

Disparities in Autism Diagnosis & Care

David S. Mandell, ScD



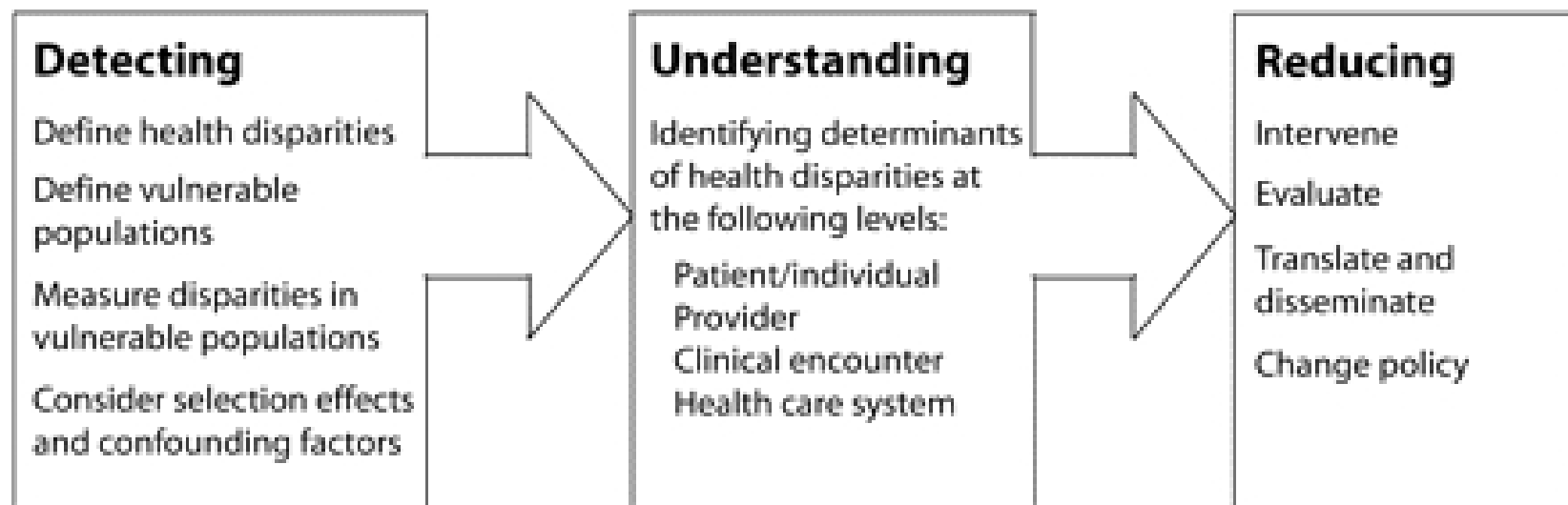
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What do we mean by disparities?

- "...racial or ethnic differences in the quality of healthcare that are not due to access-related factors or clinical needs, preferences, and appropriateness of intervention." [Institute of Medicine's *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care* \(2003\)](#)
- "...differences in the incidence, prevalence, mortality, and burden of diseases and other adverse health conditions that exist among specific population groups in the United States." [National Institutes of Health \(NIH\) *Strategic Research Plan to Reduce and Ultimately Eliminate Health Disparities* \(2000\)](#)

How do we conceptualize the study of disparities?

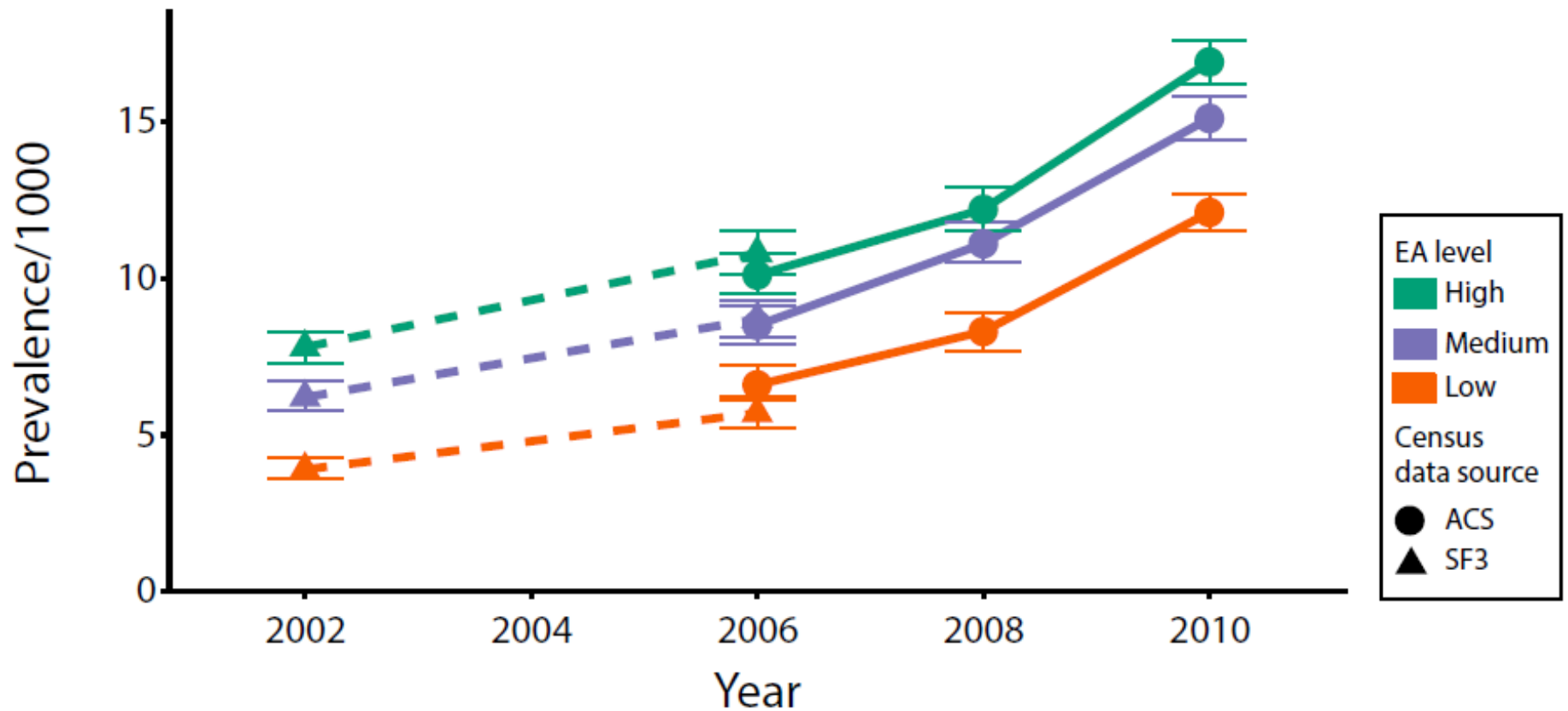


Kilbourne AM, et al. Advancing health disparities research within the health care system: a conceptual framework. *Am J Public Health.* 2006;96(12):2113-21.

