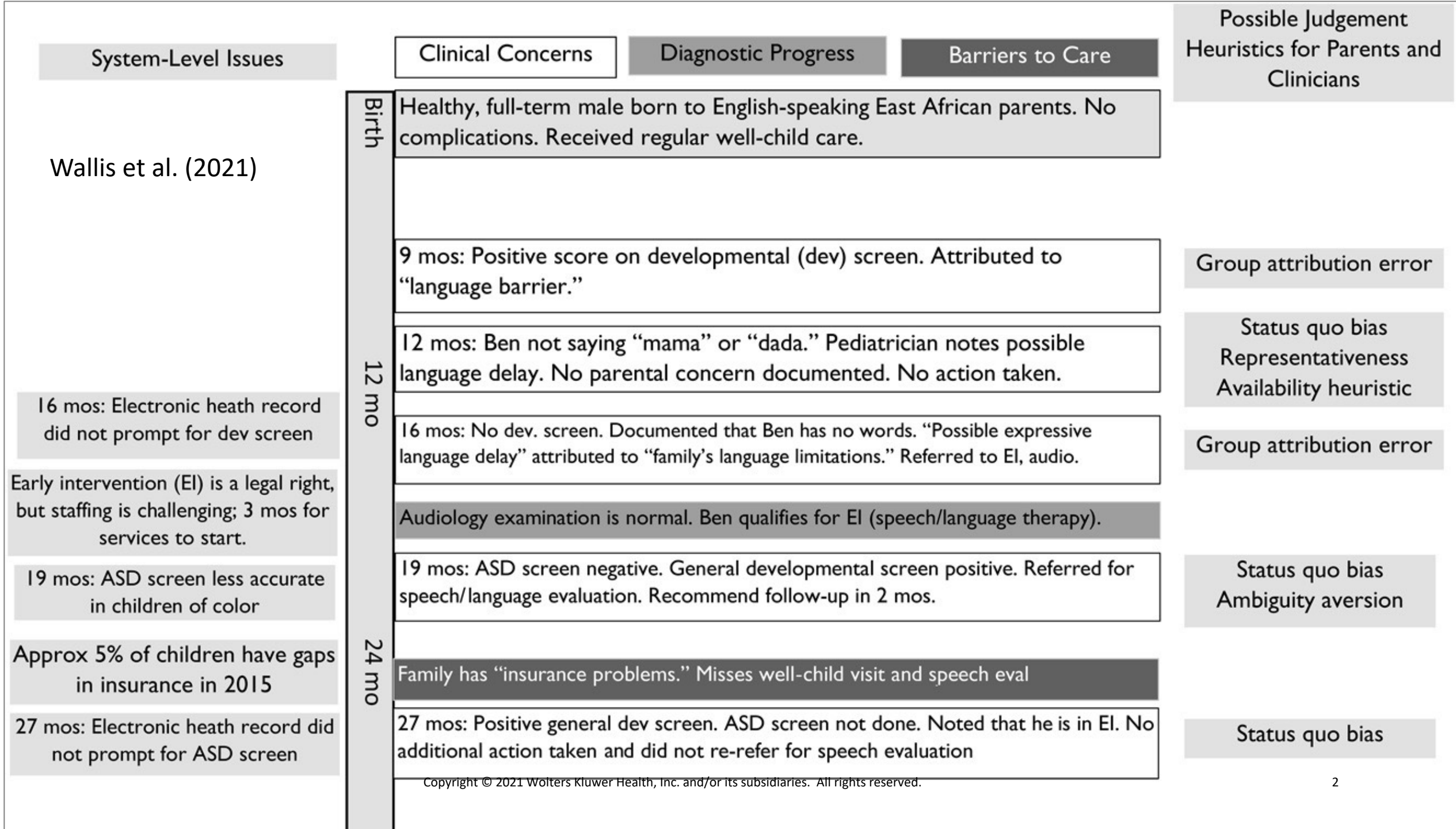
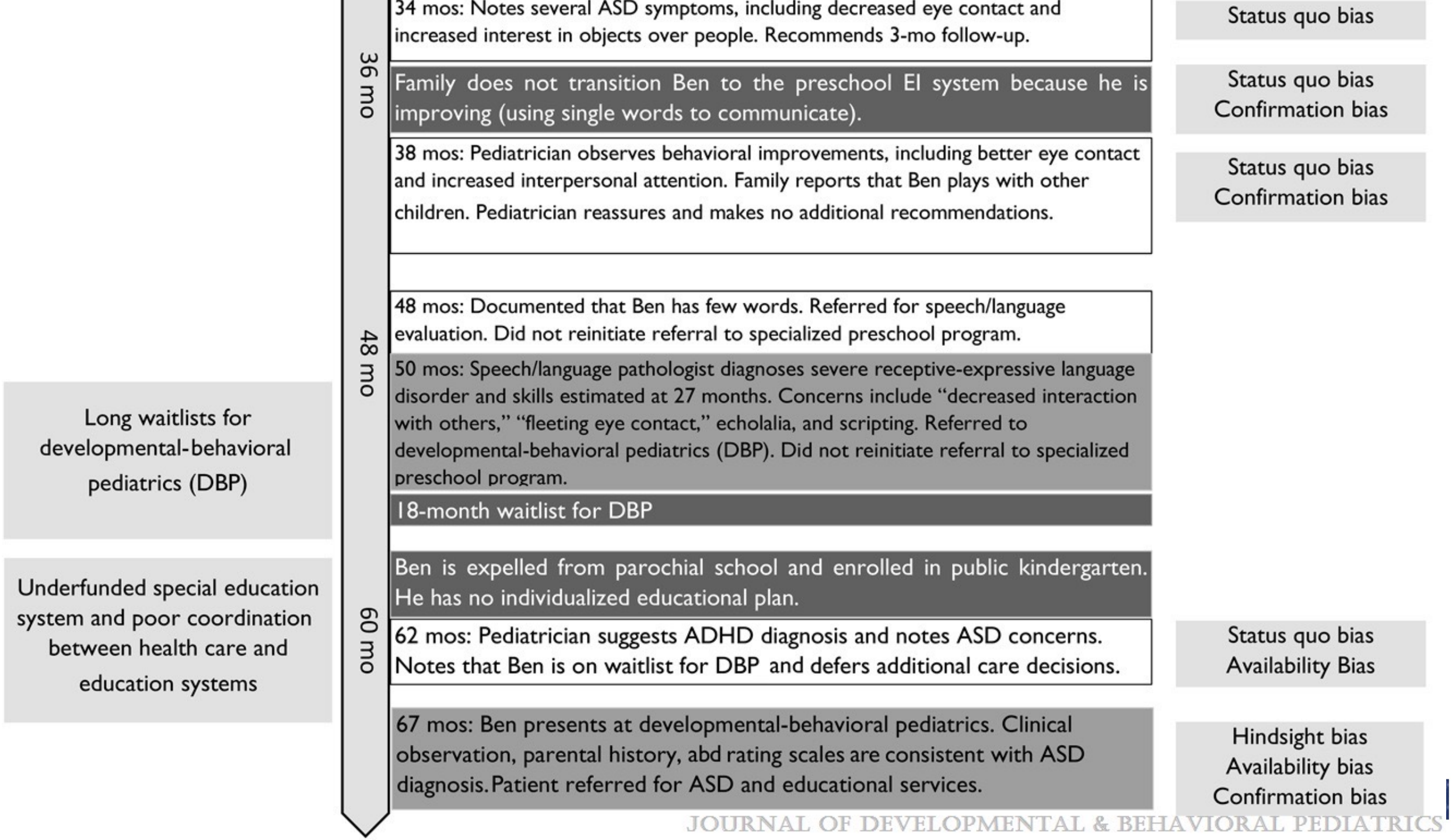
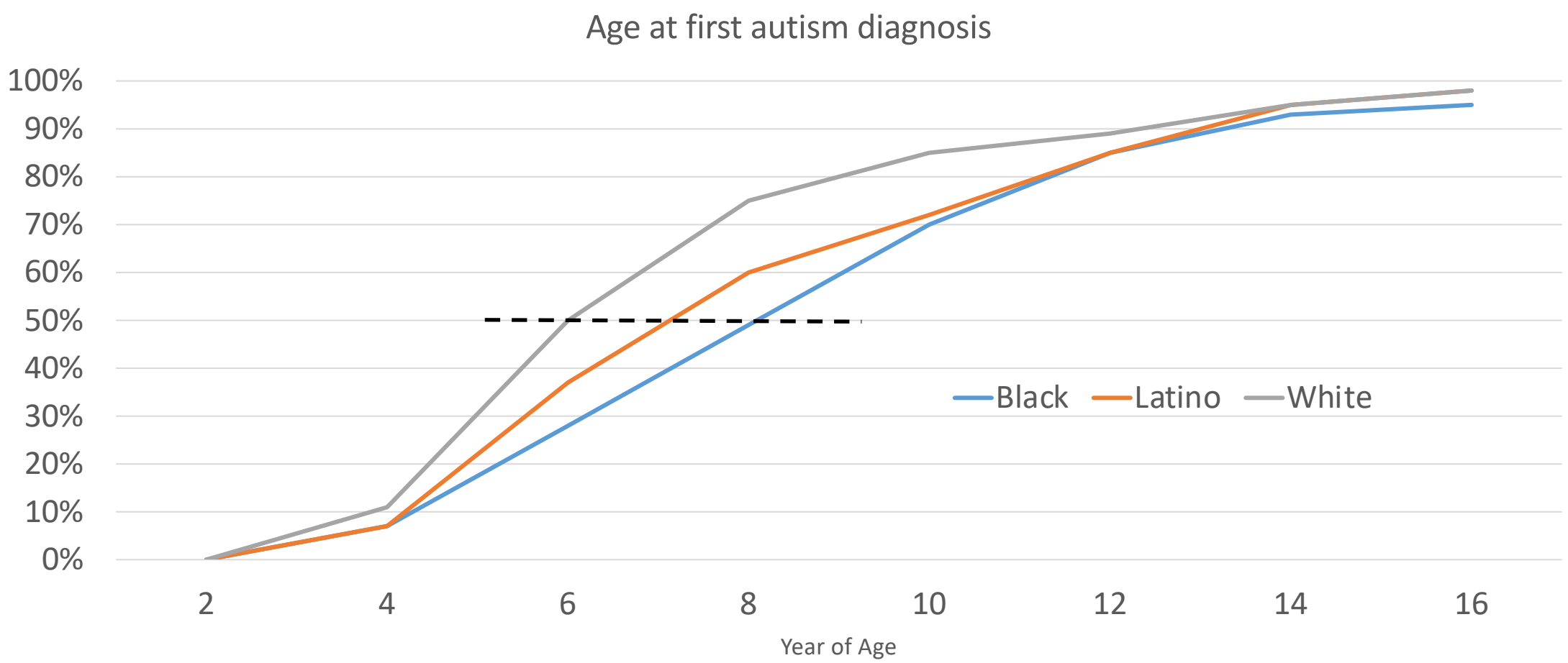
We don't need another study: ending racist structure and practice in autism

