts in Health Equity

3. Mechanistic inquiry into autism disparities

4. Promoting Equity

A STORY ABOUT BENJAMIN. . .

- 5 year, 7 months

- Parents spoke English, immigrants from East Africa

- Decreased interaction with others, fleeting eye contact, difficulty with conversation, echolalia, scripting, repetitive movements, behavioral inflexibility

- Had only recently begun using more than 1-word utterances to communicate

- Expelled from kindergarten

Wallis KE, Buttenheim AM, Mandell DS. Insights from Behavioral Economics: A Case of Delayed Diagnosis of Autism Spectrum Disorder. Journal of Developmental & Behavioral Pediatrics. 2021;42(2):109-113.

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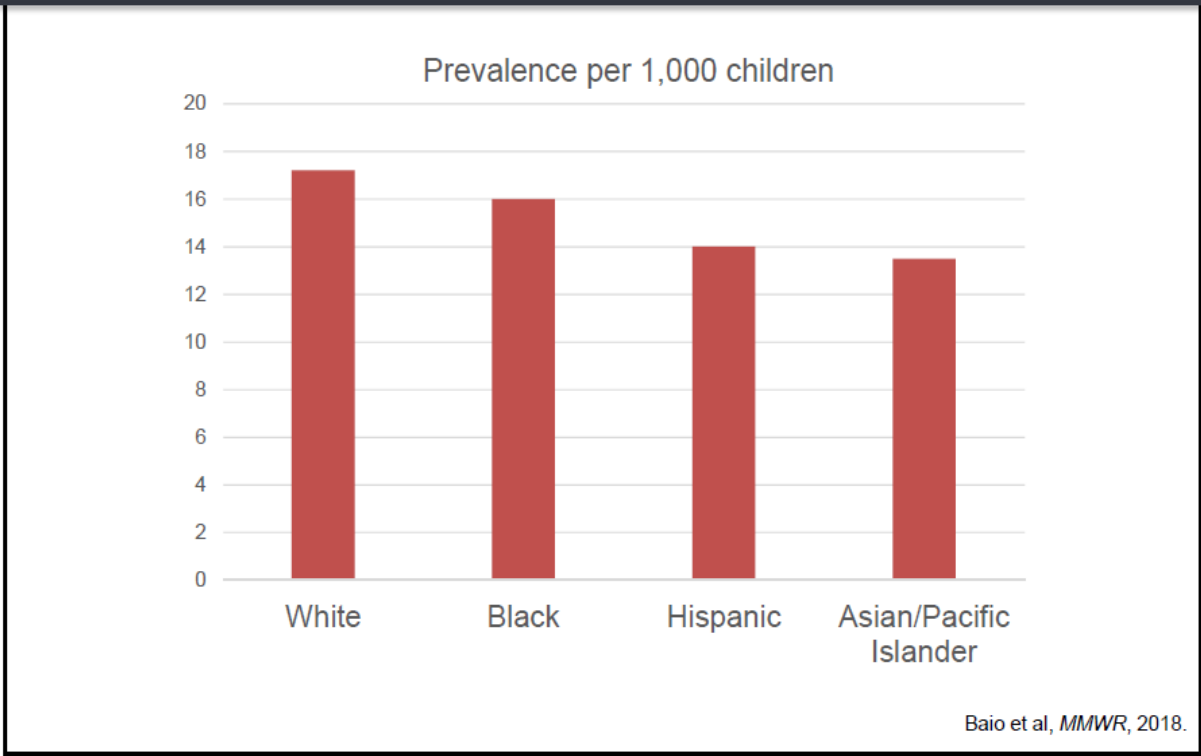# AUTISM SPECTRUM DISORDER

Deficits in social communication and social interactions

- A1: Deficits in social-emotional reciprocity

- A2: Deficits in nonverbal communicative behaviors used for social interaction

- A3: Deficits in developing, maintaining, and understand relationships

Restricted, repetitive patterns of behavior, interests, or activities

- B1: Stereotyped or repetitive motor movements, use of objects, or speech

- B2: Insistence on sameness, inflexible adherence to routines, or ritualized patterns of behavior

- B3: Highly restricted, fixated interests

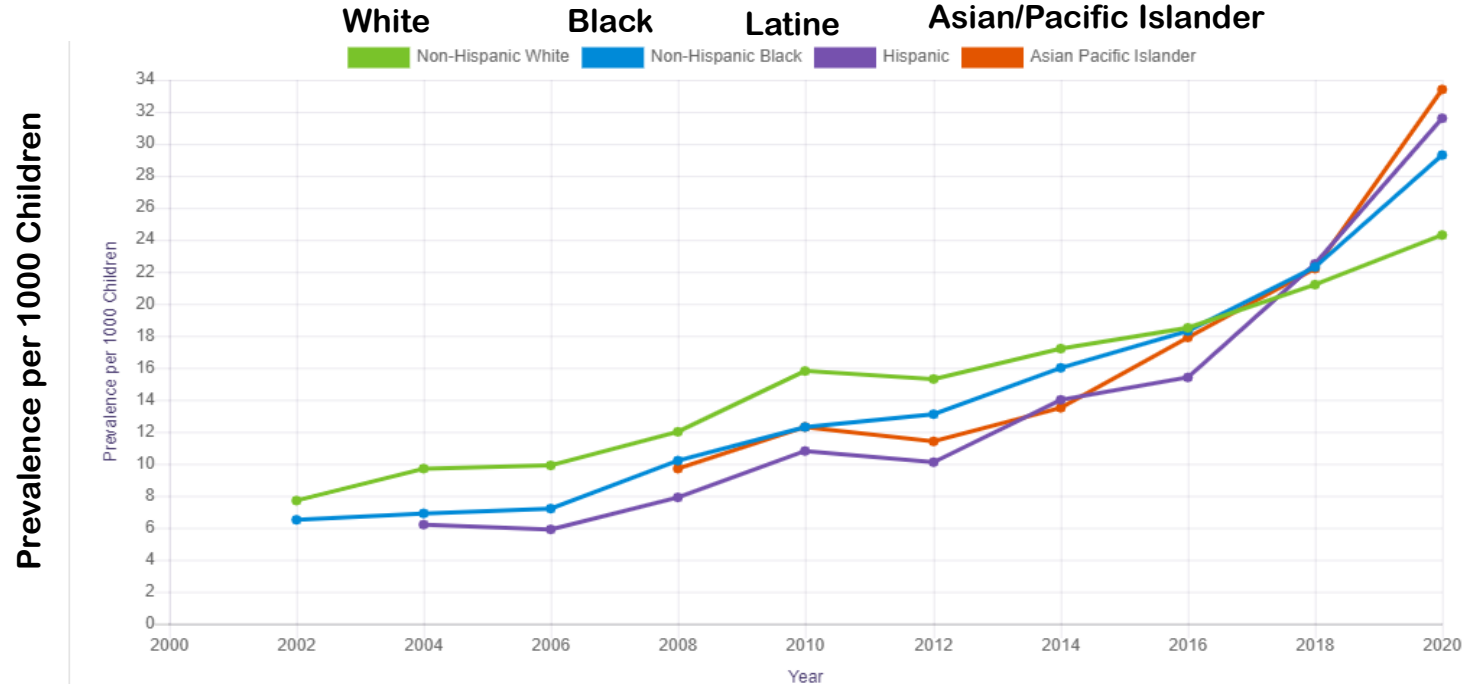- B4: Hyper- or hypo-reactivity to sensory input

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RACIAL AND ETHNIC DISPARITIES IN AUTISM

Prevalence per 1,000 children

Baio et al, *MMWR*, 2018.

*Baio, J., et al. (2018). "Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years - Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2014." MMWR Surveill Summ **67(6): 1-23.***

Prevalence by Race/Ethnicity
ADDM Network Data

White   **Black**   **Latine**   **Asian/Pacific Islander**

CDC. Autism Data Visualization Tool. https://www.cdc.gov/ncbddd/autism/data/index.html

RACIAL AND ETHNIC DISPARITIES IN AUTISM

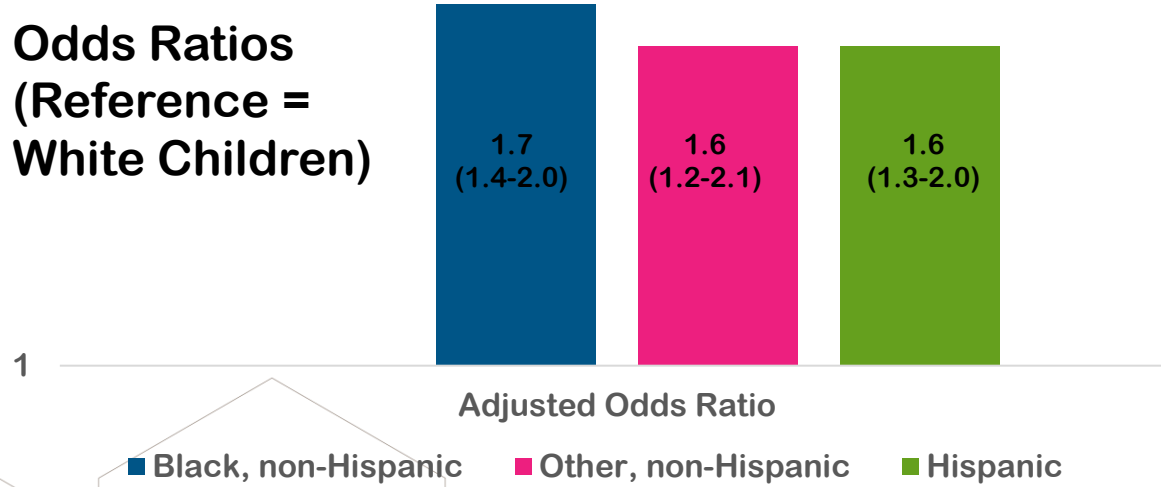## Prevalence by Race/Ethnicity
ADDM Network Data

For the first time, the ADDM Network data found the percentage of 8-year-old children identified with ASD was higher among Black, Hispanic, and Asian or Pacific Islander (A/PI) children compared with White children.