From detecting to understanding to reducing

- Detecting disparities in:
 - Diagnosis
 - Access to treatment
 - Quality of treatment
- A conceptual model for understanding reasons for disparities
- Strategies for disparity reduction
 - Caregiver empowerment
 - Band Aids on a broken system
 - Systemic change

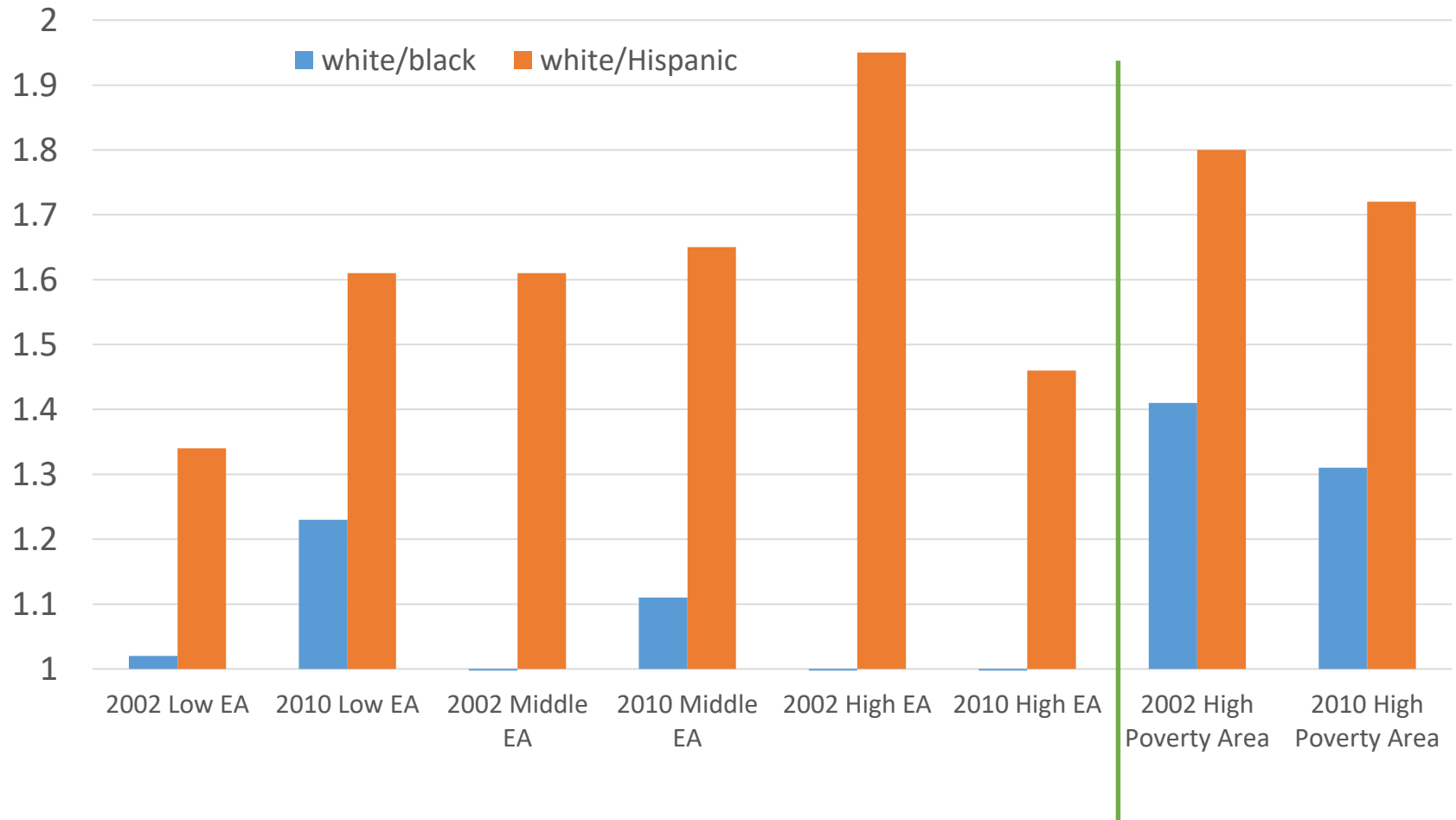
Disparities in Identification



Durkin et al. (2018). American Journal of Public Health.

Disparities in Identification

Prevalence Ratio from CDC Surveillance Studies



Disparities in Age of Diagnosis

- **African American = white**

- Mandell et al. 2005; Goin-Kochel et al., 2006; Perryman 2009; Adelman 2010; Mazurek et al., 2014

- **African-American > white**

- Mandell et al., 2002; Rosenberg et al., 2011; Valicenti-McDermott et al., 2012

- **w/ ID, African > white** (Wiggins 2006)

- **Non-white > white** (Fountain et al., 2011)

- **“other races” > white** (Shattuck et al., 2009)

- **White > “visible minority”** (Coo et al., 2012)