David S. Mandell, ScD

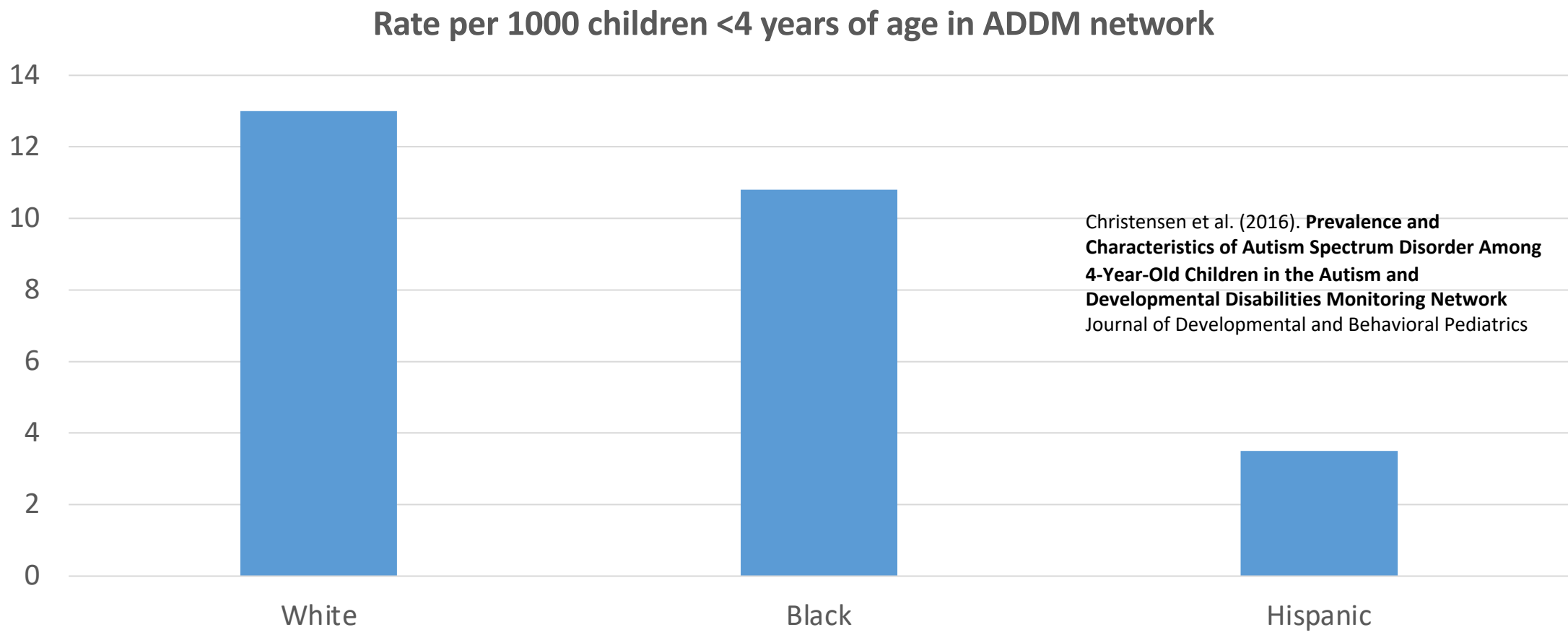



34 mos: Notes several ASD symptoms, including decreased eye contact and increased interest in objects over people. Recommends 3-mo follow-up.
Status quo bias
36 mo
Family does not transition Ben to the preschool EI system because he is improving (using single words to communicate).
Status quo bias
Confirmation bias
38 mos: Pediatrician observes behavioral improvements, including better eye contact and increased interpersonal attention. Family reports that Ben plays with other children. Pediatrician reassures and makes no additional recommendations.
Status quo bias
Confirmation bias
48 mos: Documented that Ben has few words. Referred for speech/language evaluation. Did not reinitiate referral to specialized preschool program.
48 mo
50 mos: Speech/language pathologist diagnoses severe receptive-expressive language disorder and skills estimated at 27 months. Concerns include "decreased interaction with others," "fleeting eye contact," echolalia, and scripting. Referred to developmental-behavioral pediatrics (DBP). Did not reinitiate referral to specialized preschool program.
Long waitlists for developmental-behavioral pediatrics (DBP)
18-month waitlist for DBP
Ben is expelled from parochial school and enrolled in public kindergarten. He has no individualized educational plan.
Underfunded special education system and poor coordination between health care and education systems
60 mo
62 mos: Pediatrician suggests ADHD diagnosis and notes ASD concerns. Notes that Ben is on waitlist for DBP and defers additional care decisions.
Status quo bias
Availability Bias
67 mos: Ben presents at developmental-behavioral pediatrics. Clinical observation, parental history, abd rating scales are consistent with ASD diagnosis. Patient referred for ASD and educational services.
Hindsight bias
Availability bias
Confirmation bias

We've known for a long time that Black kids are diagnosed later than White kids

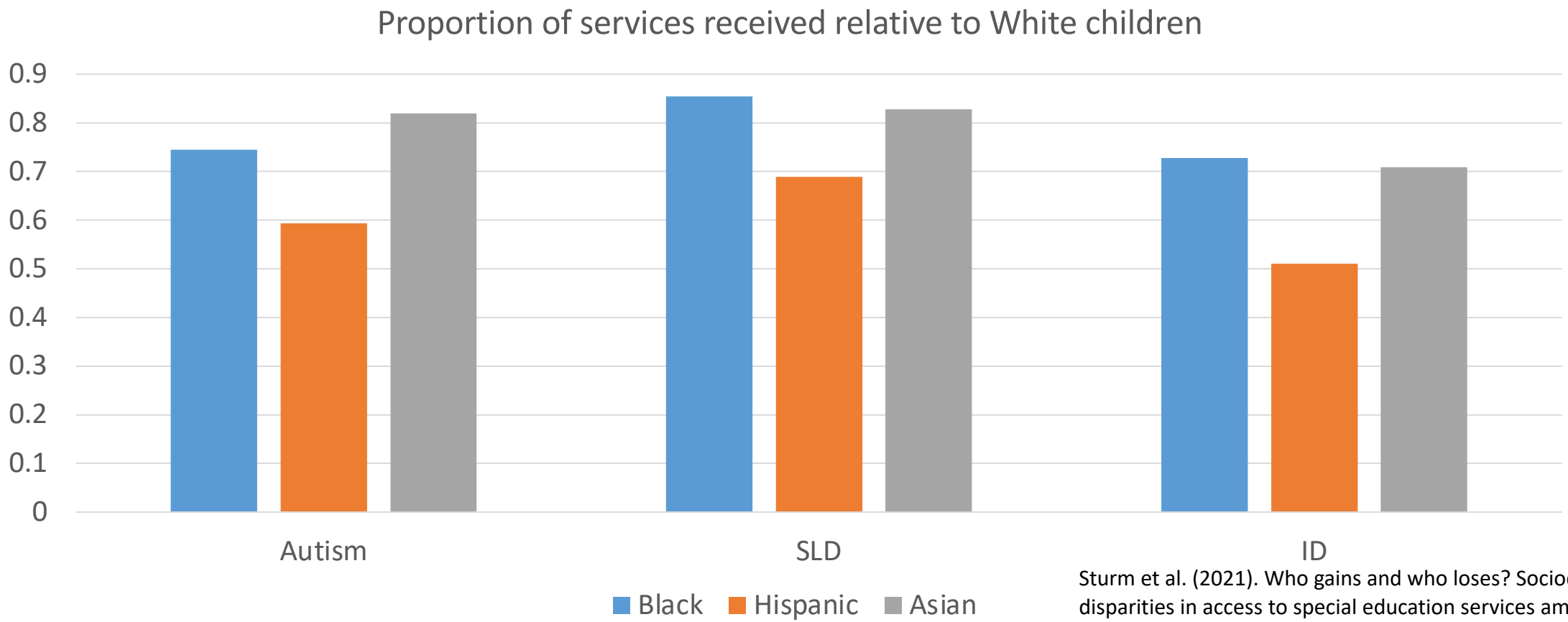


Other Studies Demonstrate the Same Thing



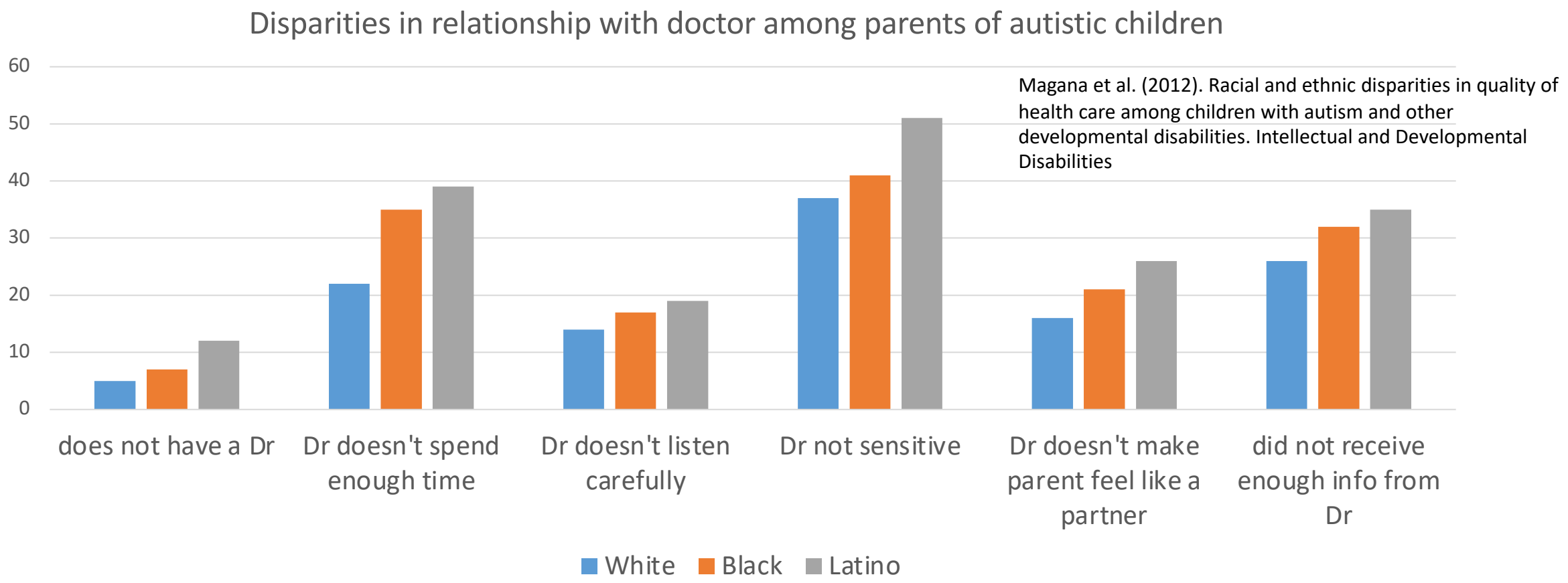
Christensen et al. (2016). **Prevalence and Characteristics of Autism Spectrum Disorder Among 4-Year-Old Children in the Autism and Developmental Disabilities Monitoring Network** Journal of Developmental and Behavioral Pediatrics

More recent studies Show the Same Discrimination in service use…



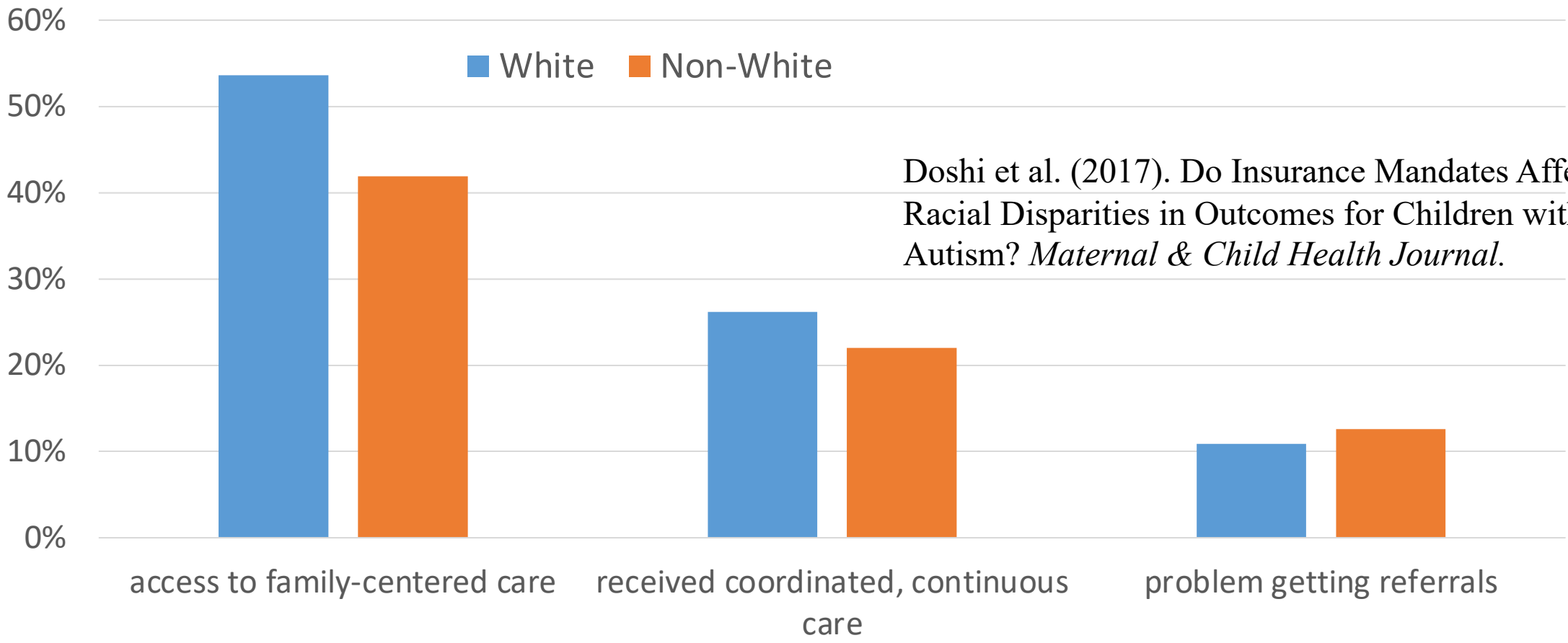
Sturm et al. (2021). Who gains and who loses? Sociodemographic disparities in access to special education services among autistic students. Autism Research