Race/Ethnicity	Prevalence
Black	29.3
Hispanic	31.6
A/PI	33.4
White	24.3

Values indicate prevalence per 1,000 children

CDC. Autism Data Visualization Tool. https://www.cdc.gov/ncbddd/autism/data/index.html

RACIAL AND ETHNIC DISPARITIES IN AUTISM: DIAGNOSIS V. IDENTIFICATION

1 in 4 children who meet ASD criteria are not diagnosed. Undiagnosed children are more likely to be non-white.

Odds Ratios (Reference = White Children)

	Black, non-Hispanic	Other, non-Hispanic	Hispanic
	1.7 (1.4-2.0)	1.6 (1.2-2.1)	1.6 (1.3-2.0)

Adjusted Odds Ratio

■ Black, non-Hispanic   ■ Other, non-Hispanic   ■ Hispanic

Wiggins, L. D., et al. (2019). "Disparities in Documented Diagnoses of Autism Spectrum Disorder Based on Demographic, Individual, and Service Factors." Autism research : official journal of the International Society for Autism Research.

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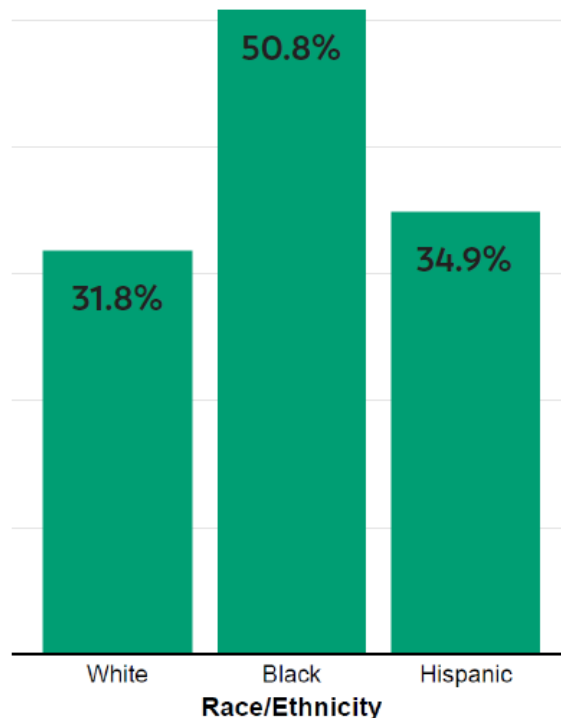# RACIAL DISPARITIES: CO-OCCURRING INTELLECTUAL DISABILITY
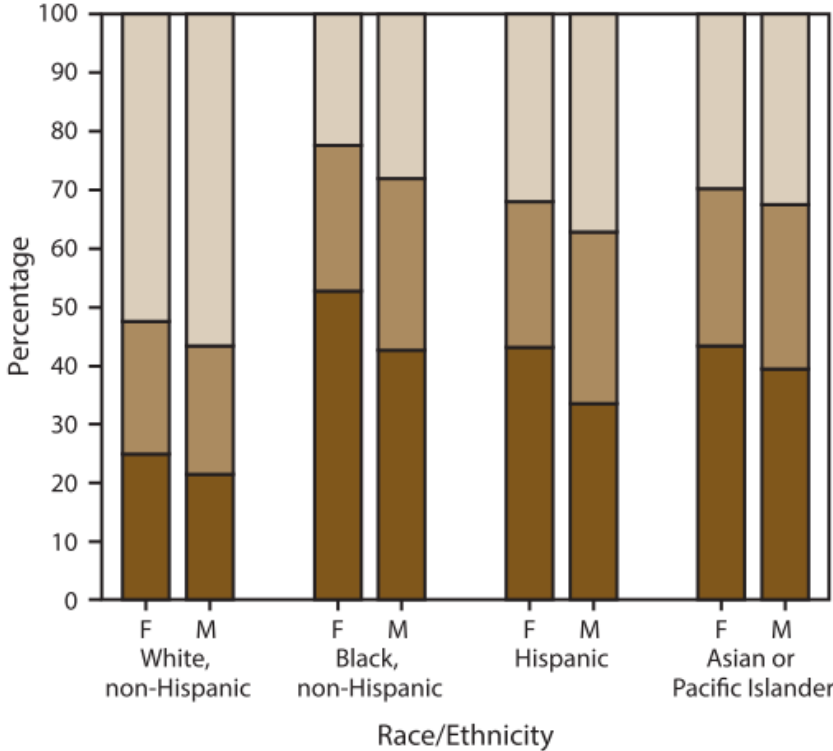
Baio, J., et al. (2018). "Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years - Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2014." *MMWR Surveill Summ* **67(6): 1-23.**

RACIAL DISPARITIES: CO-OCCURRING INTELLECTUAL DISABILITY

Percentage of 8 year-old children with autism and co-occurring intellectual disability, by race:

      31.8% of White Children
      50.8% of Black Children
      34.9% of Hispanic Children

Bar chart — Percentage by Race/Ethnicity: White 31.8%, Black 50.8%, Hispanic 34.9%

CDC. Autism Data Visualization Tool.
https://www.cdc.gov/ncbddd/autism/data/index.html

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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DIFFERENCE BETWEEN AGE OF 1ST CONCERN & DX IN BLACK FAMILIES
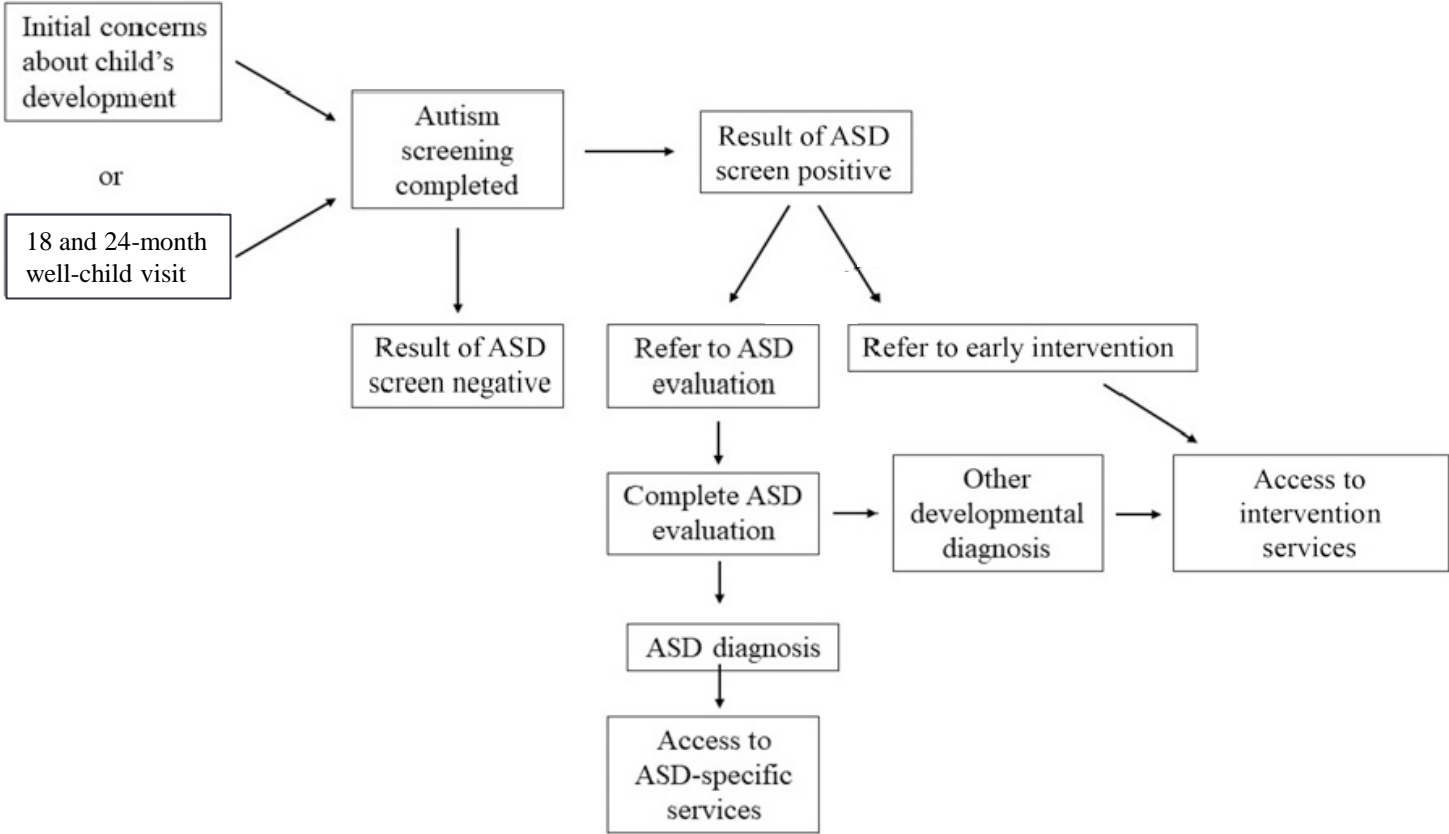
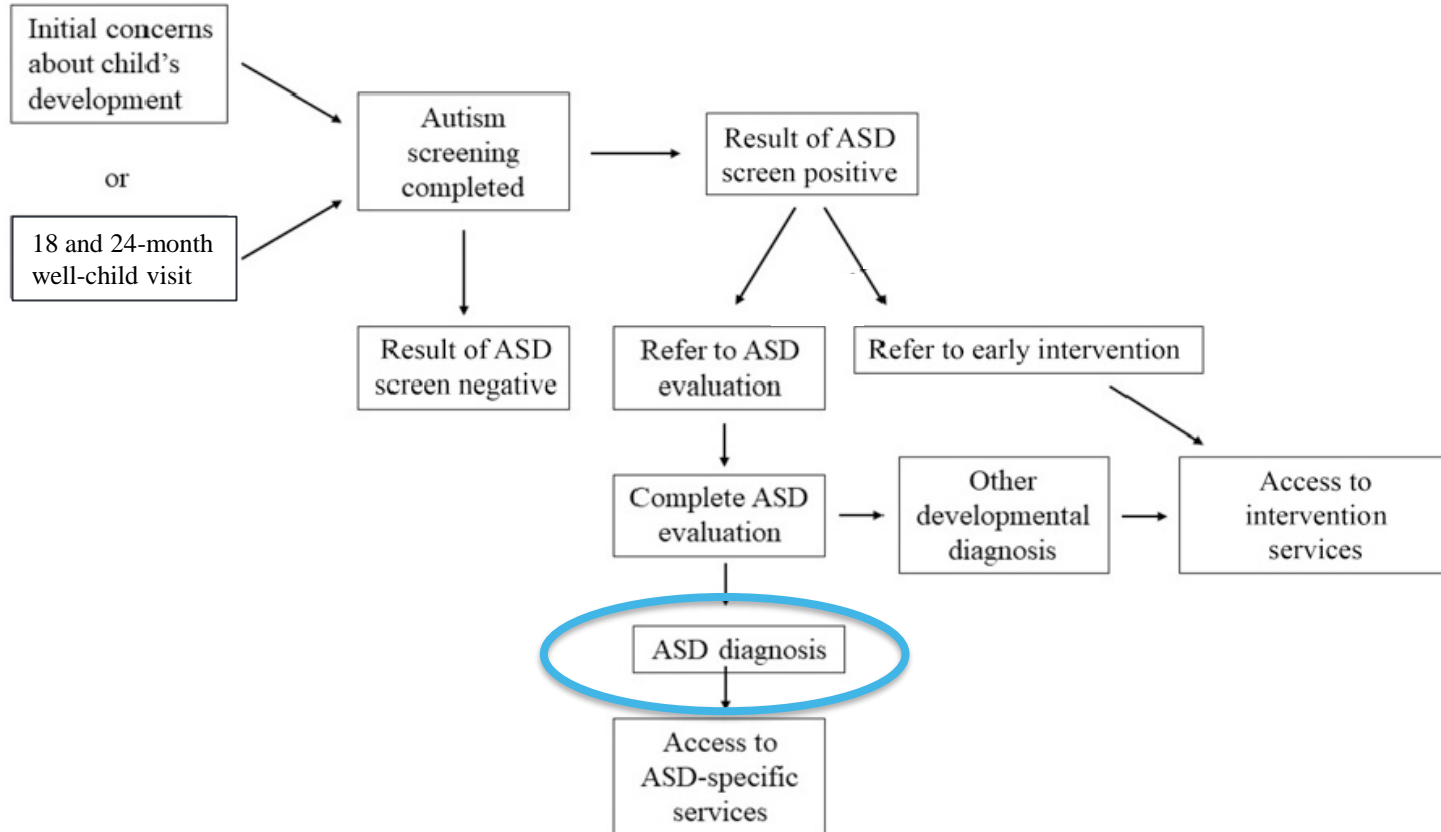**Age of First Concern:**