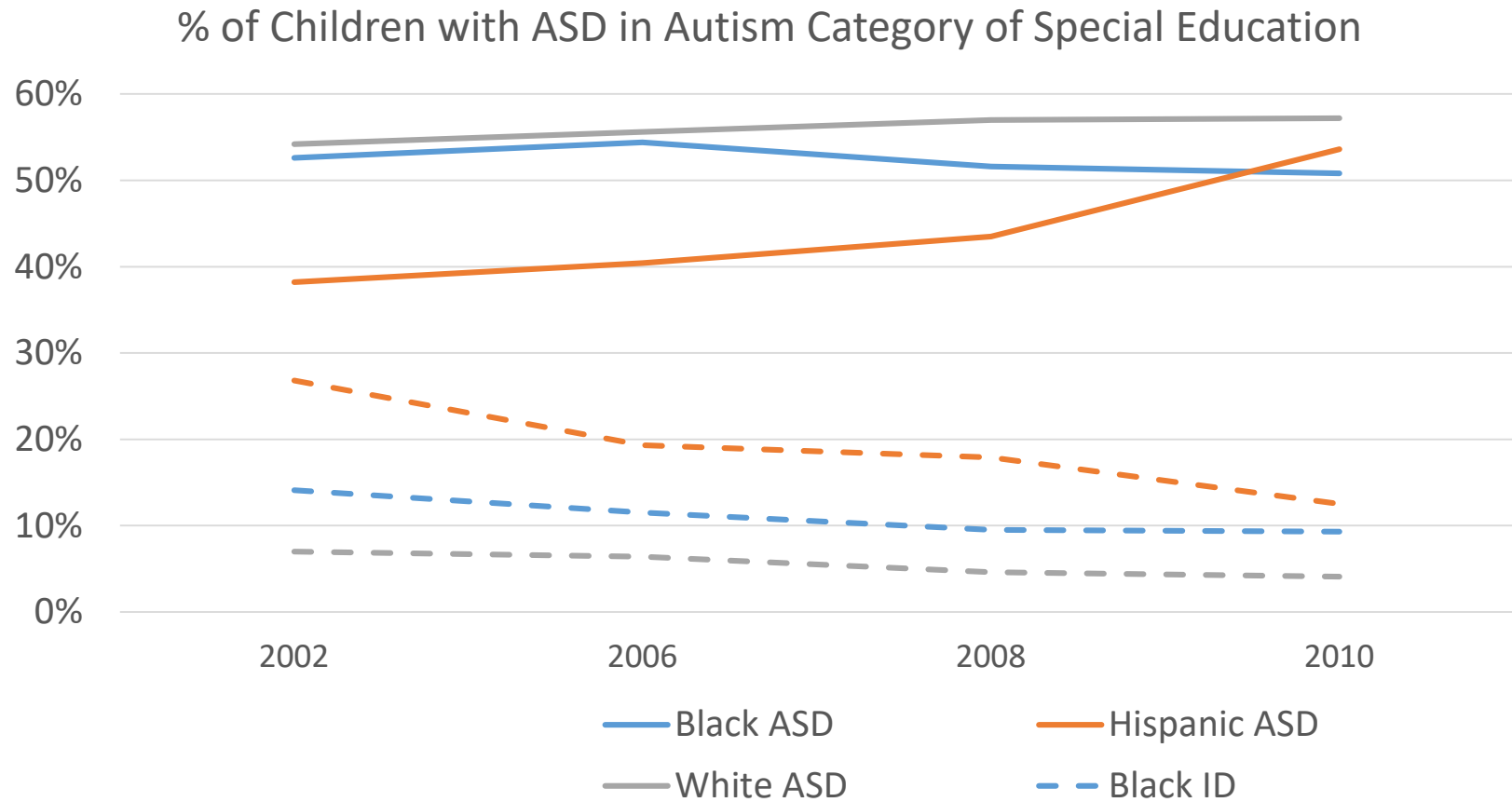
- **Hispanic = white**

- Mandell et al., 2005; Adelman 2010; Rosenberg et al., 2011

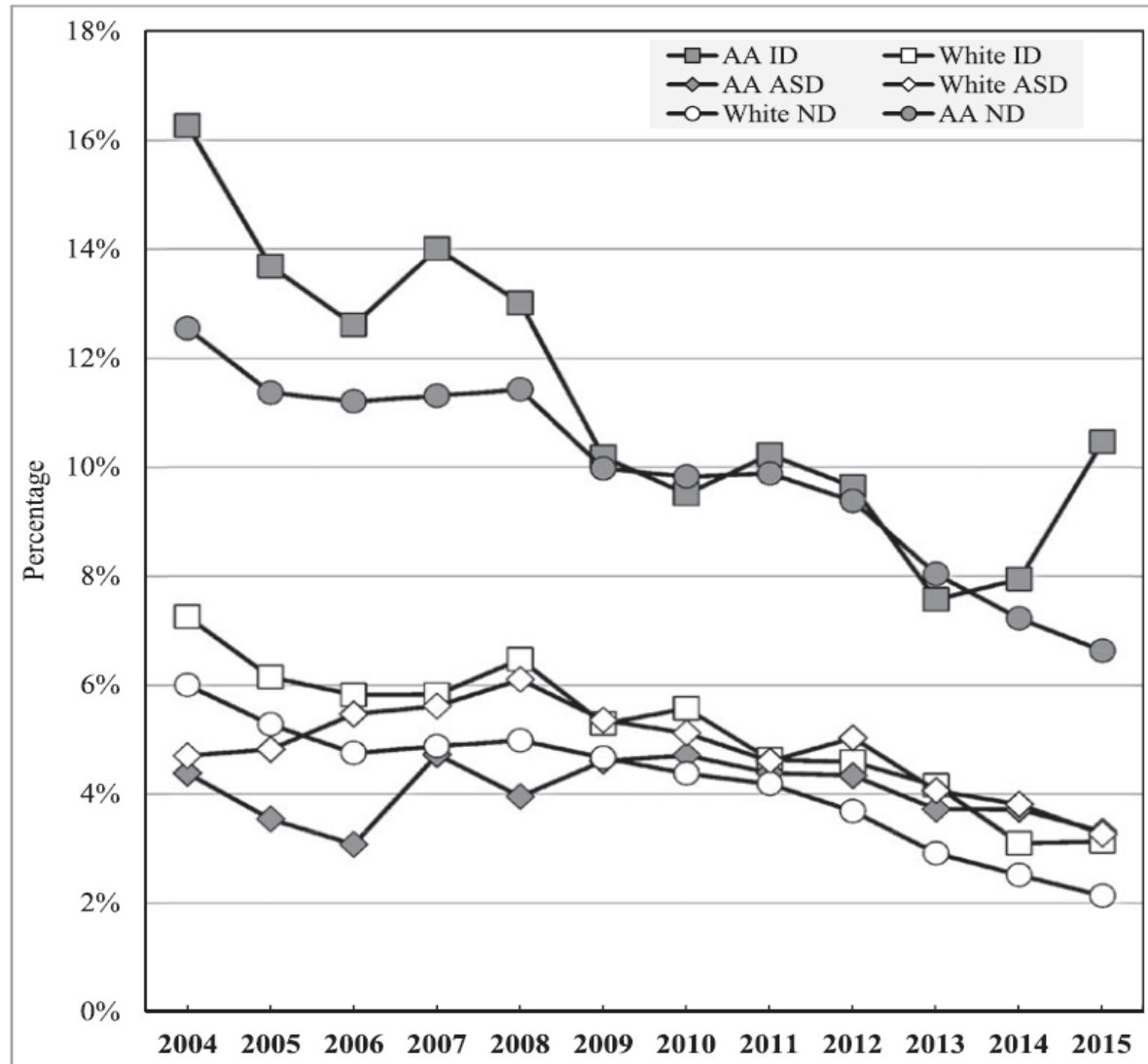
- **Hispanic > white**

- Shattuck et al., 2009; Fountain et al., 2011; Valicenti-McDermott et al., 2012

Disparities in Education Classification

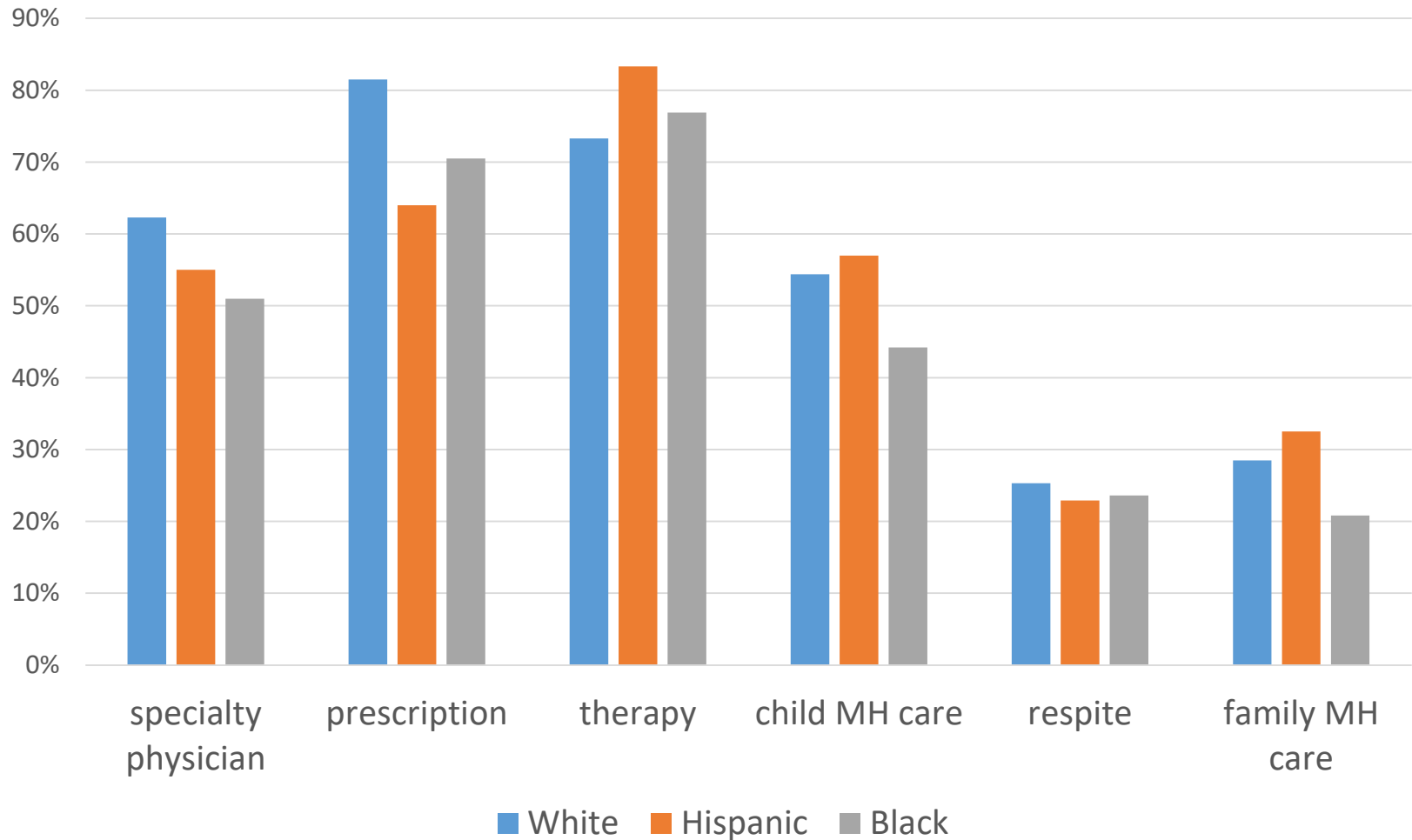


Why Education Classification Matters

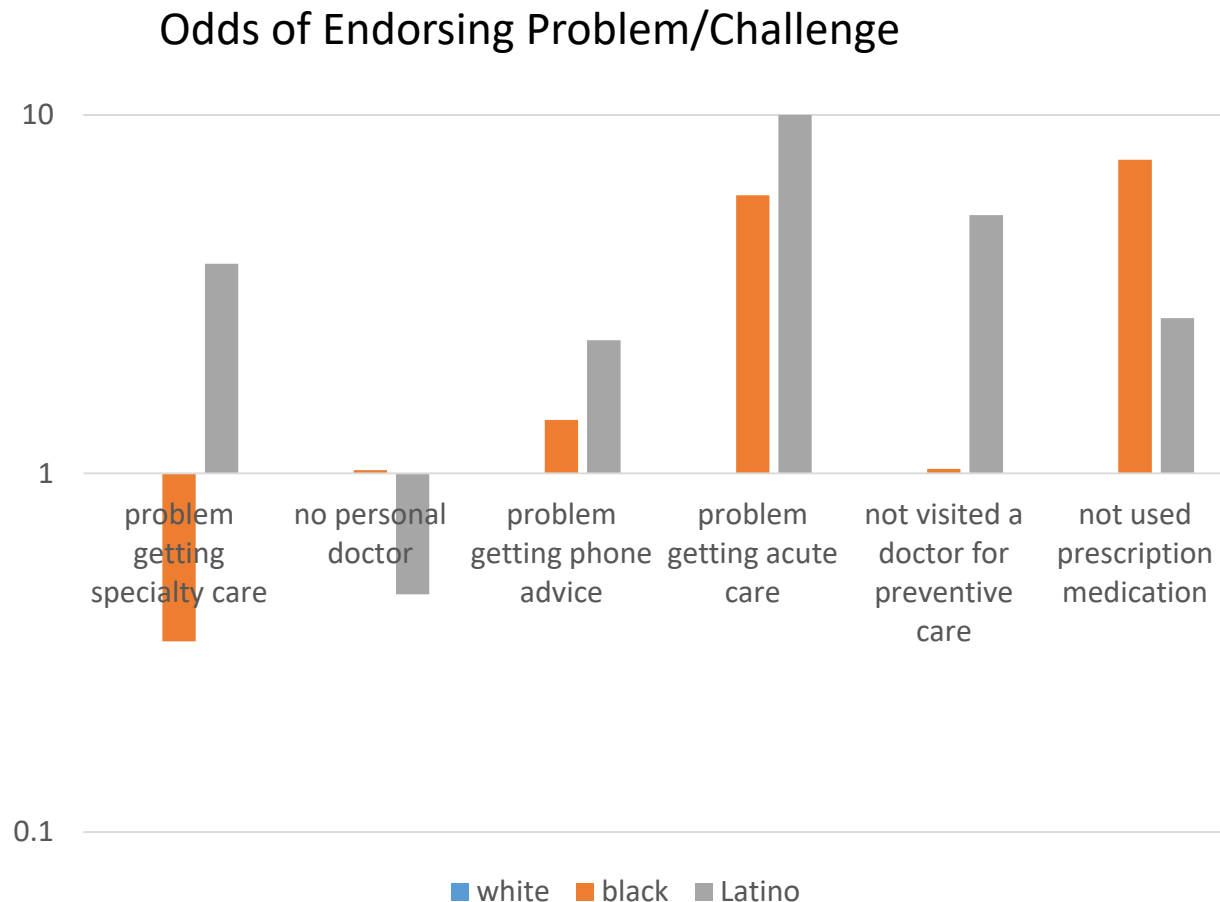


Suspension Rates in Maryland by Race & Disability Group

Disparities in Perceived Health Care Needs



Disparities in Service and Medication Use



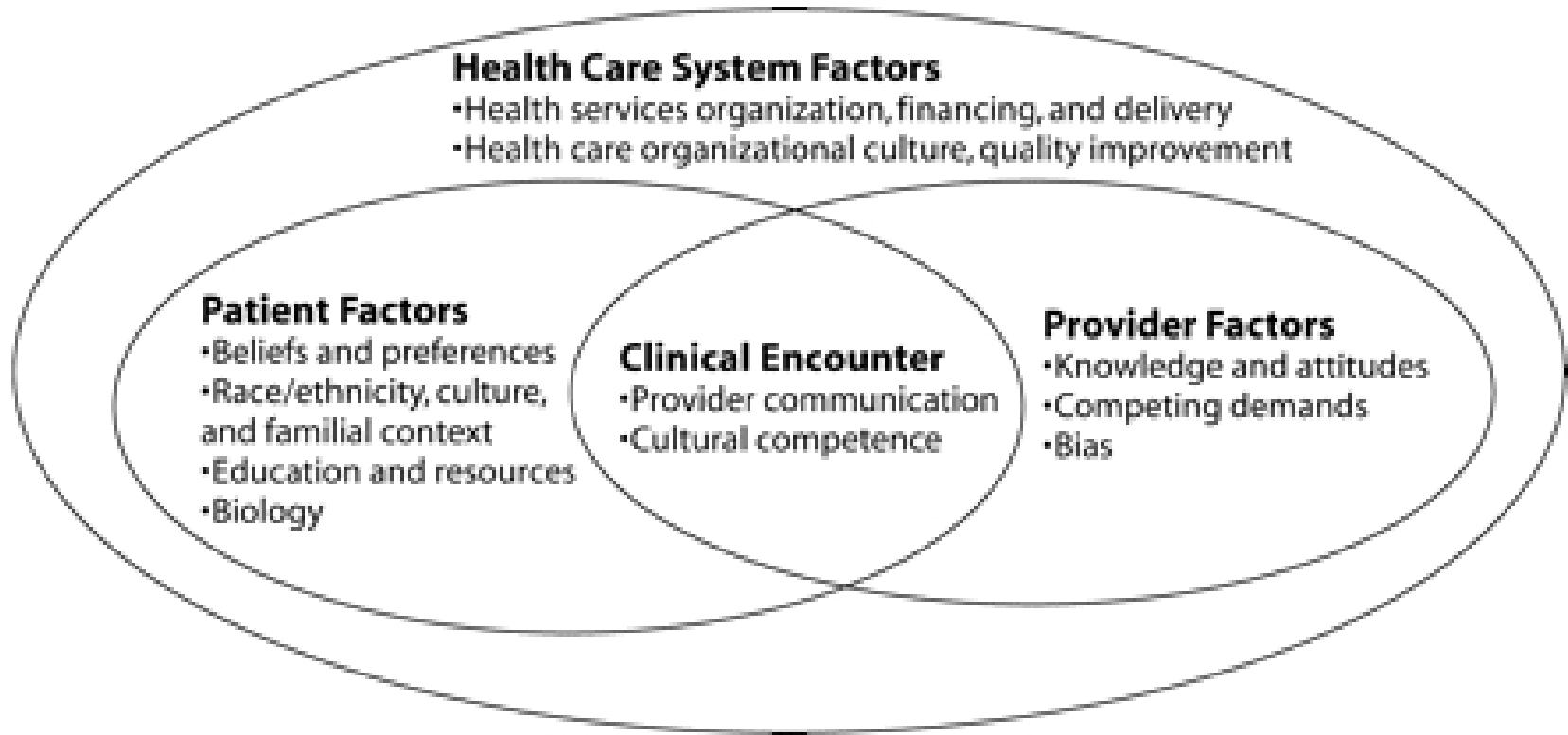