ANOTHER EXAMPLE



Magana et al. (2012). Racial and ethnic disparities in quality of health care among children with autism and other developmental disabilities. Intellectual and Developmental Disabilities

A THIRD EXAMPLE



Doshi et al. (2017). Do Insurance Mandates Affect Racial Disparities in Outcomes for Children with Autism? *Maternal & Child Health Journal.*

FEW STUDIES TEST WAYS TO FIX THIS

	Recognition	Diagnosis	Tx initiation	Tx quality
Patient/family	+++	+++	+	
Practitioner	++	++		++
Organization	++			+
System				+

DEFINITIONS

Patient/family	Interventions to educate, train or empower families to make service decisions that result in better outcomes
Practitioner	Strategies that directly target practitioners to improve practitioner performance and reduce bias in their care delivery
Organization	Change organizational culture, climate or processes to improve performance and reduce bias in care delivery
System	Changes in policy, payment, or resources to improve performance and outcomes, and reduce bias

Family Navigation

- Time-limited model of lay case management that focuses on overcoming patient-specific barriers to care
- Navigators are community members
- Can vary in lived experience or cultural matching

Family Navigation Study Results

- Feinberg et al. (2016): 95% vs. 55% completed diagnostic process
- Feinberg et al. (2021): 86% vs. 76% completed diagnostic process within a year
- DiGuieseppi (2021): Increased screening, no effect on referrals or tx initiation
- Several ongoing studies
  - Bernie 2021
  - Broder-Fingert 2018
  - Iadarola 2021

Family Navigation Pros and Cons

Pros

- Relatively inexpensive task shifting
- Lived experience and cultural matching may help families
- Modestly positive evidence to date

Cons

- Does not address underlying reasons for inequities
- Billing model unclear
- Modest evidence related only to diagnostic process
- Families vary in their experience of it (Crossman 2020)

Pros and Cons of Family Approaches

Pros

- May be easiest unit to reach
- Can tailor to specific family needs
- Education/empowerment may have long-lasting and generalizable effects

Cons

- Turns parent into clinician/case manager
- Puts burden on families
- Assumes there are good options from which to choose
- May be a band aid for systemic problems

PRACTITIONER-DIRECTED APPROACHES

IMPLICIT BIAS TRAINING

- Implicit bias: unconscious prejudices and stereotypes that are automatically activated and may affect how one treats Black people (Hagiwara 2020)
  - Very common in health care providers and educators
  - In 50% of studies associated with worse patient outcomes
- Implicit bias training
  - Lowers scores on implicit bias tests (Stone et al., 2020)
  - No evidence that they result in behavior change (Forscher, 2019)
  - Avoids larger structural changes that cause disparities in care

TRAINING IN EVIDENCE-BASED INTERVENTIONS

- Community practitioners don't use evidence-based practices the ways they were designed.
- Poor use of these interventions can lead to poor outcomes overall and disparities in care (Pellecchia 2020).
  - Example of parent coaching in early intervention
- Practitioner access to training, and supervisor expectations regarding EBP use may be lower in predominantly minority areas.

Pros and Cons of Practitioner Approaches

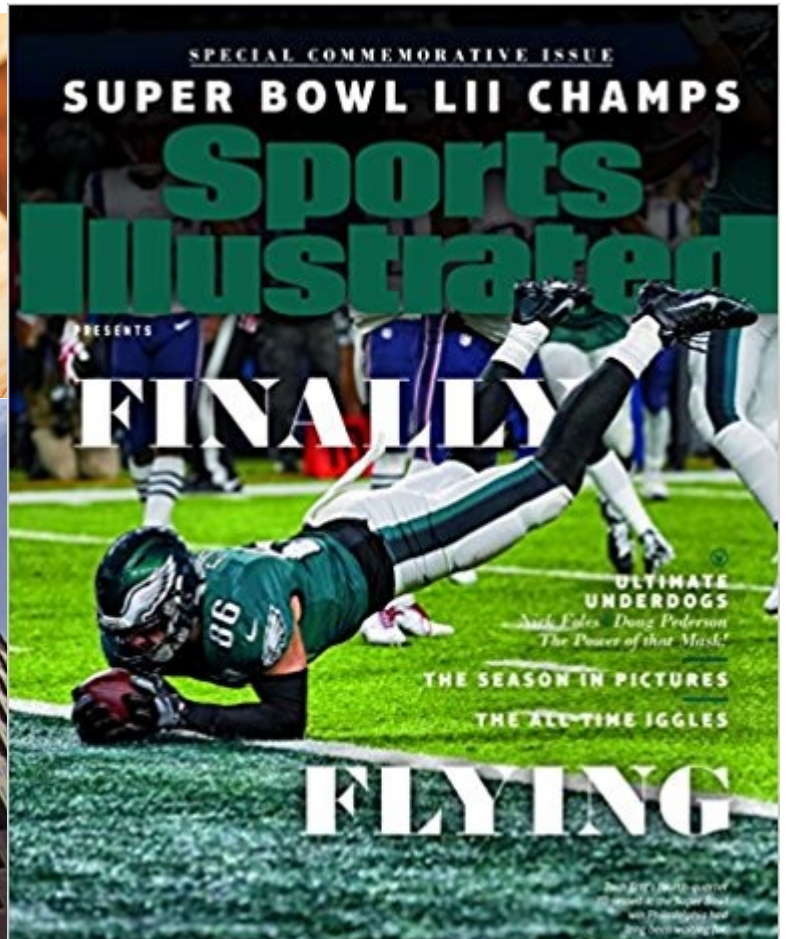
Pros

- Practitioner change can affect exponentially more children/families
- Builds on existing training/expectations
- Alleviates burden on families

Cons

- Practitioners have many competing demands
- may be difficult to sustain w/o organizational change to address incentives, supports, turnover

Our Philly Example




I CAN'T BREATHE


SILENCE IS VIOLENCE
NO JUSTICE NO PEACE
#BLM


Young Black & Unafraid!!


SILENCE IS VIOLENCE


BLACK LIVES MATTER

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.

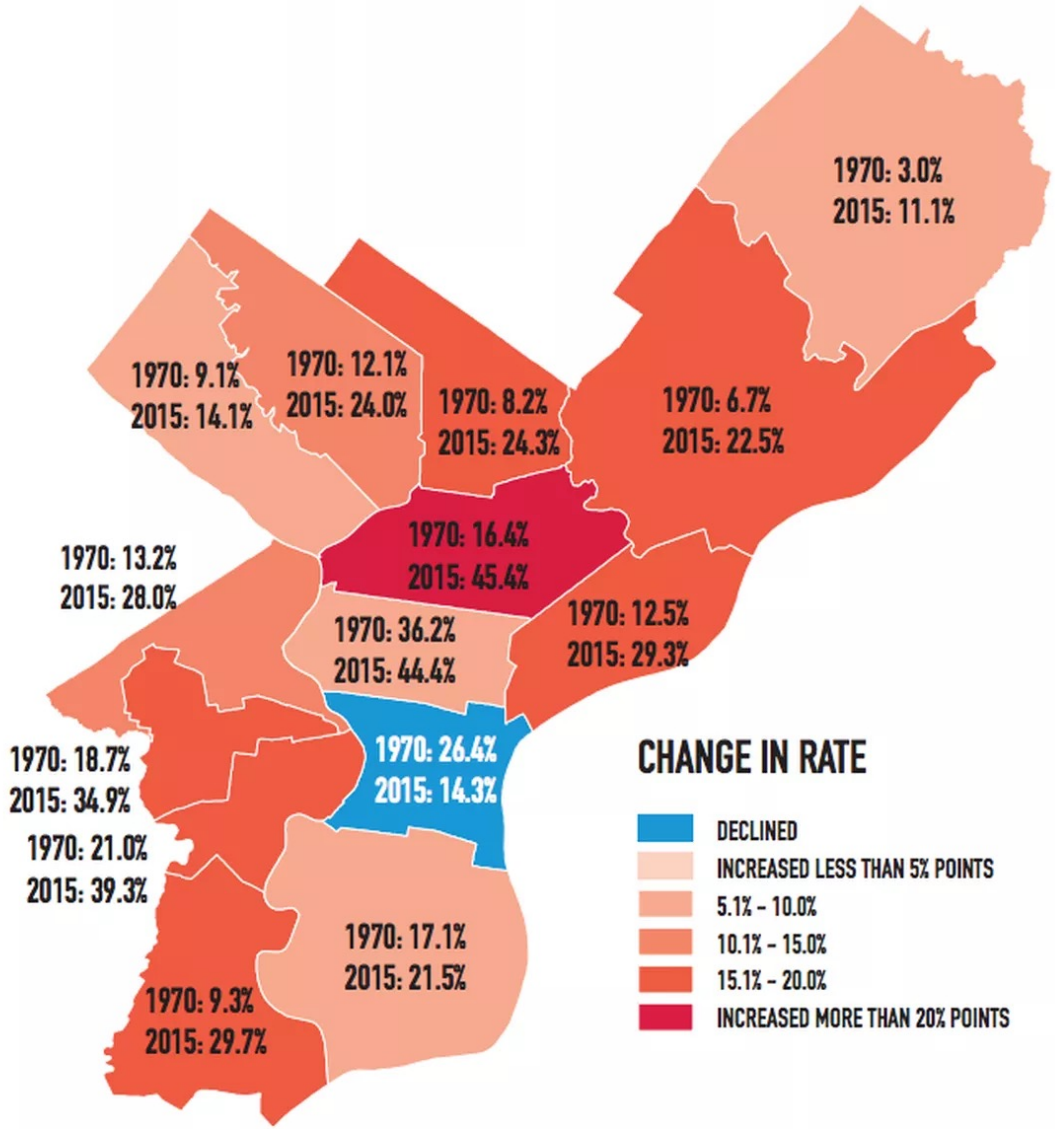
City	Poverty rate
Philadelphia	25.7%
Houston	20.8%
Phoenix	20.3%
Los Angeles	19.5%
Dallas	19.4%
Chicago	19.1%
New York	18.9%
San Antonio	18.5%
San Diego	13.1%
San Jose, Calif.	10.7%