23 months

Age at Diagnosis:

64.9 months

Constantino, J. N., et al. (2020). "Timing of the Diagnosis of Autism in African American Children." Pediatrics 146(3): e20193629.
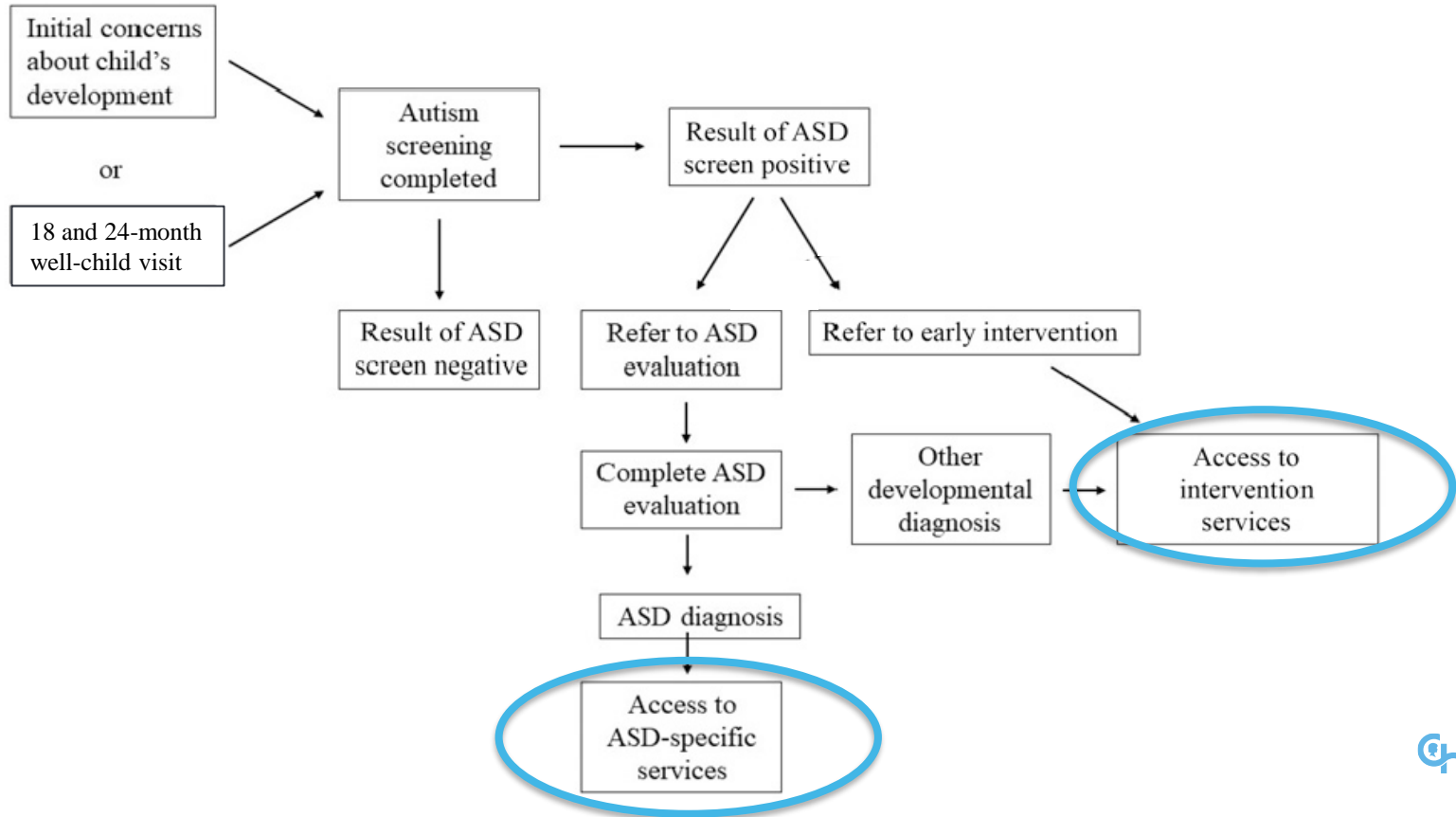
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AUTISM DIAGNOSTIC AND INTERVENTION PROCESS

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DISPARITIES IN DIAGNOSIS

DISPARITIES IN INTERVENTIONS

ASD DISPARITIES IN SERVICES

In California in 2012-2013, spending on ASD-related care was higher for White individuals across the lifespan.

BLACK/AFRICAN AMERICAN
ASIAN
HISPANIC
OTHER/UNKNOWN

Leigh, J. P., et al. (2016). "Spending by California's Department of Developmental Services for Persons with Autism across Demographic and Expenditure Categories." *PLoS One* **11(3): e0151970**

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Disparities in Service Use Among Children With Autism: A Systematic Review
Kathryn A. Smith, Jean-G. Gehricke, Suzannah Iadarola, Audrey Wolfe and Karen A. Kuhlthau
Pediatrics 2020;145;S35
DOI: 10.1542/peds.2019-1895G

A STORY ABOUT BEN. . .

Limited services in the Philadelphia Public School System.

Limited access to home-based behavioral therapy.

Wallis KE, Buttenheim AM, Mandell DS. Insights from Behavioral Economics: A Case of Delayed Diagnosis of Autism Spectrum Disorder. Journal of Developmental & Behavioral Pediatrics. 2021;42(2):109-113.

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SO WHAT DO YOU THINK IS GOING ON?

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1. An overview of autism inequities

2. **FOUNDATIONAL CONCEPTS IN HEALTH EQUITY**

3. Mechanistic inquiry into autism disparities

4. Promoting Equity

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THE ORIGINS OF "RACE"