Liptak GS et al. Disparities in diagnosis and access to health services for children with autism: data from the National Survey of Children's Health. J Dev Behav Pediatr. 2008;29(3):152-60.

Post-High School Services

Table 2. Logistic Regression Models Predicting Post-High School Use of Services Among Young Adults With Autism Spectrum Disorders From Wave 4 (2007-2008) of the National Longitudinal Transition Study 2

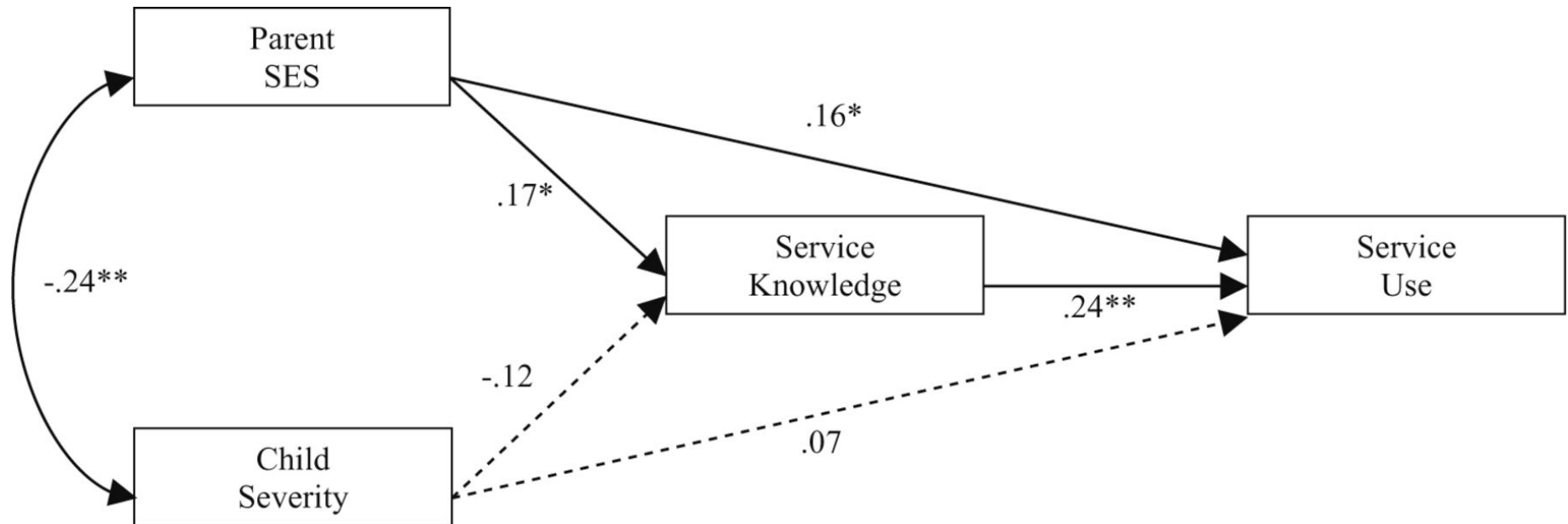
Variable	Odds Ratio (95% Confidence Interval)			
	No Services	Case Management	Mental Health Services	Medical Evaluation and Assessment
Demographic factors				
Female	0.47 (0.11-1.94)	2.02 (0.65-6.30)	1.81 (0.54-6.03)	0.95 (0.28-3.25)
Age, y				
19	1 [Reference]	1 [Reference]	1 [Reference]	1 [Reference]
20	0.50 (0.13-1.88)	1.63 (0.38-6.96)	1.22 (0.35-4.29)	1.89 (0.37-9.68)
21	0.37 (0.09-1.47)	1.87 (0.45-7.78)	0.78 (0.23-2.70)	1.96 (0.35-10.83)
22	0.37 (0.09-1.54)	2.28 (0.50-10.31)	1.12 (0.32-3.91)	1.28 (0.26-6.42)
23	0.89 (0.19-4.08)	1.23 (0.23-6.55)	0.60 (0.13-2.71)	3.39 (0.58-19.71)
Hispanic	1.33 (0.41-4.31)	0.75 (0.24-2.29)	2.39 (0.67-8.56)	0.41 (0.10-1.68)
Race				
White	1 [Reference]	1 [Reference]	1 [Reference]	1 [Reference]
African American	3.31 (1.29-8.48)	0.73 (0.26-2.02)	0.53 (0.23-1.23)	0.58 (0.19-1.79)
Other or mixed	1.30 (0.29-5.81)	1.01 (0.28-3.66)	0.30 (0.06-1.40)	0.34 (0.09-1.24)