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

Staff Graphic

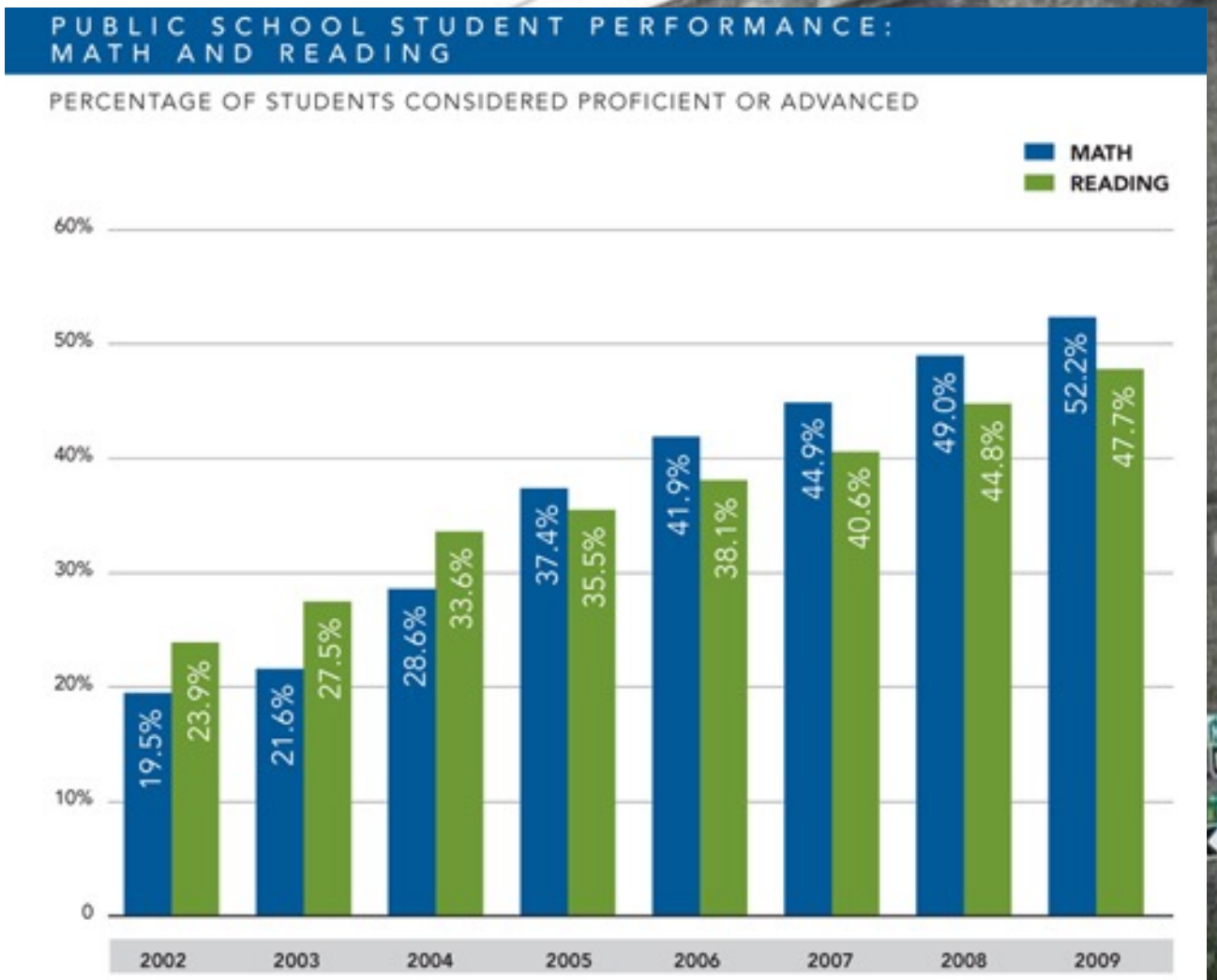
, PRACTICE AND TRAINI

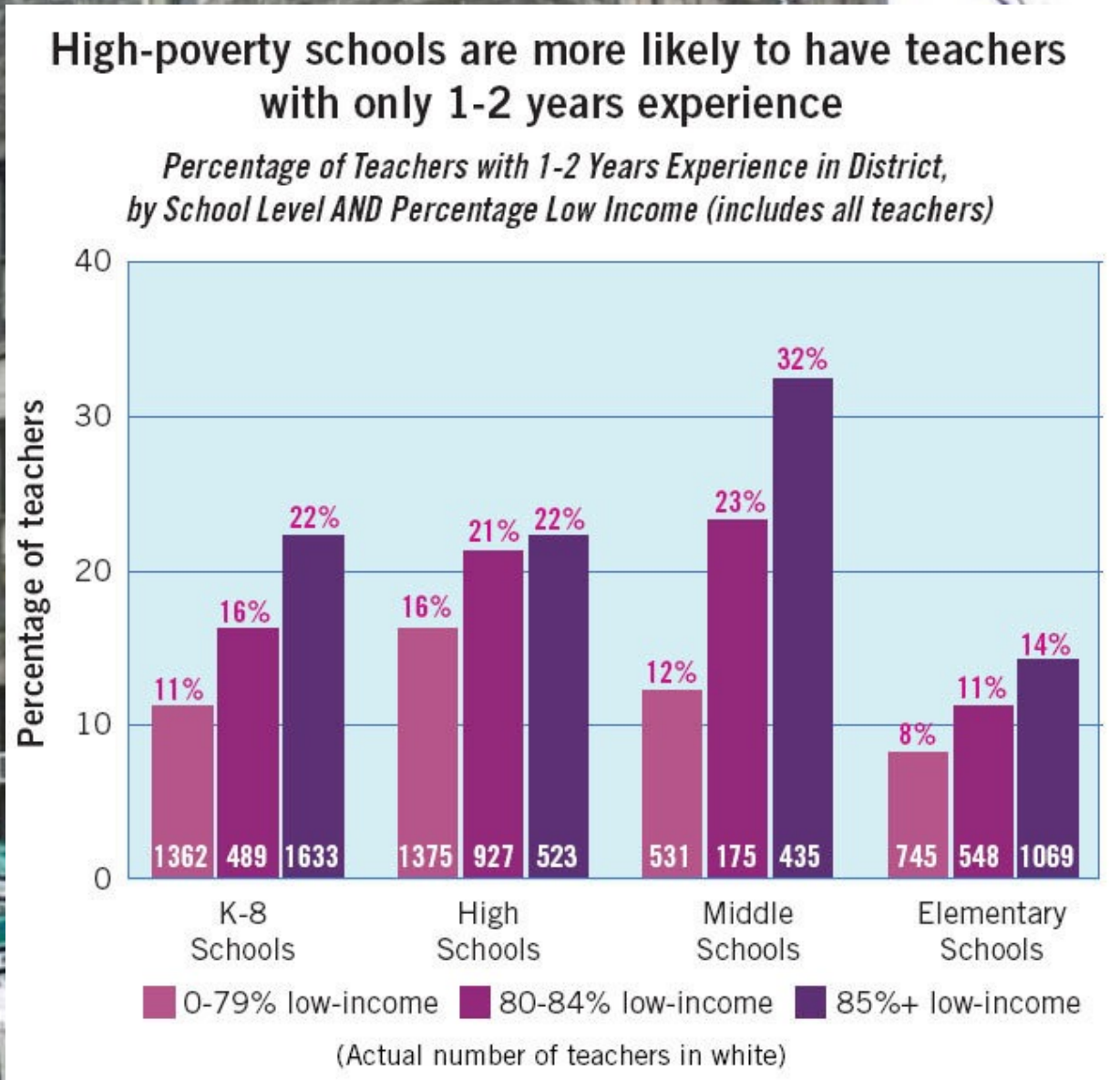
FIGURE 2: CHANGE IN POVERTY RATES, 1970–2015



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

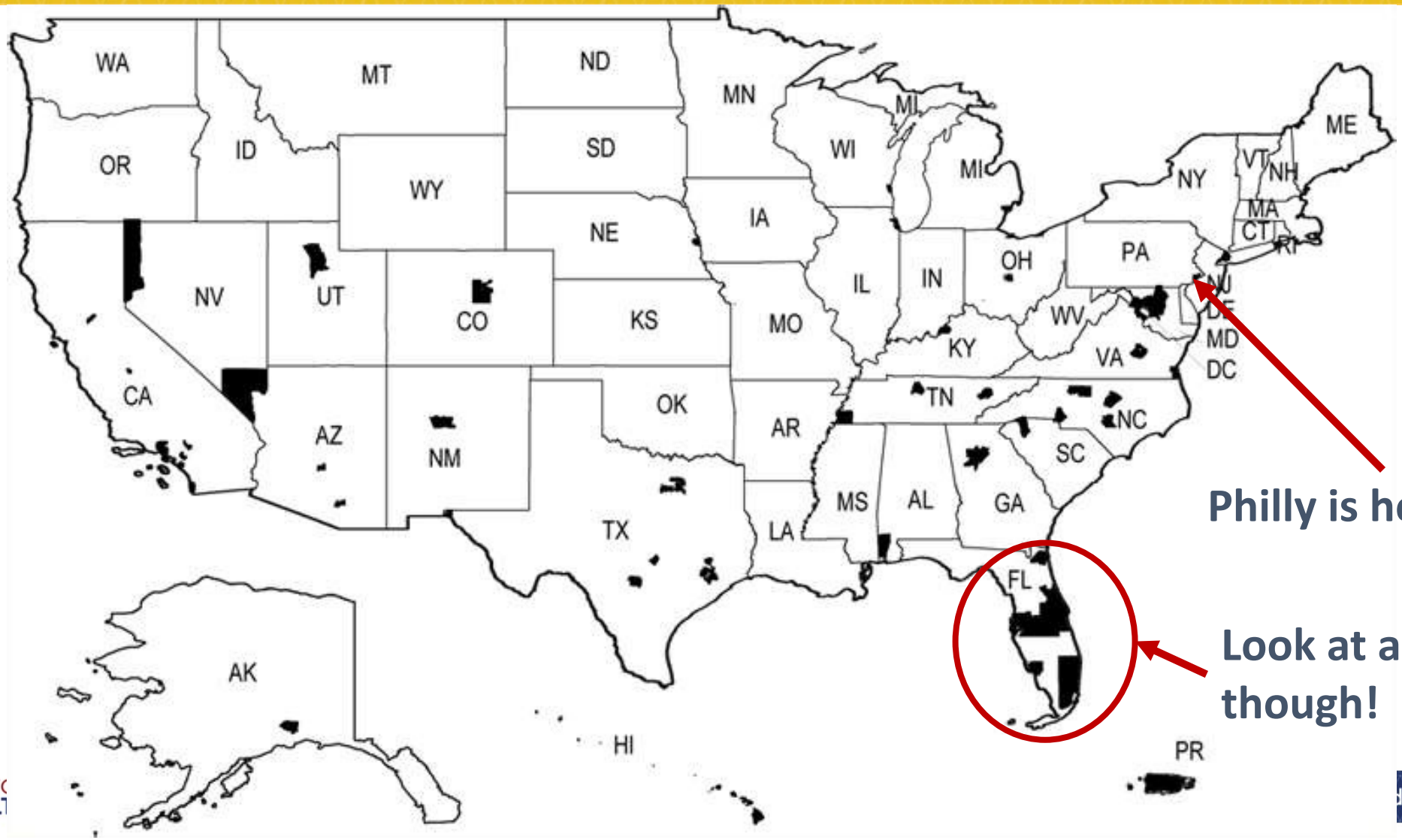
Sources: U.S. Census 1970; ACS 2015 5-Year