"Race applied to human beings is a *political* division: it is a system of governing people that classifies them into a social hierarchy based on invented biological demarcations."
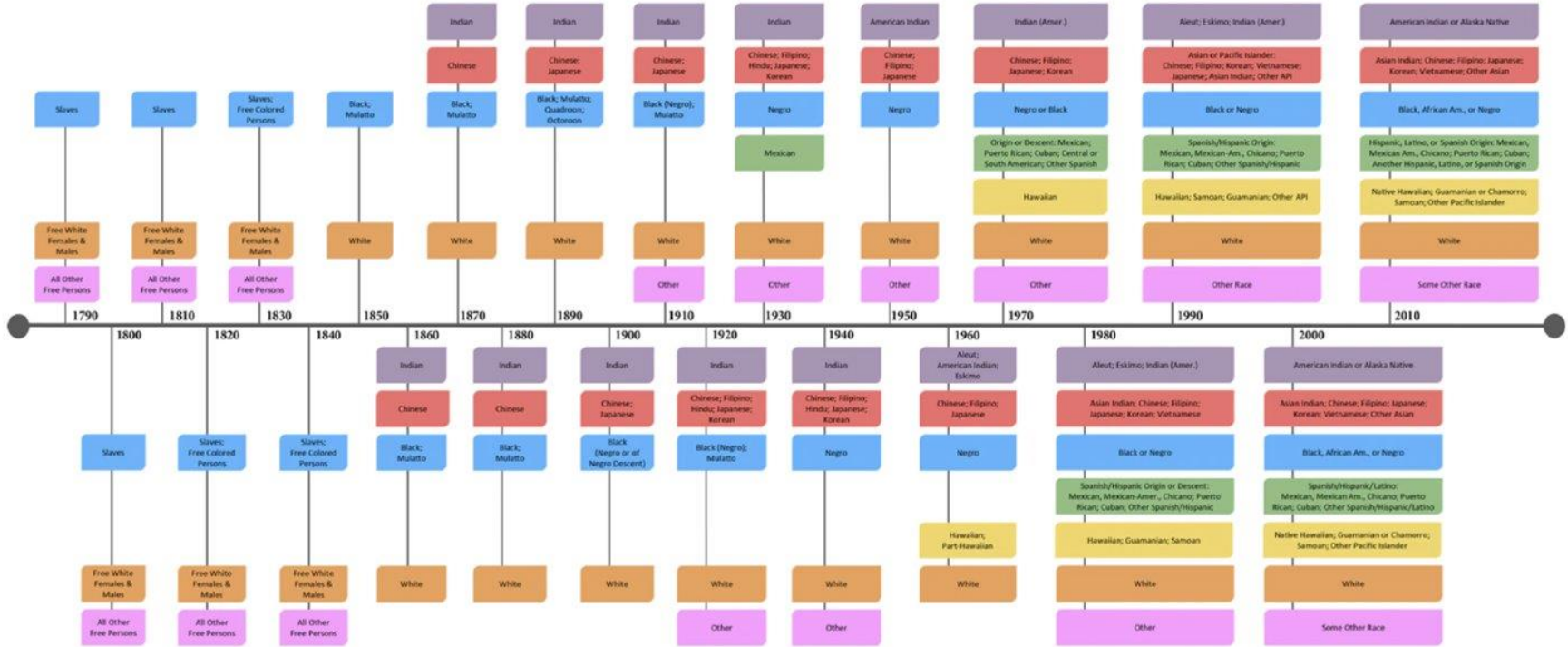
- Dorothy Roberts

- American invention used to justify enslavement.

- Genetics do not map onto conceptions of race.
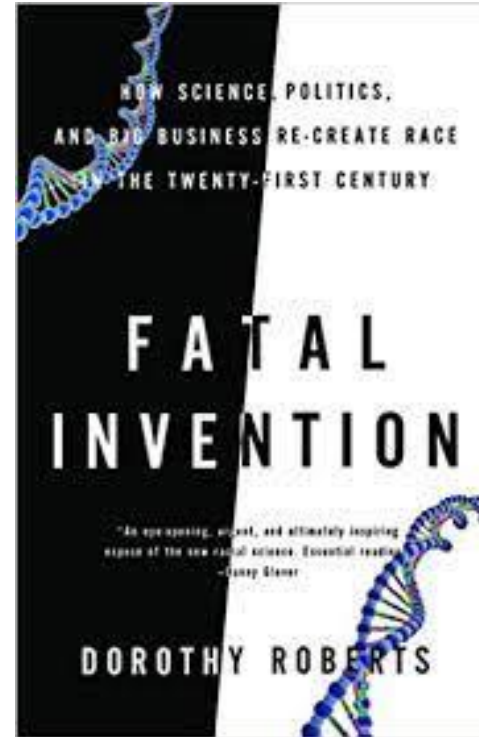
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WHAT ARE THE ORIGINS OF "RACE"?

Measuring Race and Ethnicity Across the Decades: 1790–2010
Mapped to 1997 U.S. Office of Management and Budget Classification Standards
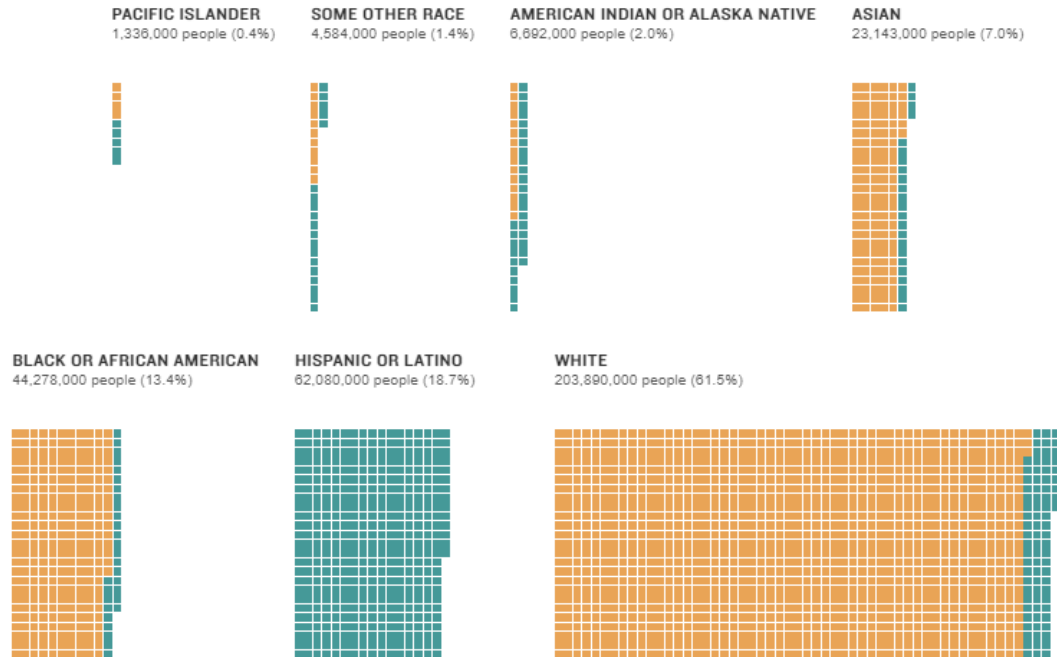
The 2020 U.S. Racial And Ethnic Makeup By Residents Including Every Race Reported

This breakdown does not include a catchall group for multiracial people because it distributes people who identified with two or more racial categories across the groups. It also groups together people who identified as Hispanic or Latino, which federal standards do not consider a racial category. How that group should be represented is a subject of much debate. The percentages represent the share of the total U.S. population.
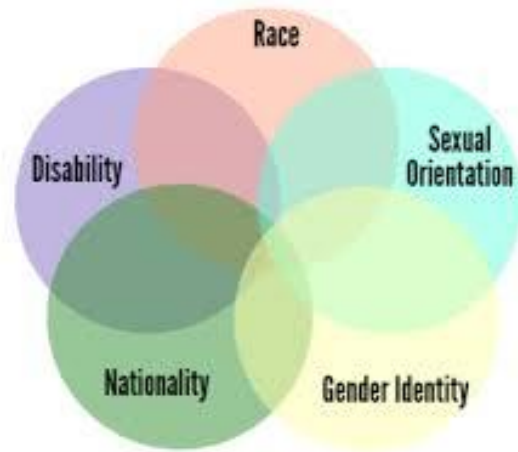
Alone   In combination

One □ = 150,000 people

PACIFIC ISLANDER
1,336,000 people (0.4%)

SOME OTHER RACE
4,584,000 people (1.4%)

AMERICAN INDIAN OR ALASKA NATIVE
6,692,000 people (2.0%)

ASIAN
23,143,000 people (7.0%)

BLACK OR AFRICAN AMERICAN
44,278,000 people (13.4%)

HISPANIC OR LATINO
62,080,000 people (18.7%)

WHITE
203,890,000 people (61.5%)

Source: US Census Bureau, Jin & Talbot, NPR

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How does research account for intersectional identities?

Professor Kimberlé Crenshaw coined the term "intersectionality" in a 1989 academic paper. | Nolwen Cifuentes for Vox

©Montoya-Williams/Wallis
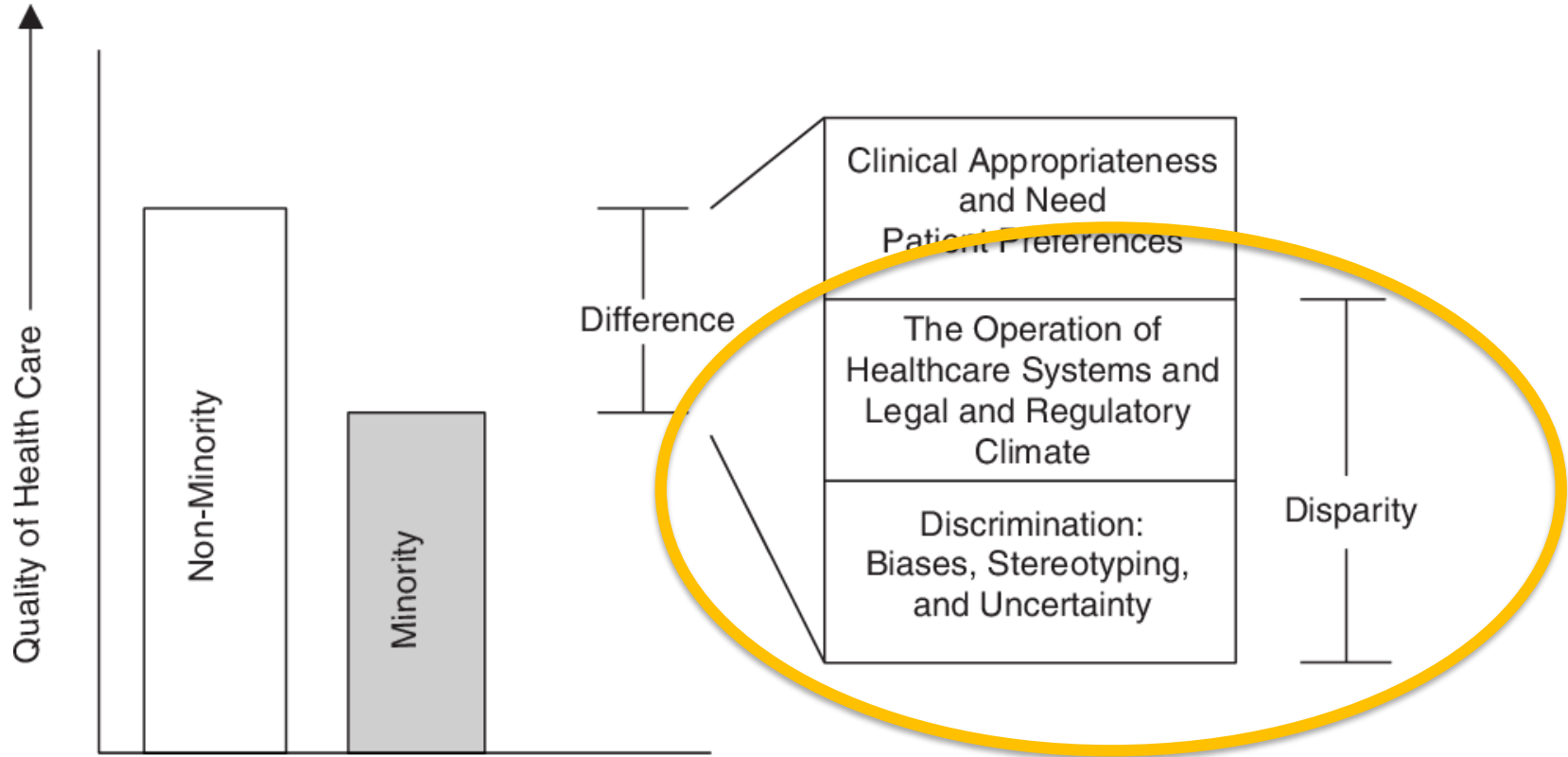
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WHAT DOES RACE ACTUALLY REPRESENT?