What Causes Disparities?

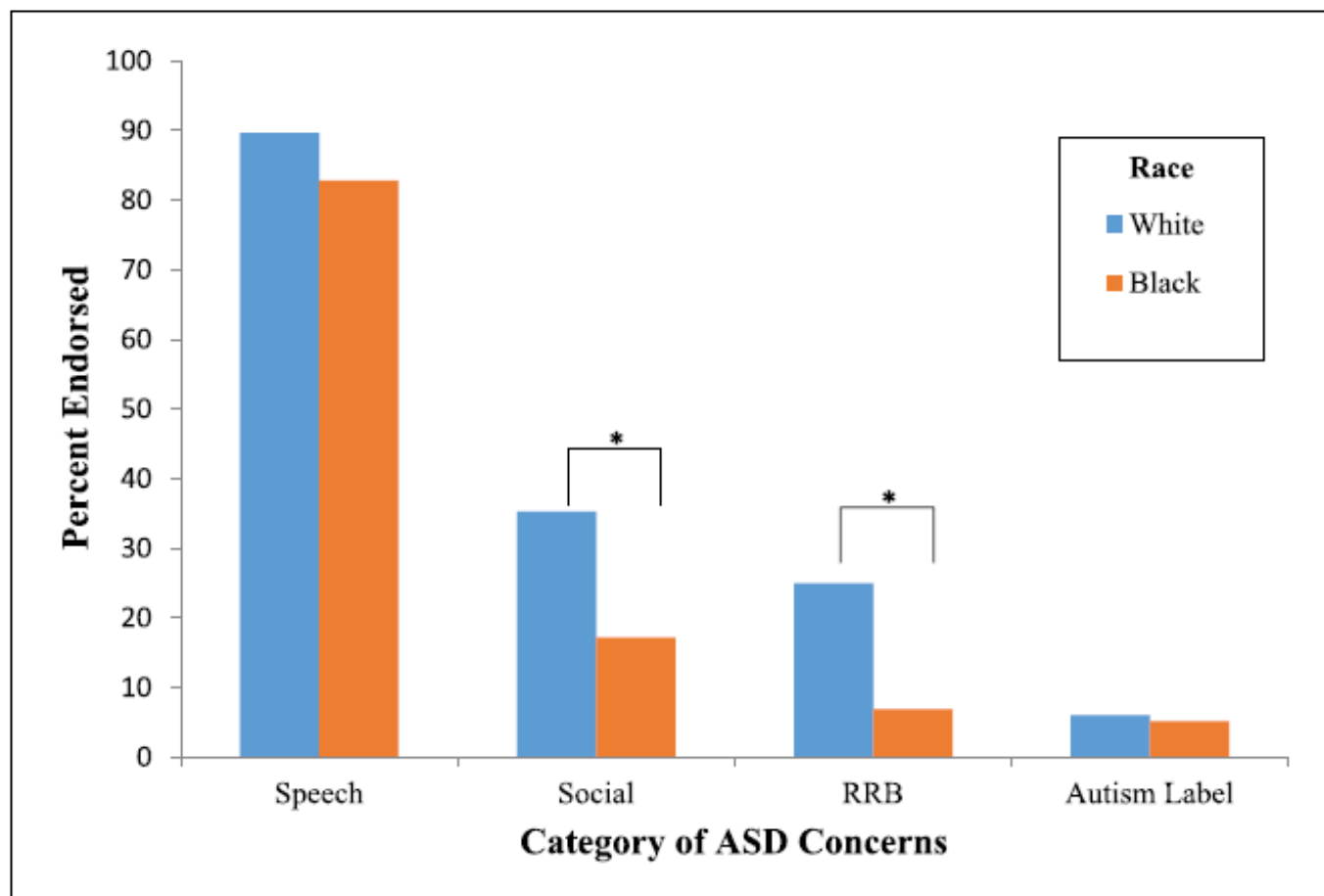


“We don’t need yet another paper showing yet another disparity in health care.”
David Asch to a young post doc proud of his first first-authored publication

Parent knowledge?



Parent endorsement of concerns



Donohue et al. (2019) Autism.

A hybrid type I randomized effectiveness-implementation trial of patient navigation to improve access to services for children with autism spectrum disorder

Sarabeth Broder-Fingert^{1,6*}, Morgan Walls¹, Marilyn Augustyn², Rinad Beidas³, David Mandell³, Shannon Wiltsey-Stirman⁴, Michael Silverstein¹ and Emily Feinberg^{1,5}

Reducing Disparities in Timely Autism Diagnosis Through Family Navigation: Results From a Randomized Pilot Trial

Emily Feinberg, Sc.D., C.P.N.P., Marcela Abufhele, M.D., M.P.H., Jenna Sandler, M.P.H., Marilyn Augustyn, M.D., Howard Cabral, Ph.D., Ning Chen, M.S., Yaminette Diaz Linhart, M.S.W., M.P.H., Zhandra Cesar Levesque, M.P.H., Megan Aebi, M.P.H., Michael Silverstein, M.D., M.P.H.