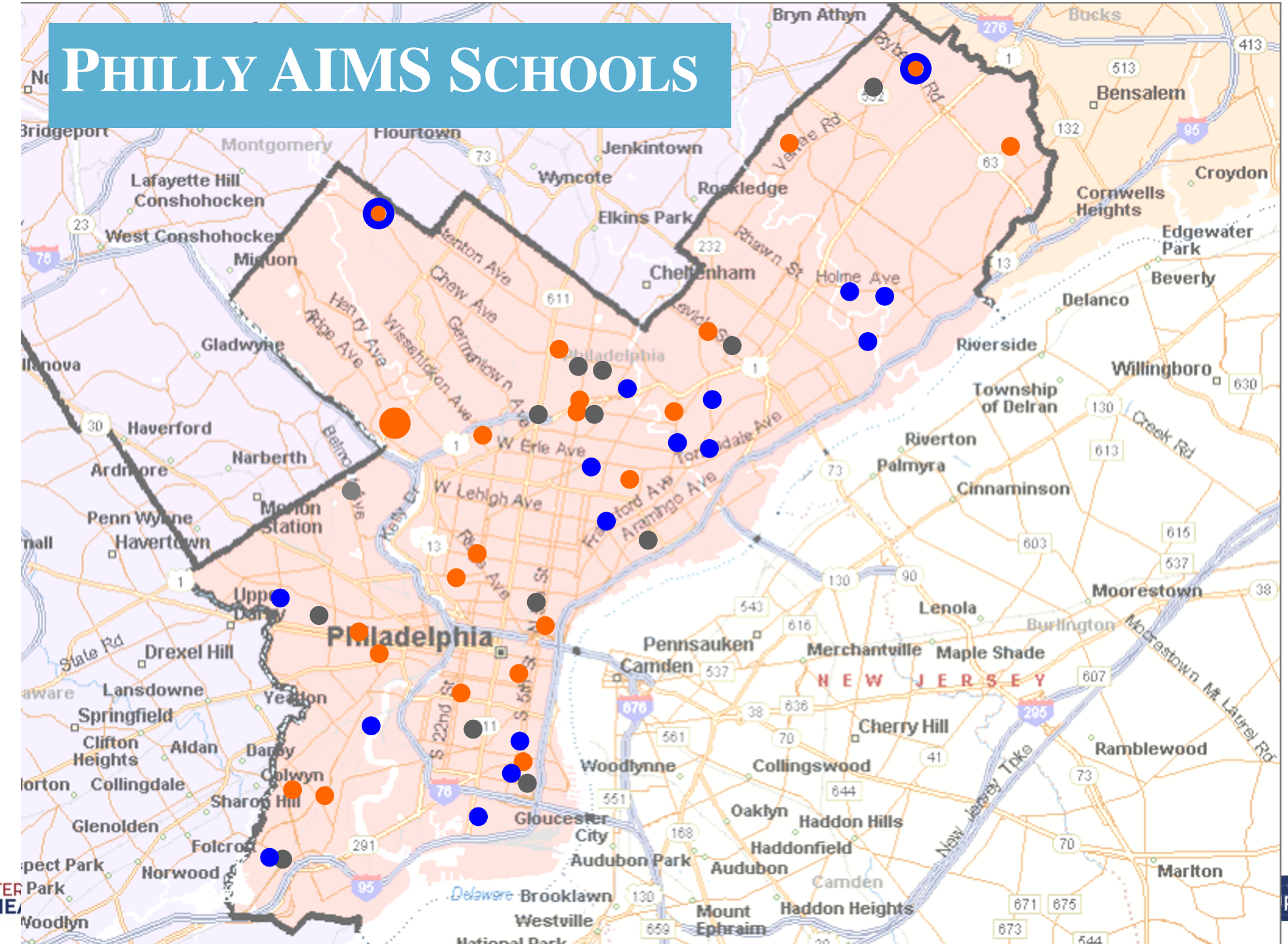


Pew Charitable Trusts 2011

Many Large Districts Face Similar Challenges



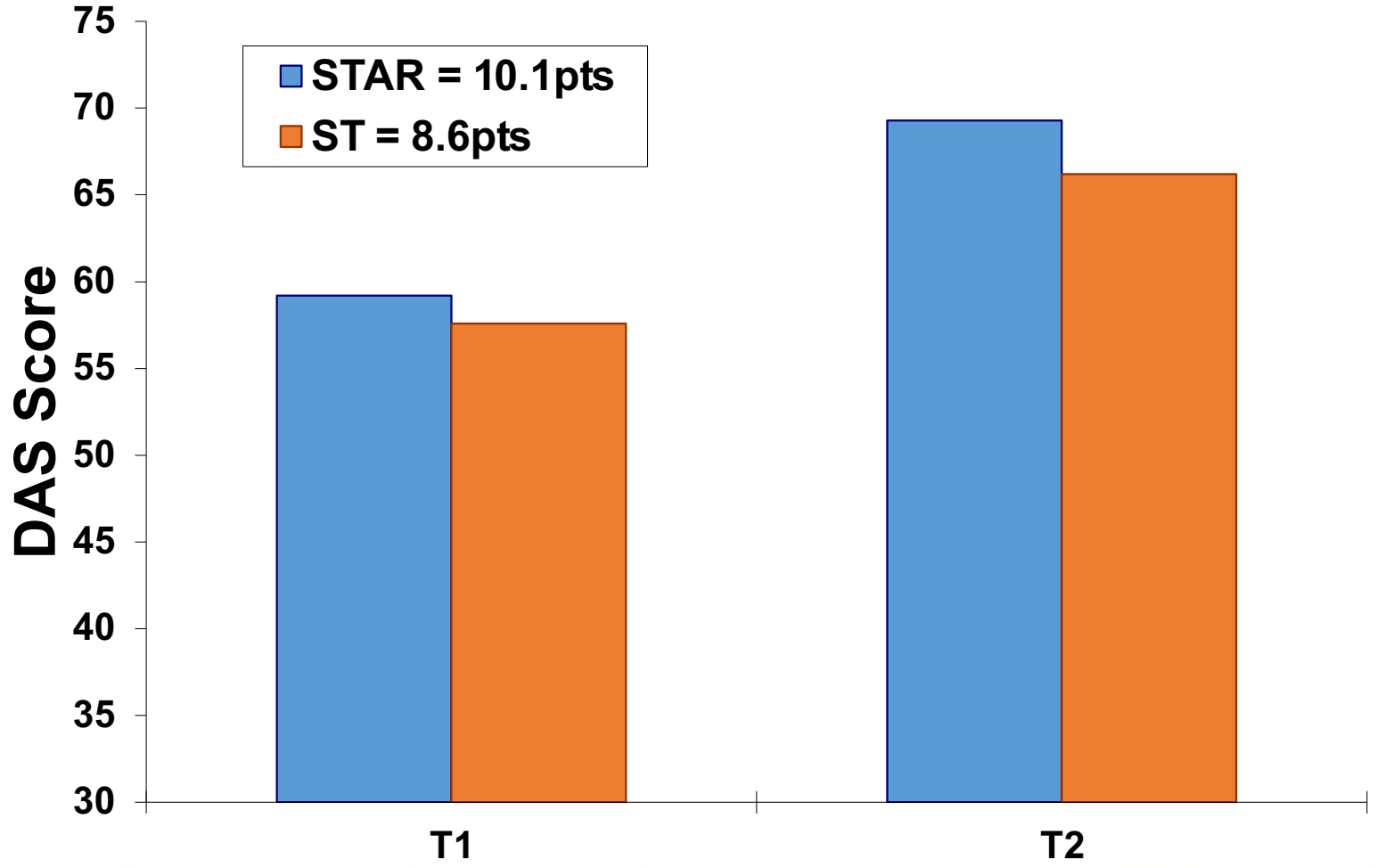
PHILLY AIMS SCHOOLS



AIMS AIMS

- Compare the effects of STAR and augmented “teaching as usual” (Structured Teaching) in improving student outcomes
  - Year 01: STAR > ST?
  - Year 02: Practice effects?
  - Year 03: Sustainable?
- What educator and organizational characteristics, moderate outcomes?

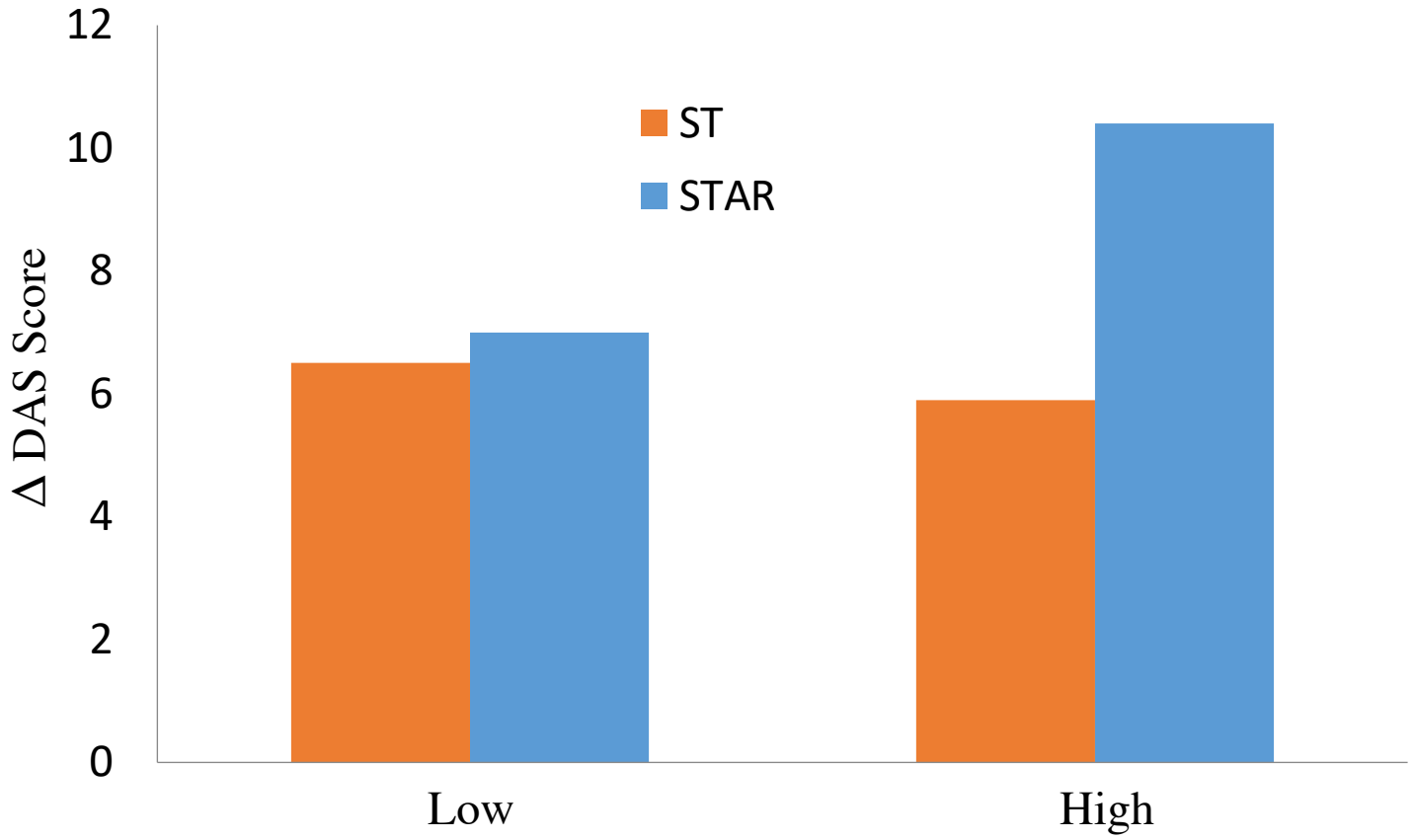
CHANGE IN DIFFERENTIAL ABILITIES SCALE SCORE



Mandell et al., 2013

Fidelity X Program

Program fidelity	STAR 57% (range 12-79%)	ST 48% (range 17-71%)



53% Black participants in high fidelity group, no difference in intervention receipt or outcome between Black and White students