Self-ascribed identity

Societally assigned identity

Proxy for:
- Socioenvironmental exposures
- Genetic ancestry
- Racism

Or… combination of all of the above?

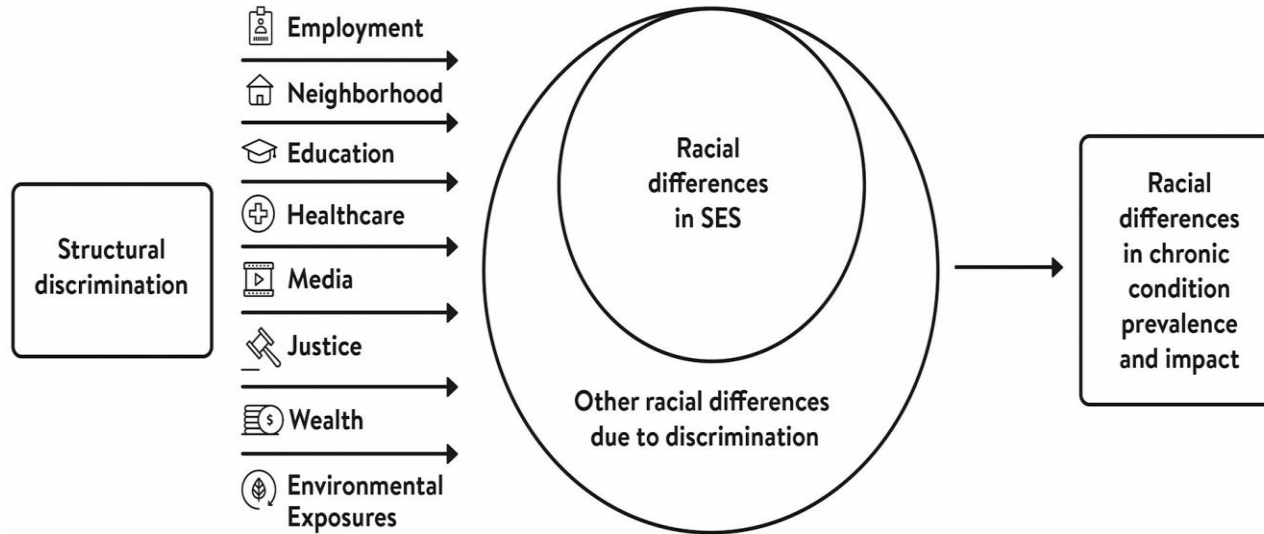Children's Hospital of Philadelphia℠
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Differences and Disparities

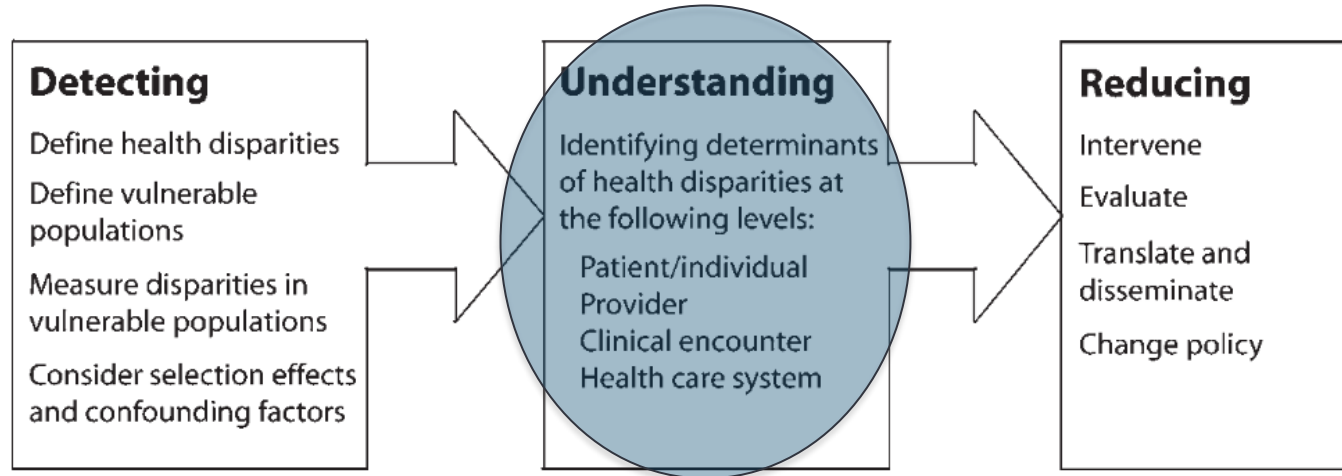Mahmoudi et al 2010, Slide borrowed from Dr. Jessica Fowler

Health Equity

The state in which everyone has "the opportunity to attain their full health potential and no one is vulnerable from achieving this potential because of their social position or other socially determined circumstances."

Maternal Child Health Bureau. Applying a Health Equity Lens to Analyze Performance Data and Inform Continuous Quality Improvement Work. Accessed 14 July 2023. https://mchb.hrsa.gov/sites/default/files/mchb/programs-impact/health-equity-lens.pdf

STRUCTURAL DISCRIMINATION: CAUSE OF CAUSES

Detecting

Define health disparities

Define vulnerable populations

Measure disparities in vulnerable populations

Consider selection effects and confounding factors

Understanding

Identifying determinants of health disparities at the following levels:

Patient/individual
Provider
Clinical encounter
Health care system

Reducing

Intervene

Evaluate

Translate and disseminate

Change policy

Note. In our framework, the health disparities research agenda progresses in 3 sequential phases of research. Phase 1 (detecting disparities) informs phase 2 studies (understanding disparities), which in turn informs phase 3 research (interventions to reduce or eliminate disparities).

FIGURE 1—The 3 phases of the disparities research agenda.

Kilbourne, A.M., et al. (2006). "Advancing Health Disparities Research Within the Health Care System: A Conceptual Framework." *Am J Public Health* **96(12): 2113-2121**137.

National Institute on Minority Health and Health Disparities Research Framework

		Levels of Influence*			
		Individual	**Interpersonal**	**Community**	**Societal**
Domains of Influence (Over the Lifecourse)	**Biological**	Biological Vulnerability and Mechanisms	Caregiver–Child Interaction Family Microbiome	Community Illness Exposure Herd Immunity	Sanitation Immunization Pathogen Exposure
	Behavioral	Health Behaviors Coping Strategies	Family Functioning School/Work Functioning	Community Functioning	Policies and Laws
	Physical/Built Environment	Personal Environment	Household Environment School/Work Environment	Community Environment Community Resources	Societal Structure
	Sociocultural Environment	Sociodemographics Limited English Cultural Identity Response to Discrimination	Social Networks Family/Peer Norms Interpersonal Discrimination	Community Norms Local Structural Discrimination	Social Norms Societal Structural Discrimination
	Health Care System	Insurance Coverage Health Literacy Treatment Preferences	Patient–Clinician Relationship Medical Decision-Making	Availability of Services Safety Net Services	Quality of Care Health Care Policies
Health Outcomes		👤 **Individual Health**	👥 **Family/ Organizational Health**	🏠 **Community Health**	👥 **Population Health**

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National Institute on Minority Health and Health Disparities
Research Framework

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Health Outcomes		**Individual Health**	**Family/ Organizational Health**	**Community Health**	**Population Health**

National Institute on Minority Health and Health Disparities, 2018
*Health Disparity Populations: Race/Ethnicity, Low SES, Rural, Sexual/Gender Minority
Other Fundamental Characteristics: Sex/Gender, Disability, Geographic Region

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National Institute on Minority Health and Health Disparities Research Framework

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1. An overview of autism inequities