Building Better
Bridges



Doctor-Family Communication



Make it Easier to Diagnose



Responds to name

Circle one:
Yes **No**

**The Developmental Check-In:
Development and initial testing
of an autism screening tool targeting
young children from underserved
communities**

Yvette M Janvier¹, Caroline N Coffield², Jill F Harris³ , David S Mandell⁴ and Zuleyha Cidav⁴

**Screening for autism spectrum disorder
in underserved communities: Early
childcare providers as reporters**

Yvette M Janvier¹, Jill F Harris², Caroline N Coffield³,
Barbara Louis⁴, Ming Xie⁵, Zuleyha Cidav⁵ and
David S Mandell⁵

Poverty Rates Among the Largest U.S. Cities

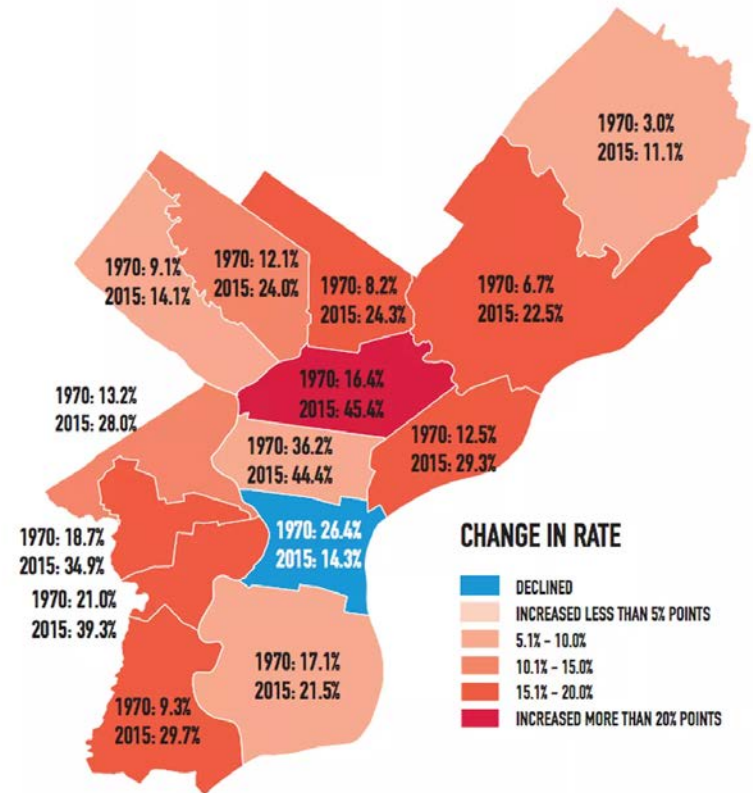
Philadelphia retains its distinction of having the highest poverty rate among the 10 largest U.S. cities, according to 2016 census estimates.

City	Poverty rate
Philadelphia	25.7%
Houston	20.8%
Phoenix	20.3%
Los Angeles	19.5%
Dallas	19.4%
Chicago	19.1%
New York	18.9%
San Antonio	18.5%
San Diego	13.1%
San Jose, Calif.	10.7%

SOURCE: U.S. Census Bureau, 2016 American Community Survey

Staff Graphic

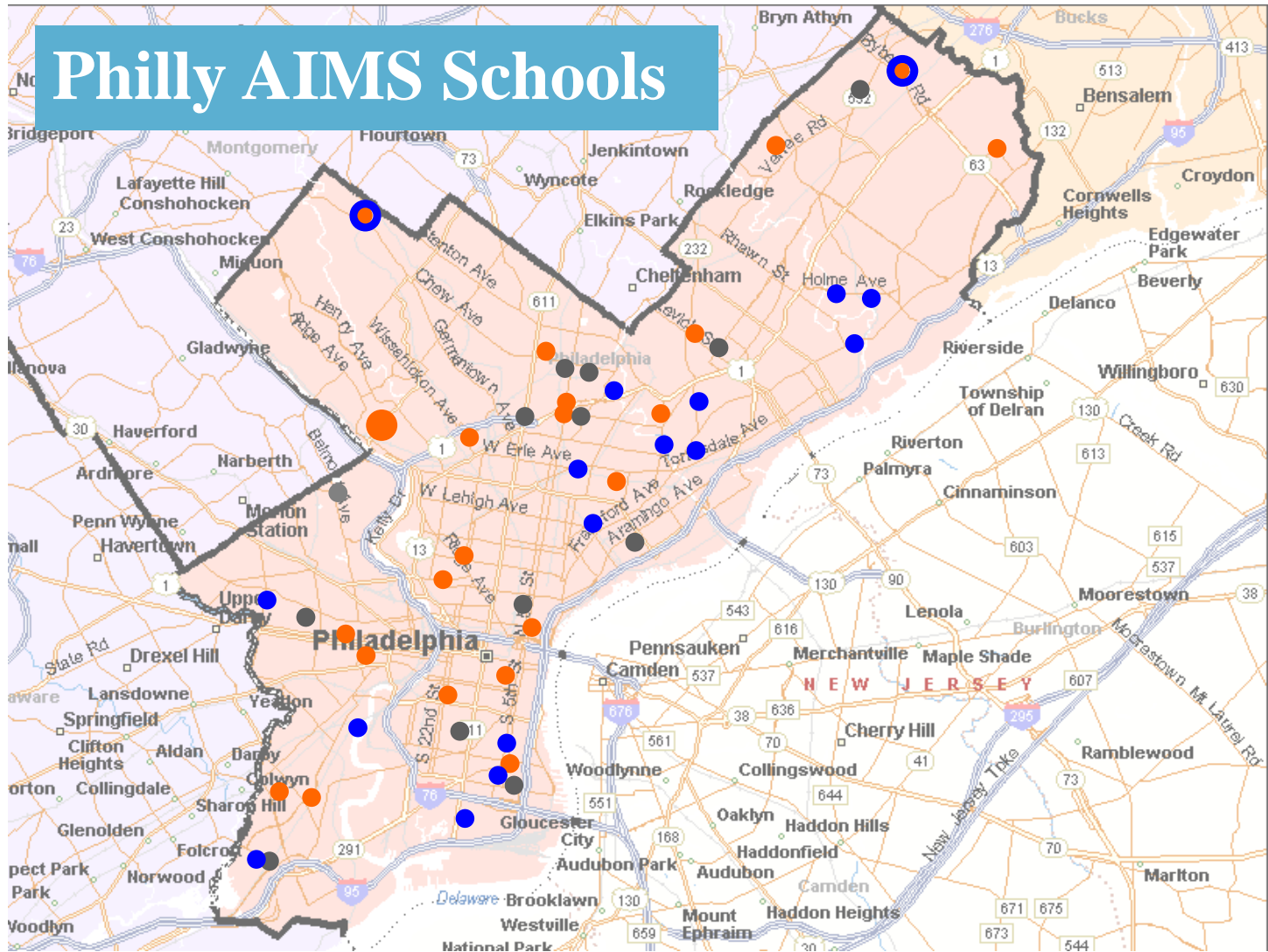
FIGURE 2: CHANGE IN POVERTY RATES, 1970-2015



*Boundaries on the maps above are based on Philadelphia City Planning Commission Districts.