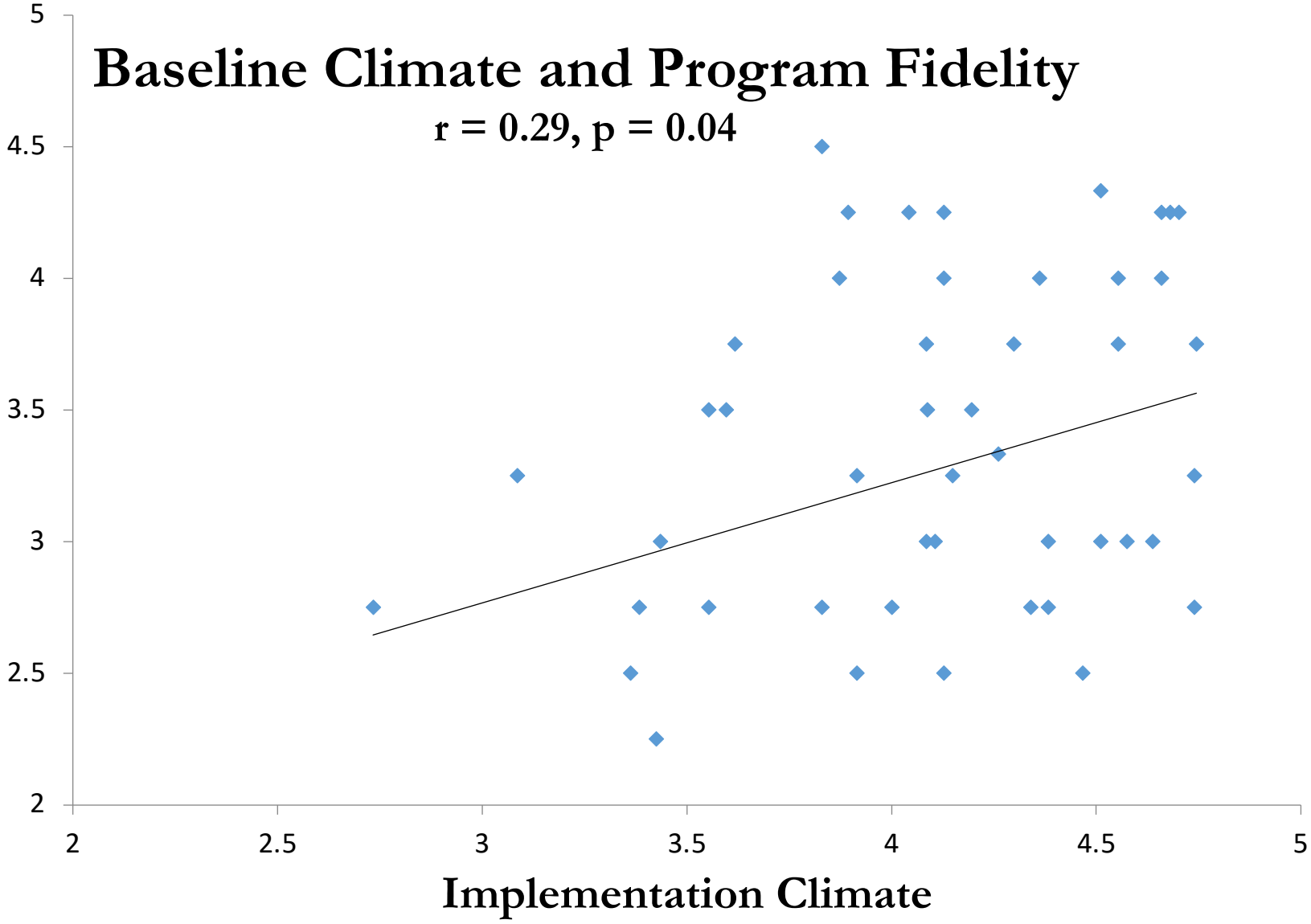

Extra training
Functional routines
Pivotal response training
New curriculum
Discrete trial
EBPs

- Their lives are hard
- They need support for new programs
- The program may not be right for their setting
- They are managing a bunch of adults as well as a bunch of kids
- These complicated interventions make their lives harder

So please make it simple!

Innovation Implementation Climate

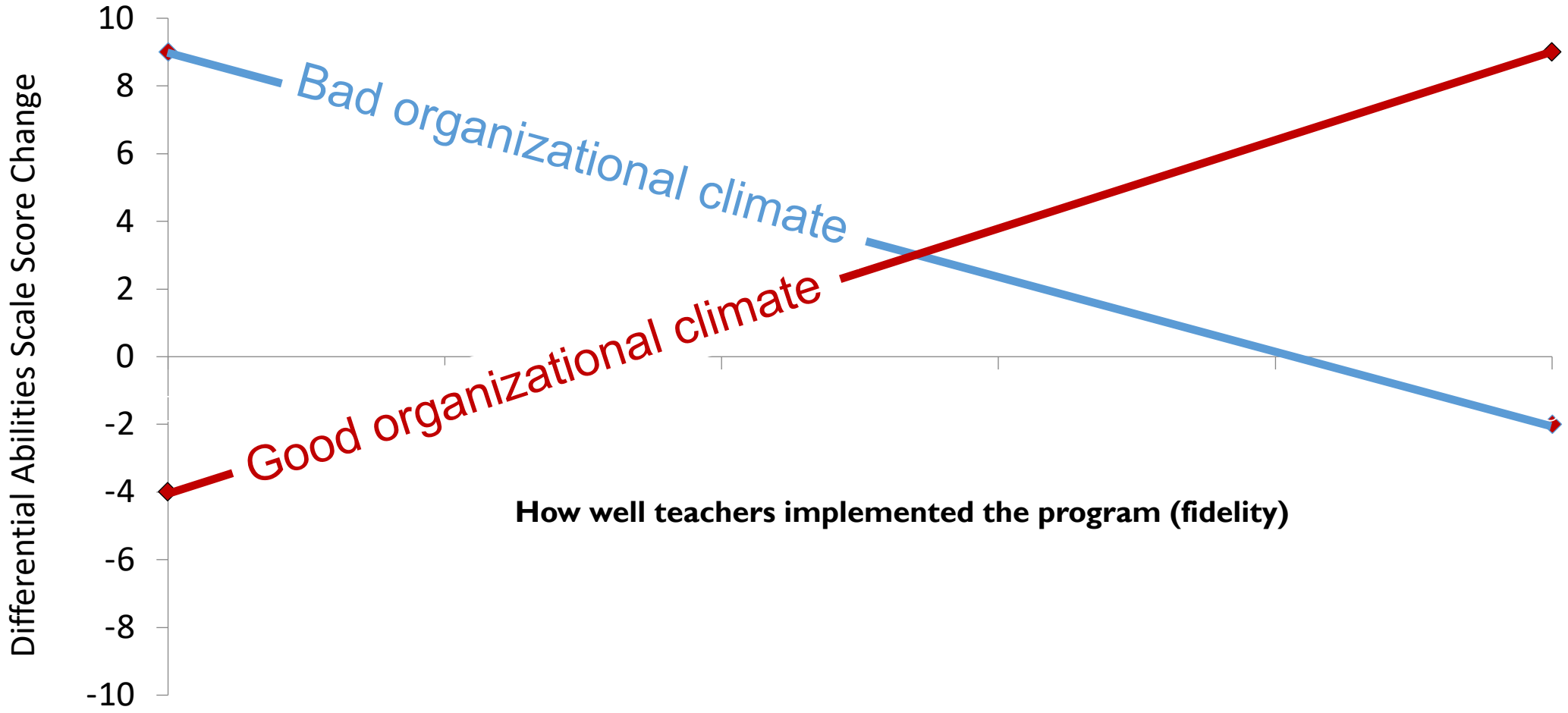
- The extent to which use of the intervention is:
  - Expected
  - Supported
  - Rewarded
- Assesses:
  - Ease of use
  - Associated stress
  - Communication about innovation
  - Support for its use



Kratz et al., 2018

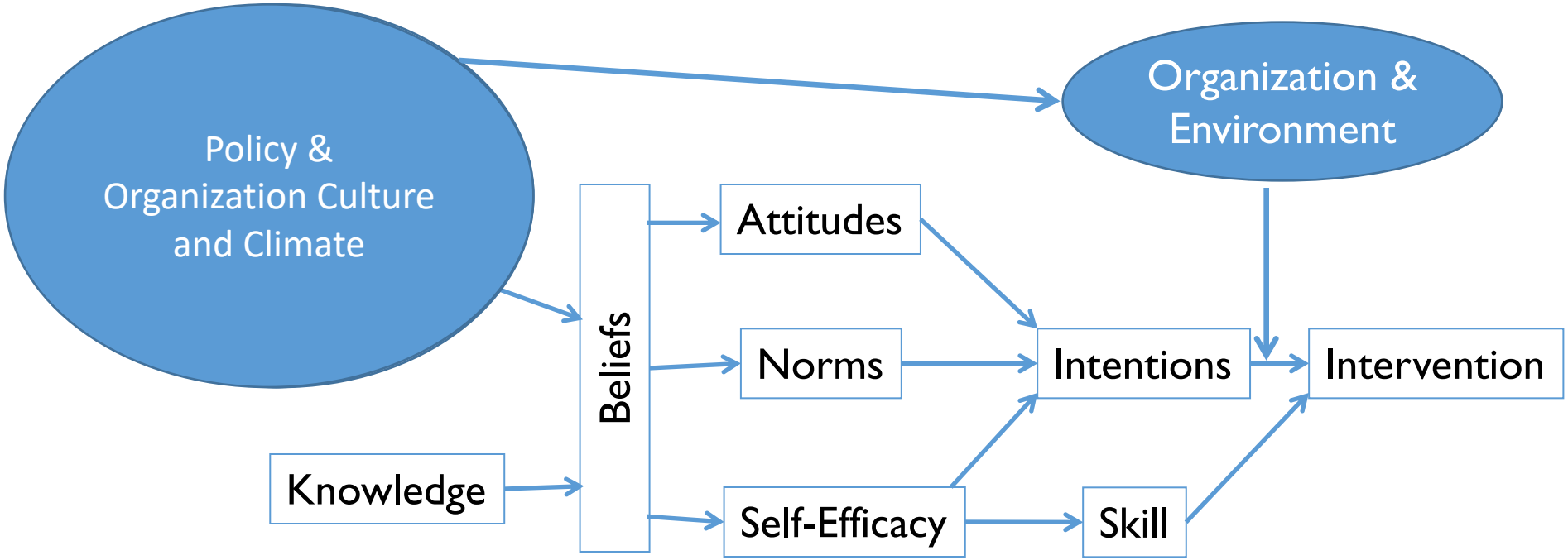
IMPLEMENTATION CLIMATE

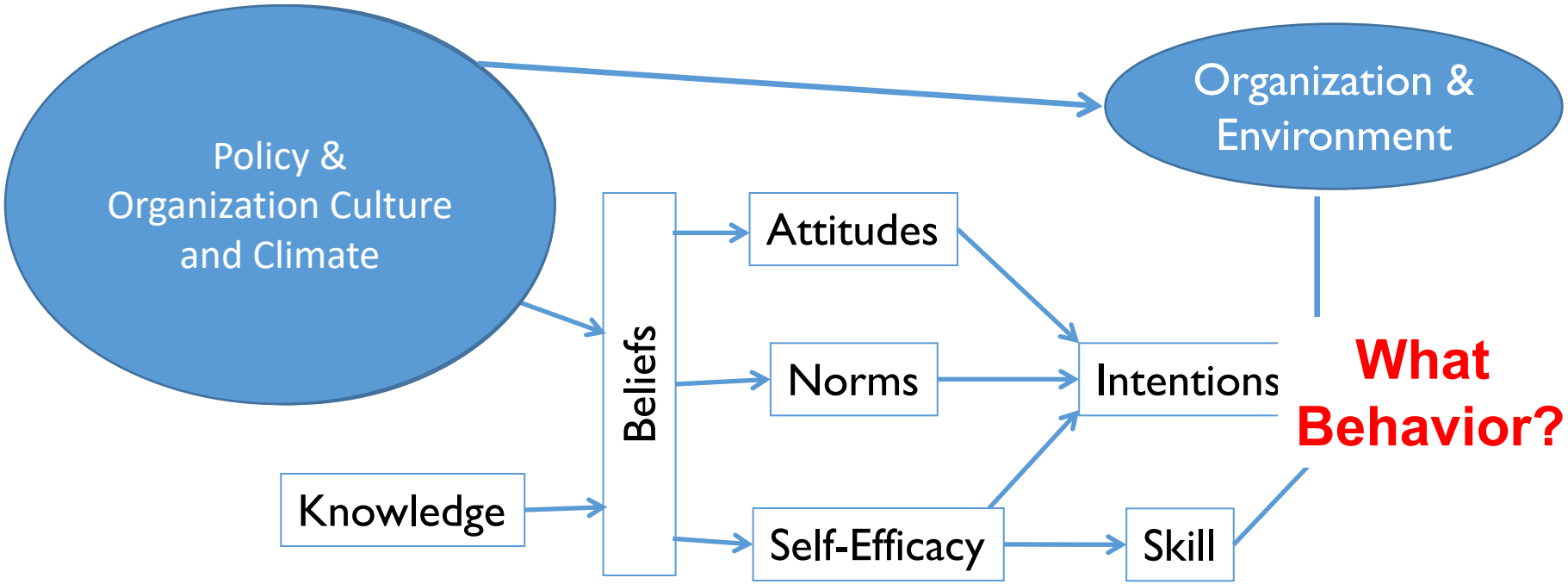
(IS USE OF THE INTERVENTION EXPECTED, SUPPORTED AND REWARDED?)