2. Foundational Concepts in Health Equity

3. MECHANISTIC INQUIRY INTO AUTISM DISPARITIES

4. Promoting Equity

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DISPARITIES IN AUTISM RECOGNITION
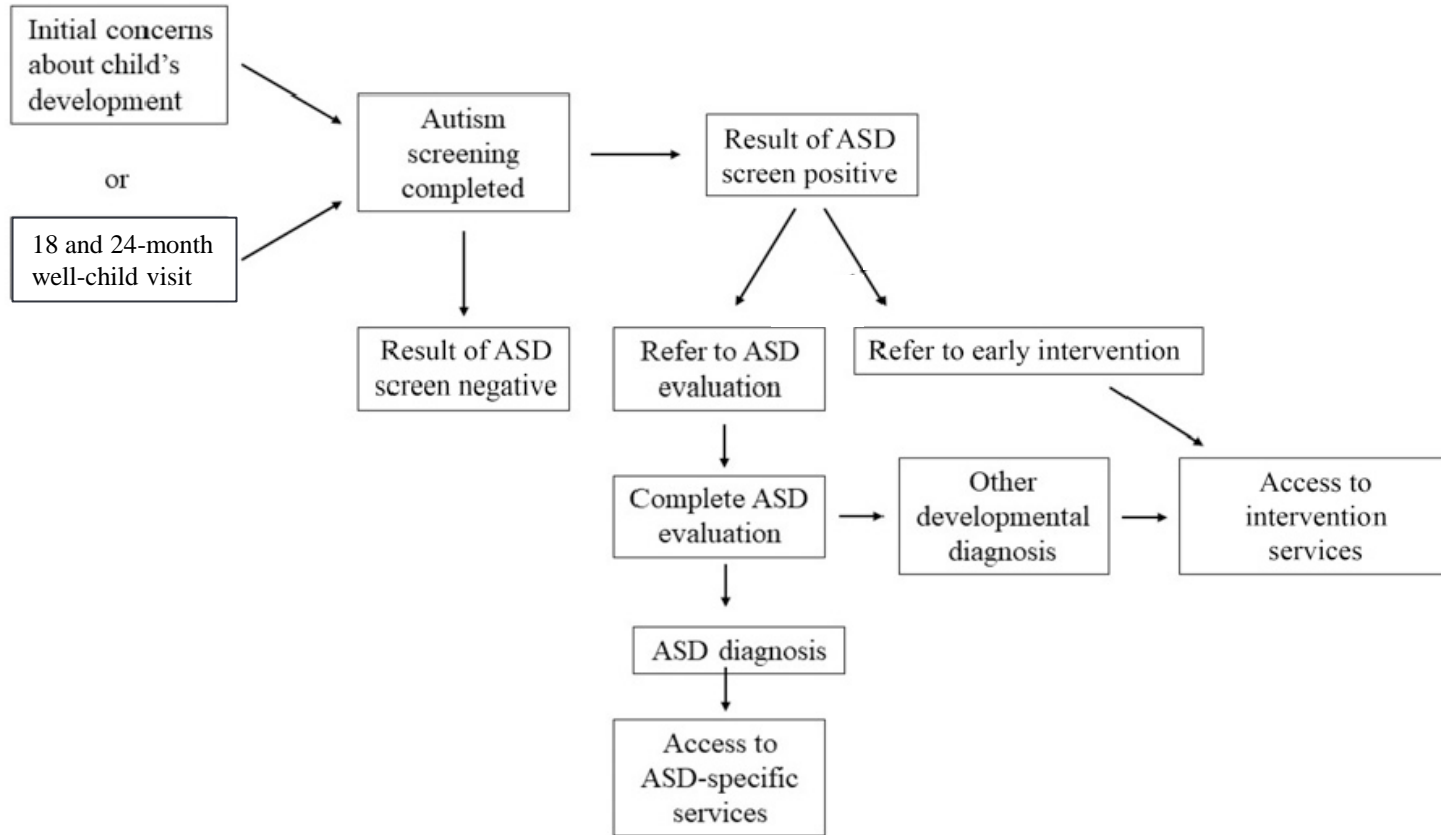
IMPLICIT BIAS

Category	Item
Autism Spectrum Disorder	Repeats body movements, Avoids eye contact, Displays rigid routines, Notices little details, Repeats certain words
Conduct Disorder	Escapes from home, Shoplifts small items, Starts fires deliberately, Disregards rules repeatedly, Hurts people/animals
African Americans	
European Americans	

Obeid, R., et al. (2021). "Do Implicit and Explicit Racial Biases Influence Autism Identification and Stigma? An Implicit Association Test Study." J Autism Dev Disord 51(1): 106-128.

DISPARITIES IN SCREENING
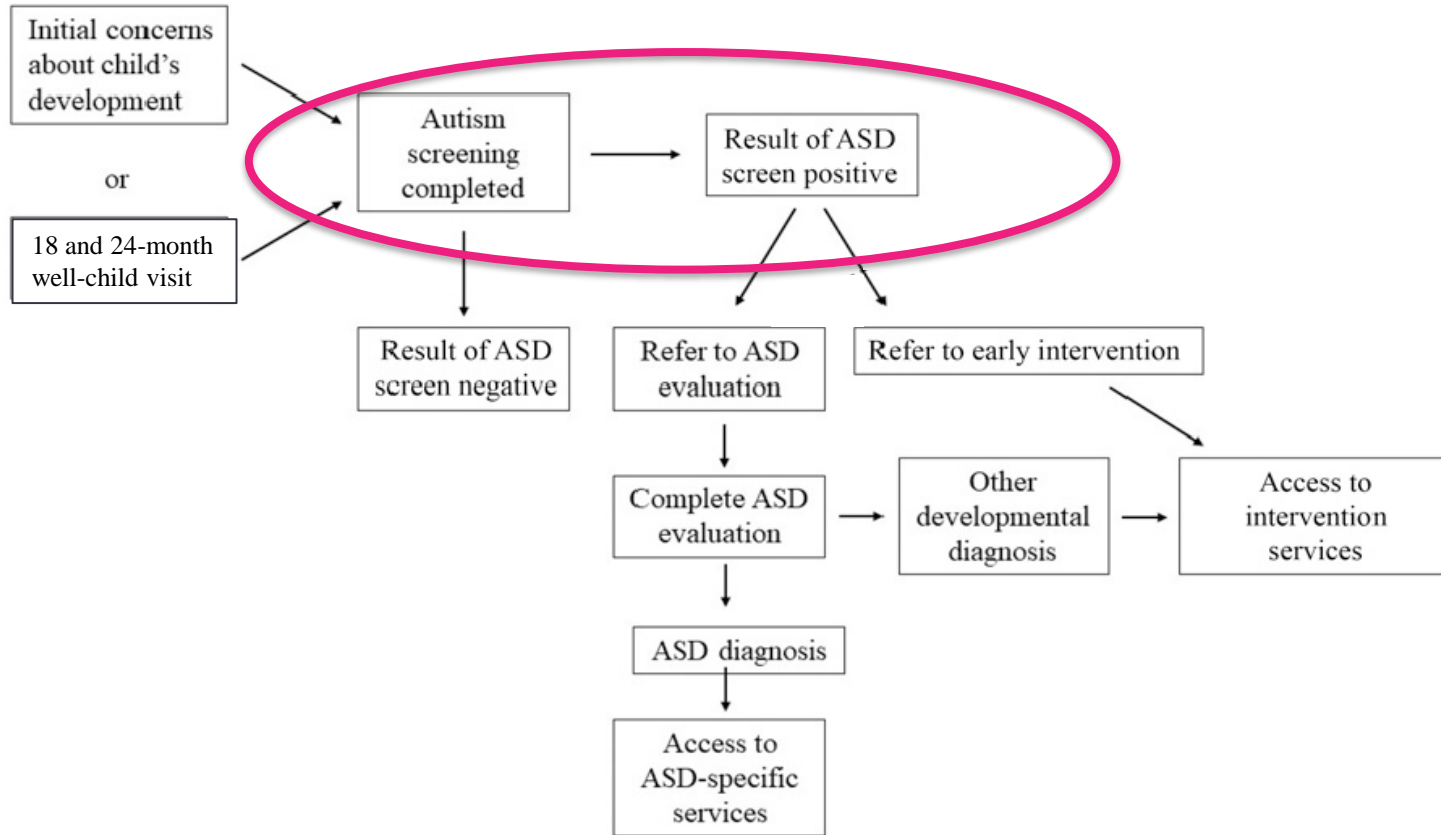
SCREENING COMPLETION AND ACCURACY

Identified an epidemiological cohort, electronic health record data

1) All children with a well-child visit in CHOP Care Network at 16-26 months

2) Continued to receive care at 4+ years of age

    Diagnostic outcome: ASD + at least 2 diagnoses of 299.00

Calculation of screen completion

Calculation of psychometrics of screen

Stratified by sex, race, ethnicity, family language, SES (median household income at neighborhood level, insurance status)

*Guthrie, W., Wallis, K.E., Bennett, A. et al. (2019). "Accuracy of Autism Screening in a Large Pediatric Network." Pediatrics **144(4).***

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SCREENING COMPLETION

25,999 children with well-child visits

⬇ **91%**

23,634 screened

⬇ **48%**

12,418 screened at 18 **and** 24 months
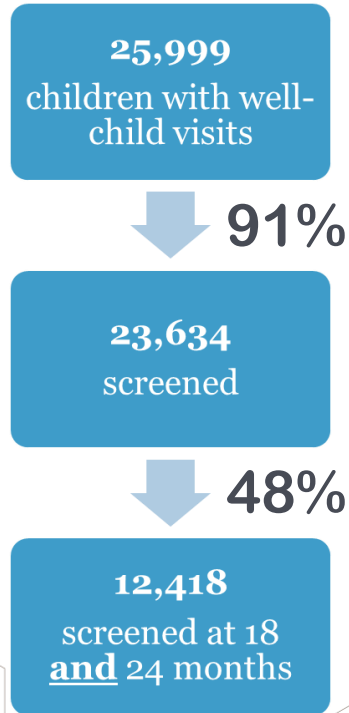
- Those not screened more likely to be:
  - Minoritized racial or ethnic groups
    - White children (97%)
    - Black children (83%; OR=5.98)
    - Asian children (92%, OR=2.76)
    - Other racial backgrounds (92%, OR=2.70)
  - Non-English language spoken at home (84%; OR=2.02)
  - Publicly insured (86%, OR=3.45)
  - Lower median income (85%, OR=5.23)

Guthrie, W., Wallis, K.E., Bennett, A. et al. (2019). "Accuracy of Autism Screening in a Large Pediatric Network." Pediatrics 144(4).

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A STORY ABOUT BEN. . .