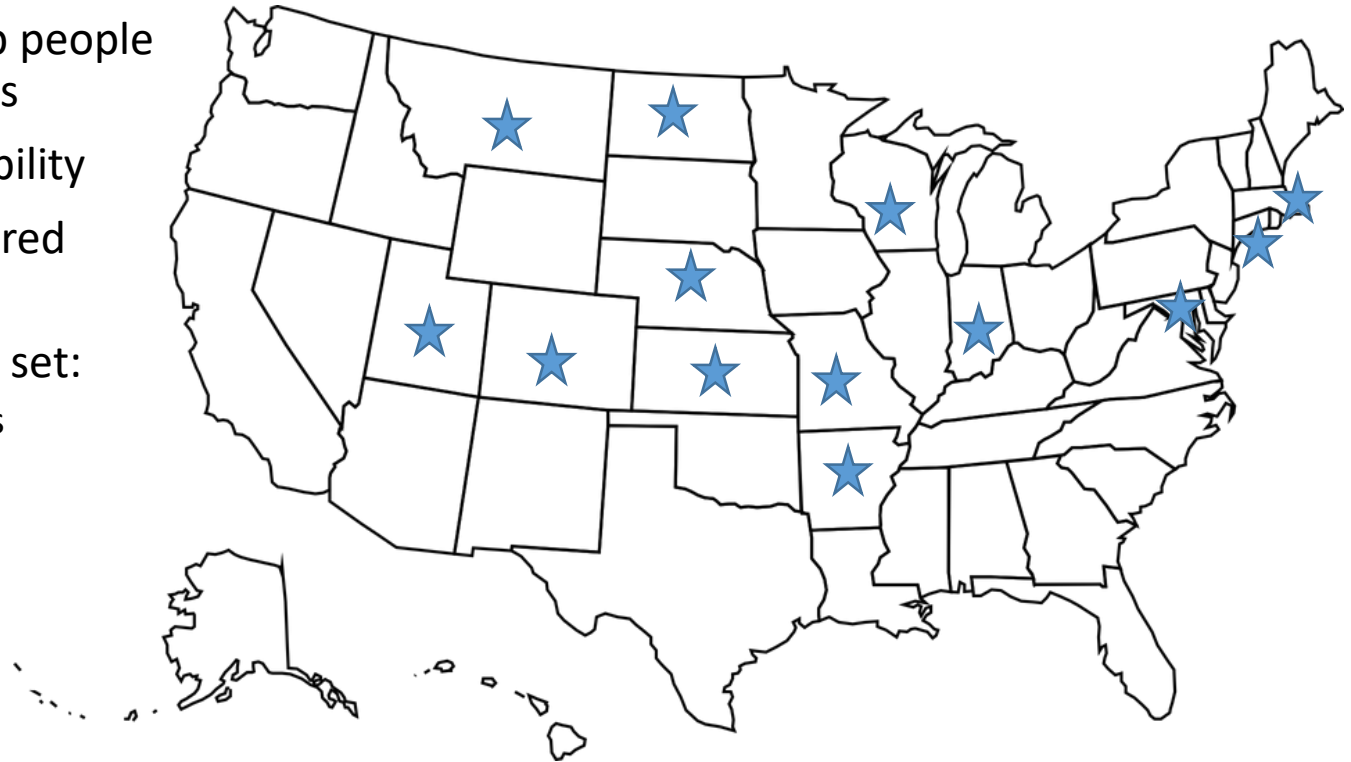
Sources: U.S. Census 1970; ACS 2015 5-Year

Philly AIMS Schools

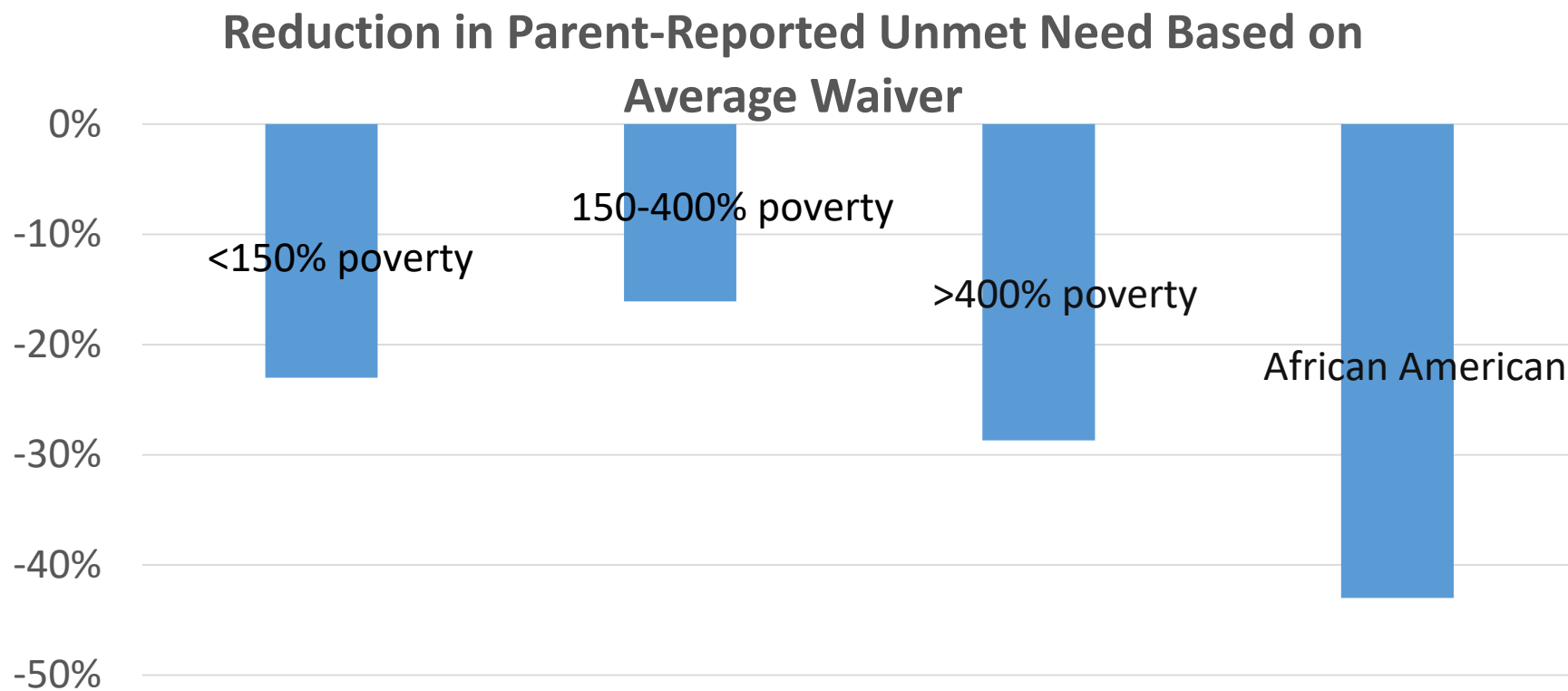


Policy Changes: Autism Medicaid Waivers

- Designed to keep people out of institutions
- Can expand eligibility
- Can expand covered services
- Require states to set:
 - Enrollment caps
 - Spending caps
- Are binding



Waivers Reduce Unmet Need in Children with ASD



Where do we put our resources?

Systematic reform > change provider behavior >
Band Aids > change parent behavior

But most importantly, reducing disparities is
about partnering with the communities we
Want to help.

THANK YOU.



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