Kratz et al., 2018

APPLYING ORG. AND PSYCH. THEORIES TO TEACHER BEHAVIOR

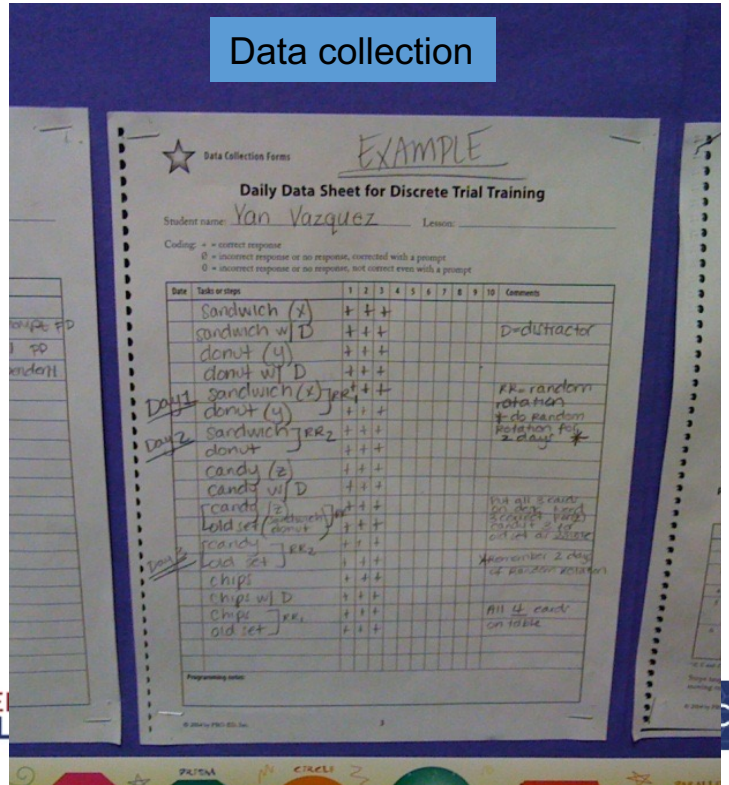



Policy &
Organization Culture
and Climate
Organization &
Environment
Beliefs
Attitudes
Norms
Knowledge
Self-Efficacy
Intentions
Skill
What
Behavior?

Visual schedules

Positive reinforcement

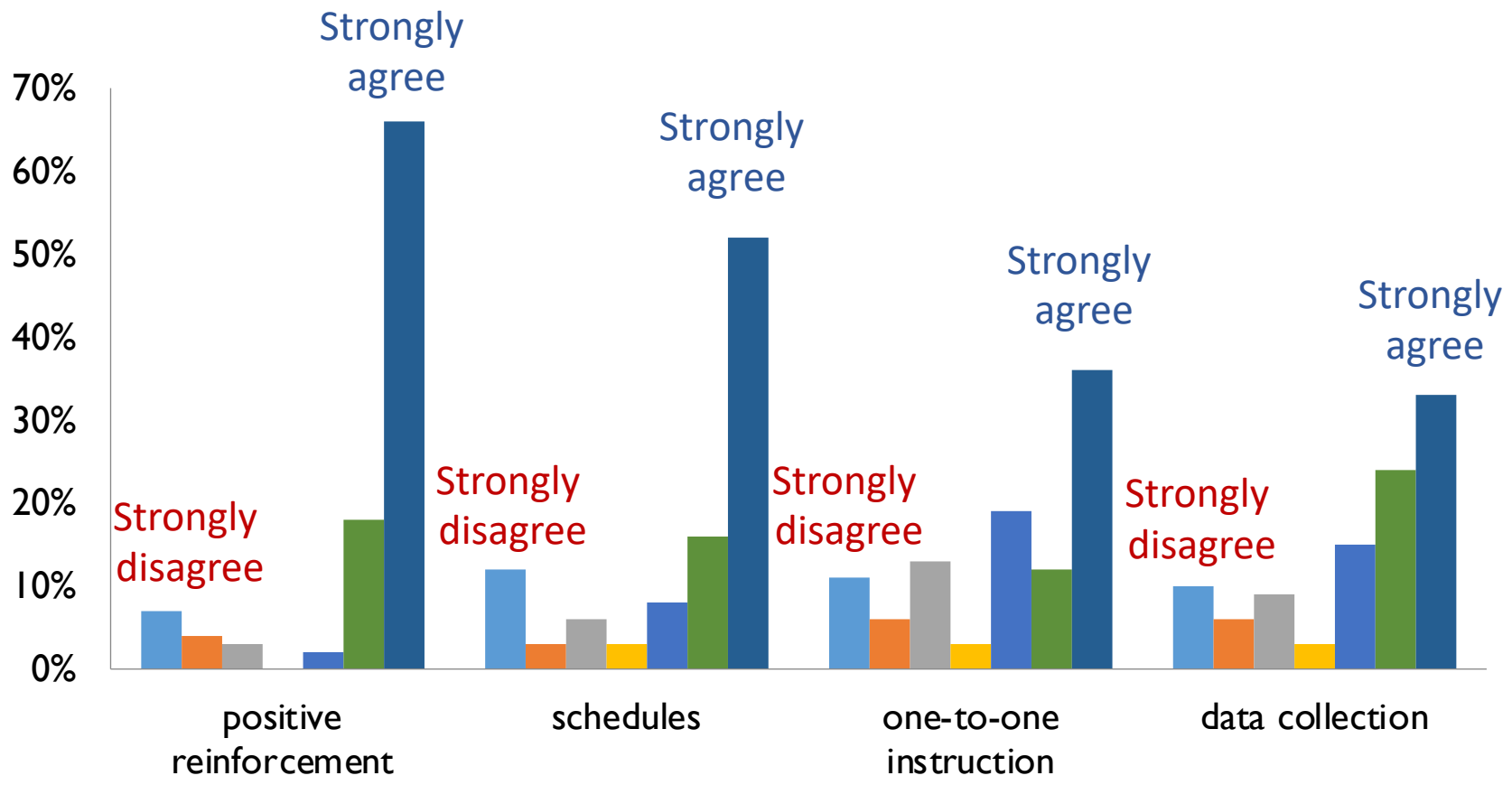
Data collection



One-to-one(?) intervention each day

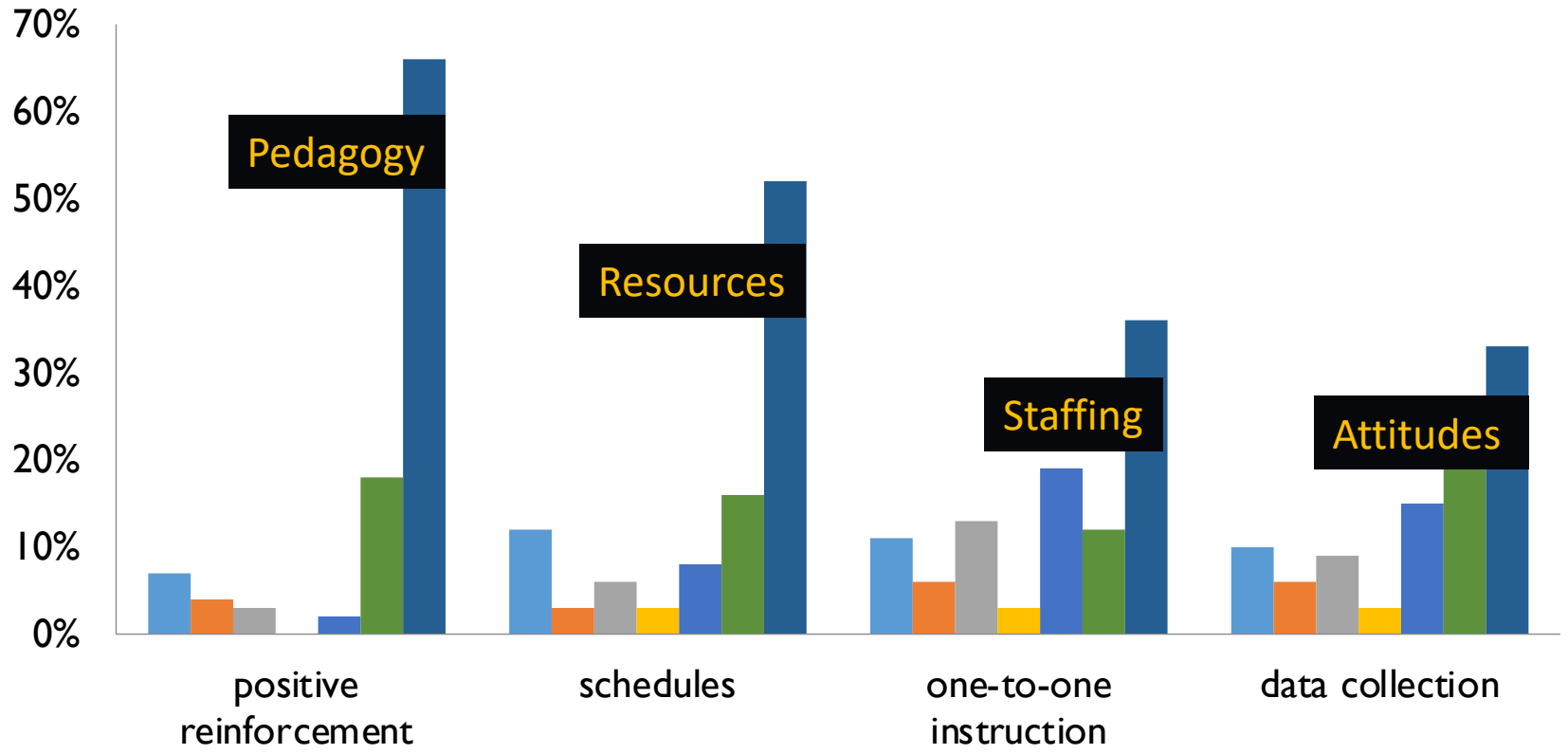
PENN CE
MENTAL
CY, PRACTIC

TEACHER'S INTENTIONS TO USE THESE PRACTICES

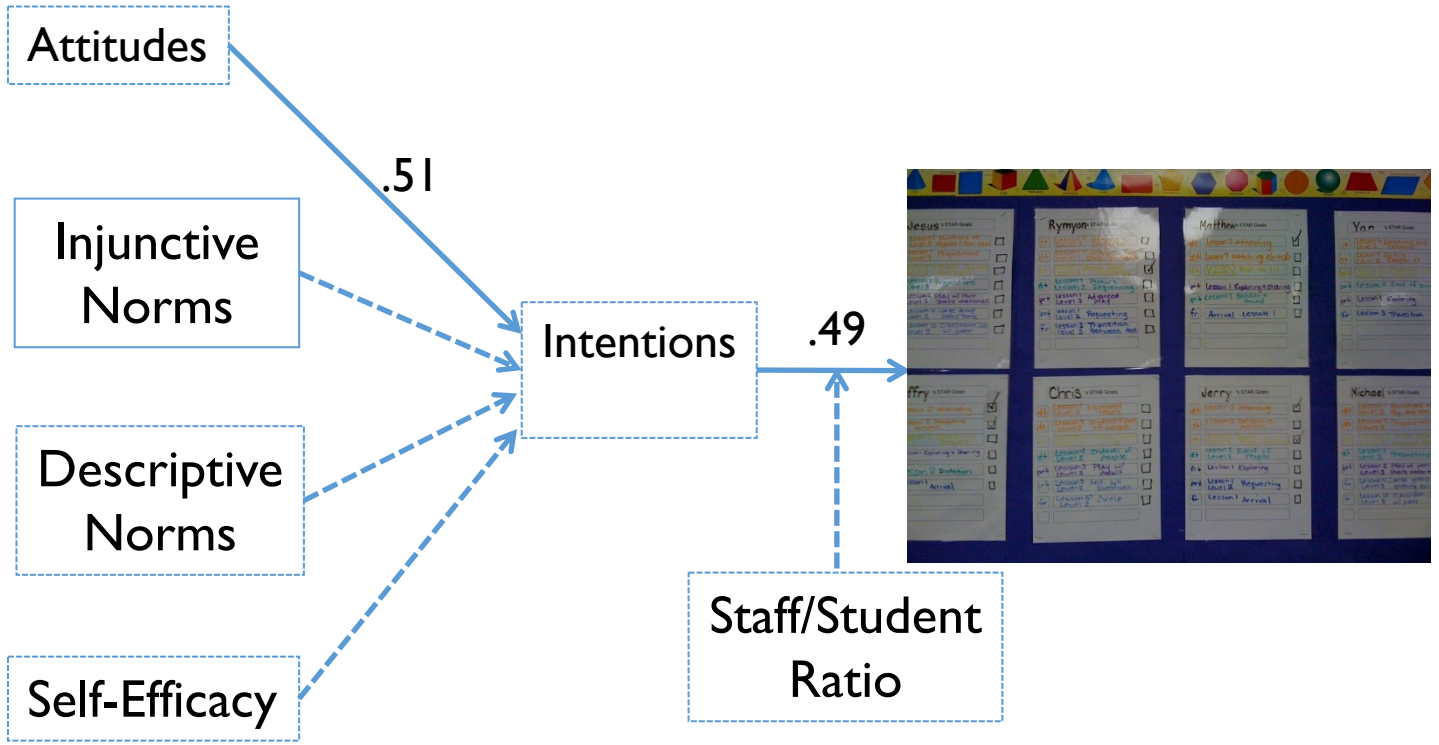


Fishman et al., 2018

WHAT WAS ASSOCIATED WITH INTENTIONS?