- Ben had a (false) negative screen at 18 months

- Never re-screened

  – Insurance lapse
  – Provider did not screen when he returned to care outside of the prompted window (27 months)

Wallis KE, Buttenheim AM, Mandell DS. Insights from Behavioral Economics: A Case of Delayed Diagnosis of Autism Spectrum Disorder. Journal of Developmental & Behavioral Pediatrics. 2021;42(2):109-113.

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REFERRALS AFTER A POSITIVE SCREEN

- Identified children with positive screen for ASD in primary care, 2014-2016.

- Digitally extracted referral info from that visit:

  - Early intervention
  - ASD Evaluation: speech/language therapy, occupational therapy, developmental-behavioral pediatrics, neurology, psychiatry, psychology, or genetics.
  - Drop-down response to positive screen, referrals placed, letters, notes or AVS mention
  - 90% concordance with manual chart review findings

  N=2882

*Wallis, K. E., Guthrie W., Bennett, A. et al. (2020). "Adherence to screening and referral guidelines for autism spectrum disorder in toddlers in pediatric primary care." PLoS One **15(5): e0232335***

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REFERRALS AFTER A POSITIVE SCREEN

42%- Previously initiated EI	More likely: White than Black or Asian English-Speaking
26%- Referred on day of positive screen	More likely: White than Black English-Speaking
11%- Referred for ASD evaluation	More likely: White than Asian English-Speaking
42%- Not referred to EI immediately after positive screen	More likely: Black than White Asian than White Non-English-Speaking

Wallis, K. E., Guthrie W., Bennett, A. et al. (2020). "Adherence to screening and referral guidelines for autism spectrum disorder in toddlers in pediatric primary care." PLoS One **15(5): e0232335**

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- Screened positive with a general developmental screen at 9 and 27 months:

  – No referrals made at either of those visits

Wallis KE, Buttenheim AM, Mandell DS. Insights from Behavioral Economics: A Case of Delayed Diagnosis of Autism Spectrum Disorder. Journal of Developmental & Behavioral Pediatrics. 2021;42(2):109-113.

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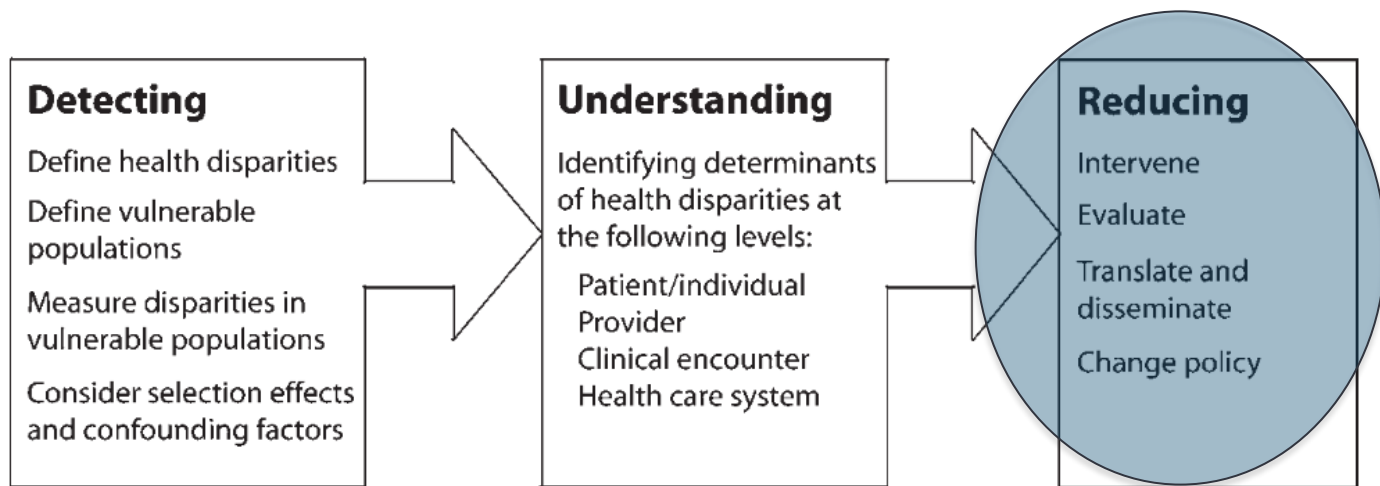
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DISPARITIES RESEARCH FRAMEWORK

Detecting

Define health disparities

Define vulnerable populations

Measure disparities in vulnerable populations

Consider selection effects and confounding factors

Understanding

Identifying determinants of health disparities at the following levels:

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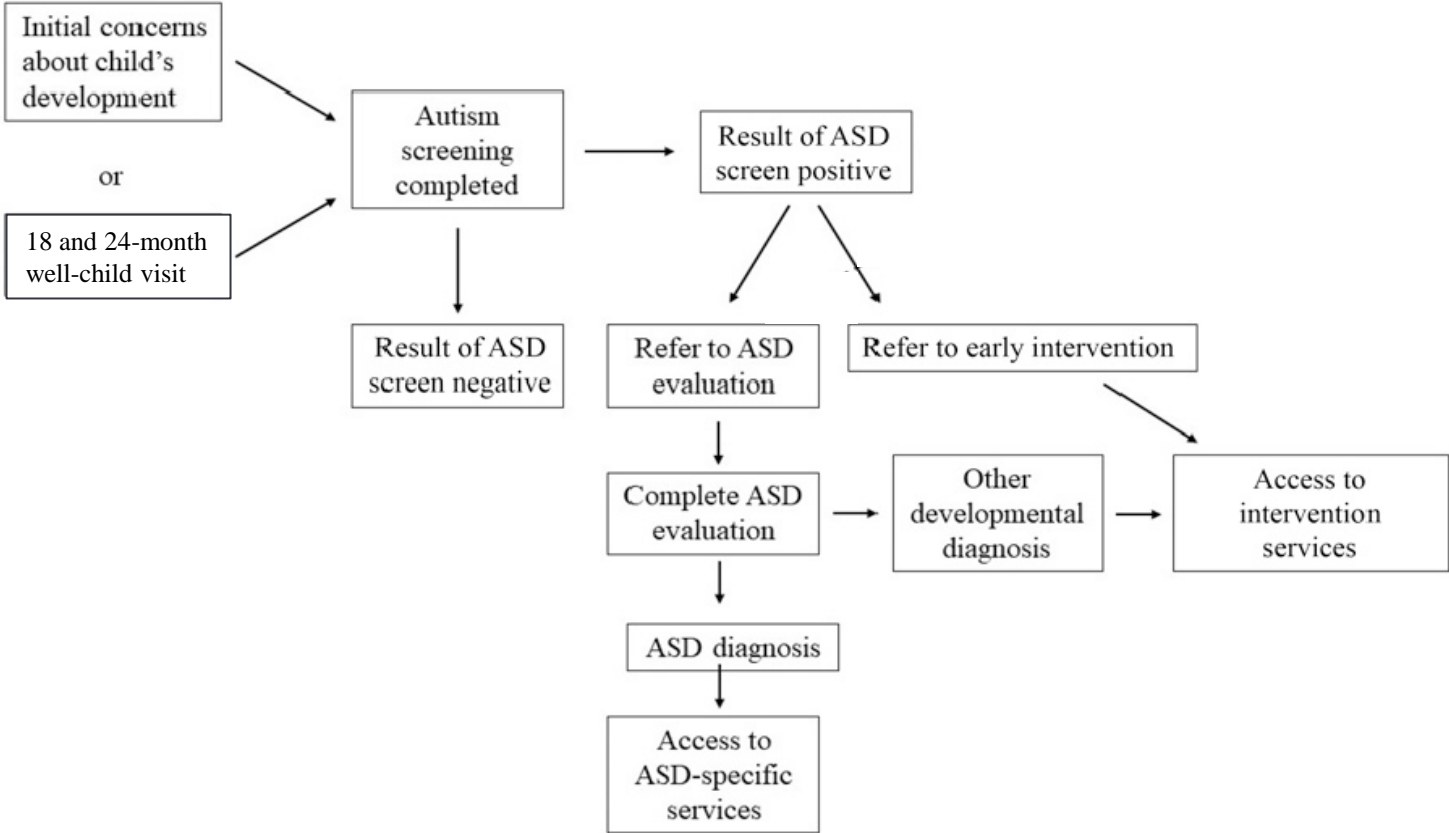
NOVEL SCREENING TOOLS

Tools to better identify children with ASD risk with diverse socio-demographic backgrounds

- Pictorial tools

- Targeted to individuals with lower literacy, languages other than English

*Harris, J. F., et al. (2021). "Validation of the Developmental Check-In Tool for Low-Literacy Autism Screening." Pediatrics **147(1).***

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Effect of Family Navigation on Diagnostic Ascertainment Among Children at Risk for Autism
A Randomized Clinical Trial From DBPNet

Emily Feinberg, ScD, CPNP; Marilyn Augustyn, MD; Sarabeth Broder-Fingert, MD, MPH; Amanda Bennett, MD, MPH; Carol Weitzman, MD; Jocelyn Kuhn, PhD; Emily Hickey, PhD; Andrea Chu, MPH; Julia Levinson, MSc; Jenna Sandler Eilenberg, MA, MPH; Michael Silverstein, MD, MPH; Howard J. Cabral, PhD; Gregory Patts, MPH; Yaminette Diaz-Linhart, MSW, MPH; Ivys Fernandez-Pastrana, JD; Jessica Rosenberg, MPH; Judith S. Miller, PhD; James P. Guevara, MD, MPH; Ada M. Fenick, MD; Nathan J. Blum, MD

Children who received family navigation had a greater likelihood of reaching diagnostic ascertainment over the course of 1 year.

Magnitude of effect greater for Hispanic families

Feinberg, E., et al. (2021). "Effect of Family Navigation on Diagnostic Ascertainment Among Children at Risk for Autism: A Randomized Clinical Trial From DBPNet." JAMA Pediatrics 175(3): 243-250.

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PATIENT NAVIGATION

Using a family navigator to help families connect with care has shown beneficial at closing gaps in care.

- Ongoing work examining role of patient navigation on connecting families with Early Intervention Services.

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PROVIDER OUTREACH AND TRAINING

Extension for Community Healthcare Outcomes (ECHO) framework

- Virtual learning to allow for geographically unlimited consultation and training

- Increased access to expertise, training

- Evidence-based practice to increase participant competence and confidence

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PROVIDER OUTREACH AND TRAINING

ECHO Autism at CHOP

Share: [facebook] [twitter] [linkedin] [email] [print]   WATCH THIS PAGE 👁

What is ECHO Autism?

ECHO Autism is a virtual learning network of providers offering real-time access to autism and behavioral experts. ECHO Autism takes the principles of ECHO and adds the components of interdisciplinary expertise, including the integration of parent expertise. Our interdisciplinary team advises providers across the country and even internationally to support best practices in autism care for medical, behavioral and education concerns. This innovative system allows professionals to increase their confidence in identifying and treating autism and expand their knowledge about treatments and solutions.

- https://www.research.chop.edu/services/echo-autism-at-chop#:~:text=ECHO%20Autism%20is%20a%20virtual,the%20integration%20of%20parent%20expertise.

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INCREASING WORKFORCE CAPACITY

Training primary care providers in ASD diagnosis and initial management to reduce reliance on subspecialty care
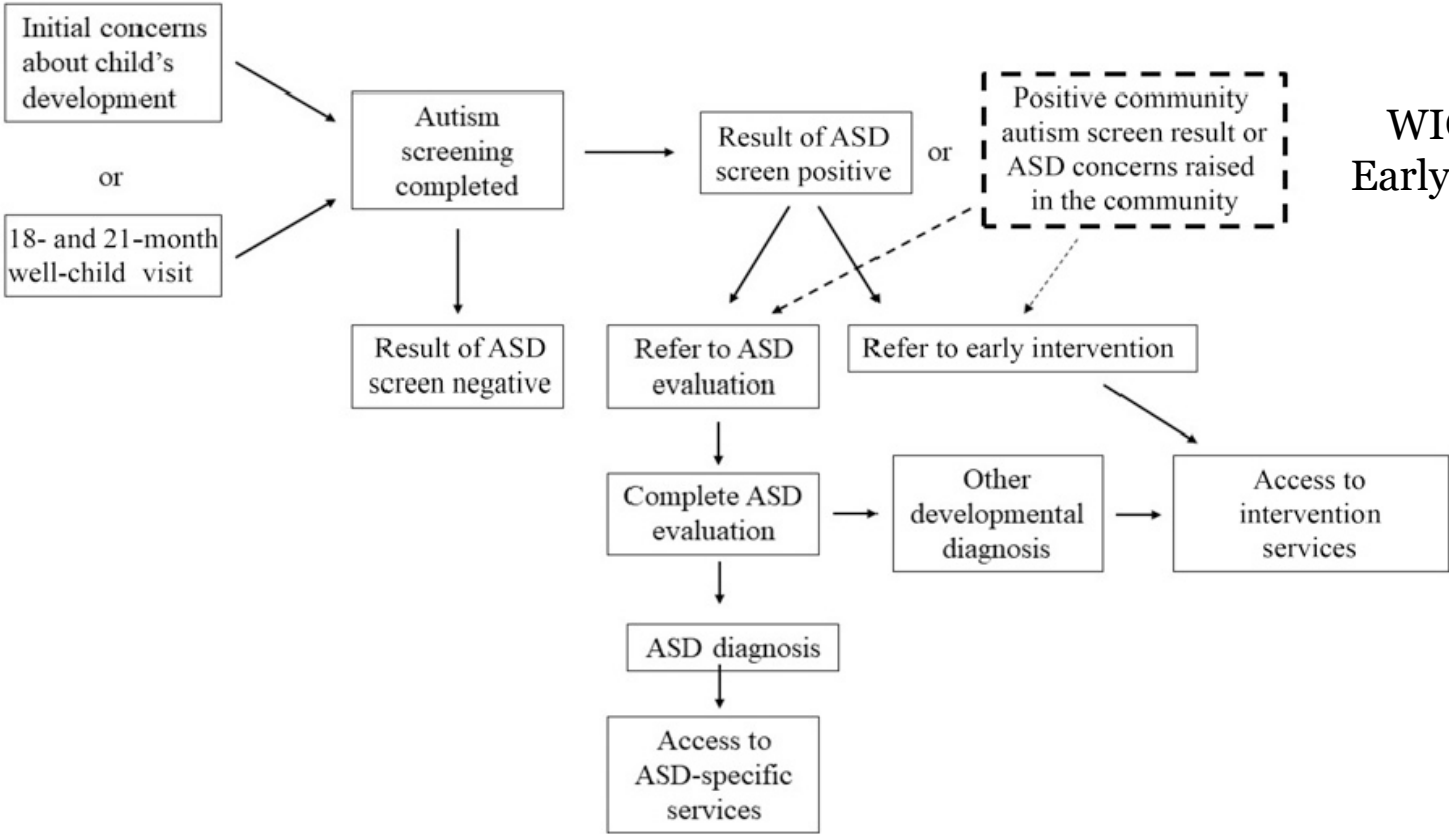
• Pediatricians receive training, including in use of diagnostic tools, to diagnose high-risk individuals

• Completion of documentation to access services

• Expedite intervention for high-risk individuals

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ARTIFICIAL INTELLIGENCE / TECHNOLOGY SOLUTIONS

Emerging technologies being developed/studied to aide in screening, diagnosis.

• But always caution about the source of the data, equity of the data and inclusion, and the potential for algorithmic bias.

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WIC offices
Early Childcare

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AUTISM DIAGNOSTIC AND INTERVENTION PROCESS

Initial concerns about child's development

Access to intervention services

Access to ASD-specific services

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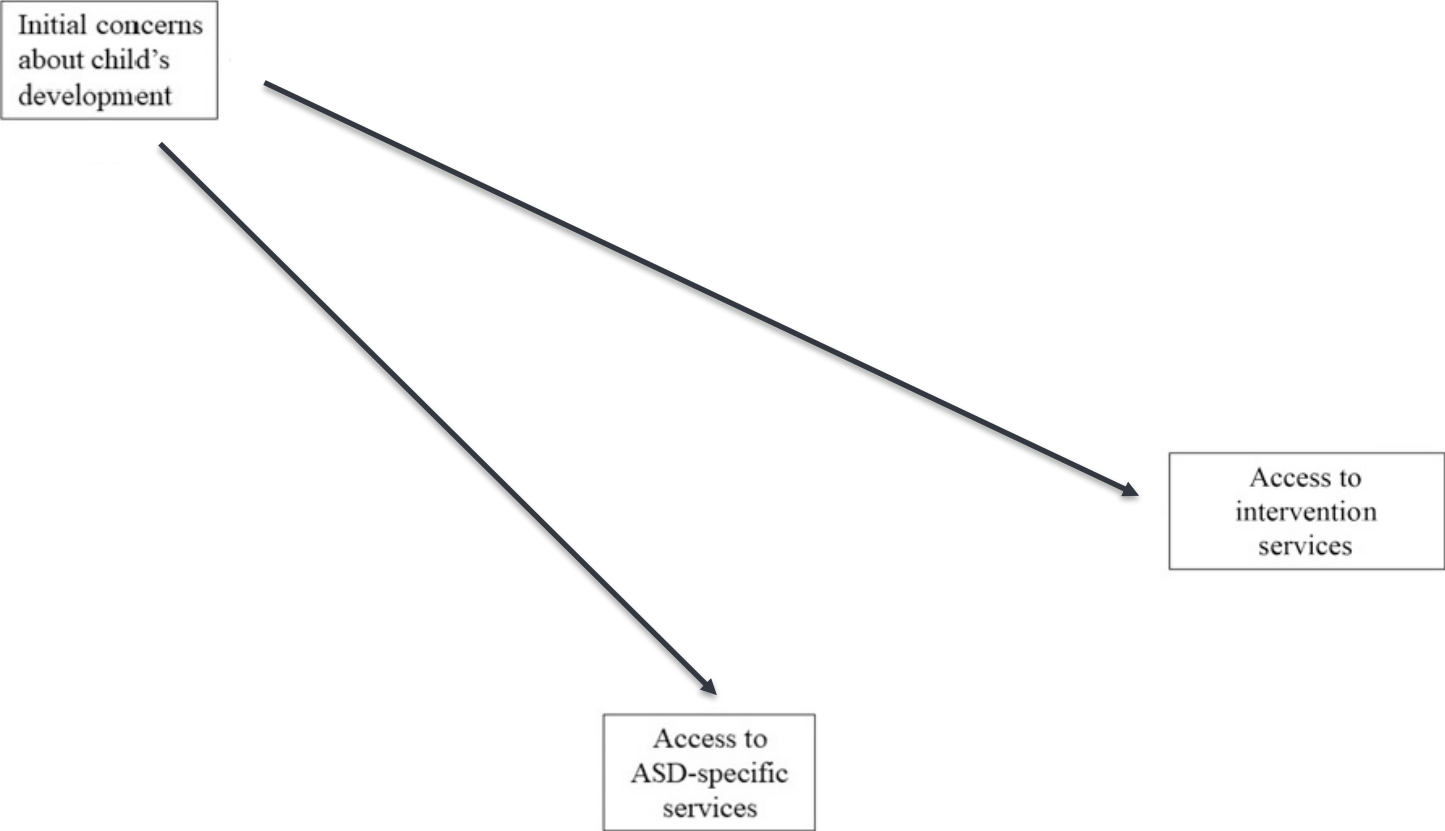
A STORY ABOUT BEN. . .

- Goals:

  – Decrease barriers to diagnosis and care

  – Increase support for primary care clinicians

  – Prevent negative outcomes, such as school expulsion

  – Improve access to services and promote developmental progress

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WHAT SHOULD OUR NEXT STEPS BE?

RESOURCES

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QUESTIONS AND COMMENTS?

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