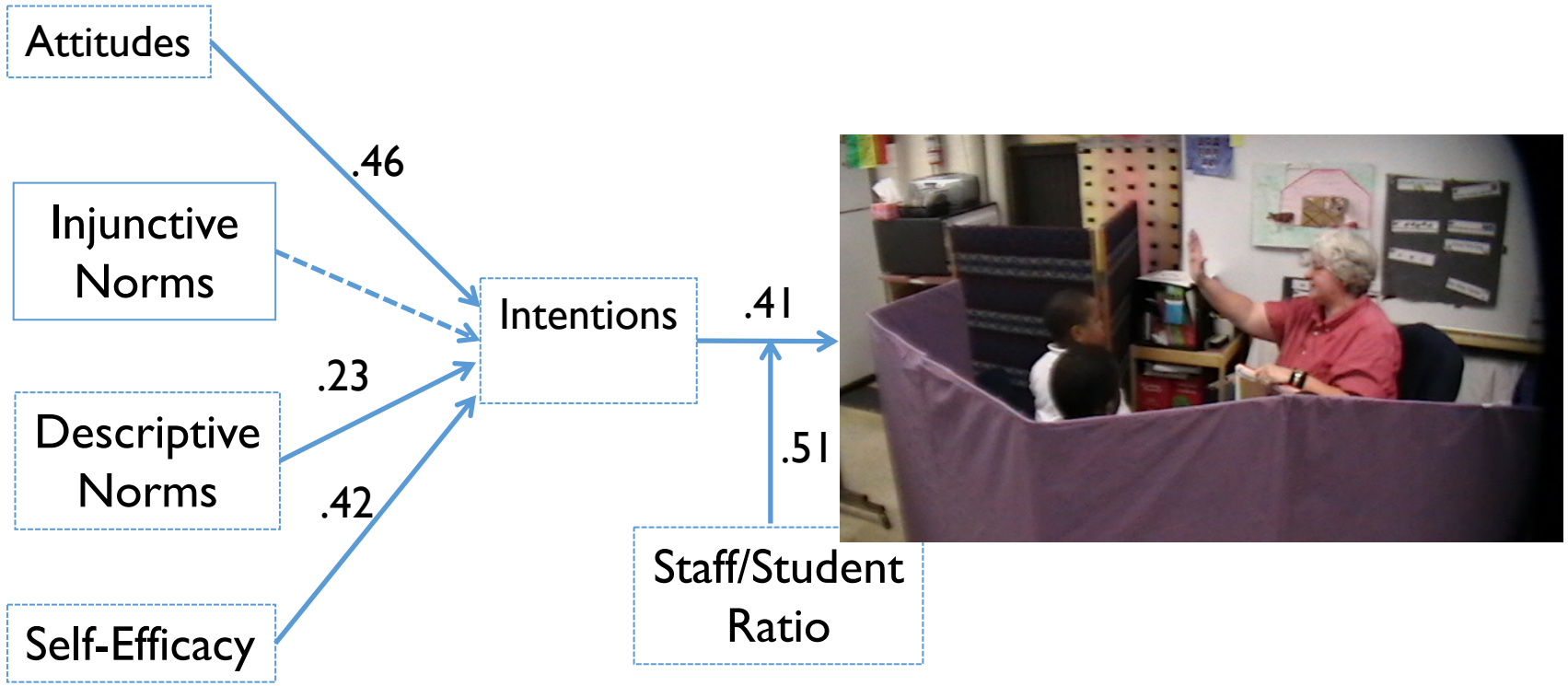


Predicting Use of Visual Schedules



Fishman et al., under review

Predicting Use of Pivotal Response Training



POLICY OPTIONS THAT LEVERAGE…

Attitudes

Position security

Performance-based ladder

Stories of success

Norms

Mandated program

Clear eval. standards

Consistent messaging

Self-Efficacy

Competency training

Ongoing coaching

Intentions → **EBP use**

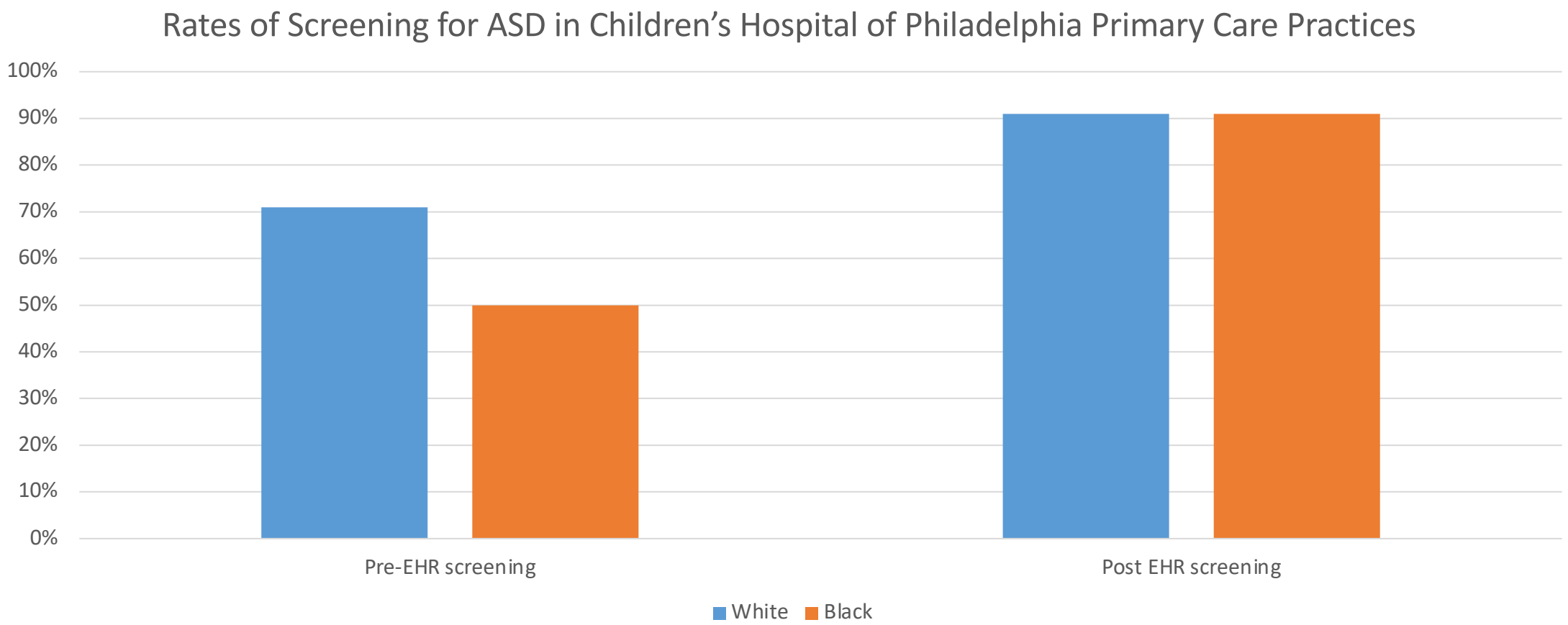
Classroom management

Staffing

Reminders

On-site problem solving

SOME ORGANIZATIONAL CHANGES ARE EASIER



Pros and cons of organizational approaches

Pros

- May result in more lasting change to practitioner behavior and child outcomes
- Some approaches (like EHR changes) may be relatively easy to implement

Cons

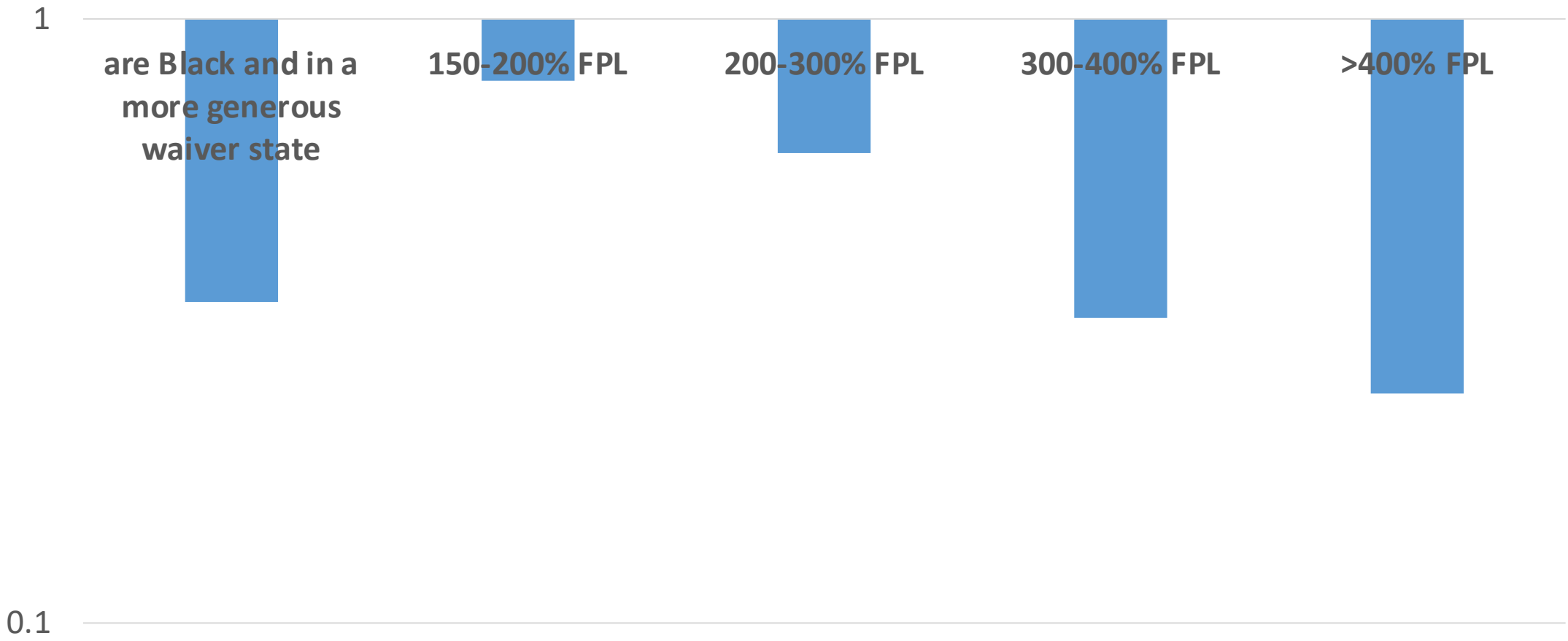
- Organizations have multiple competing priorities
- Often requires leadership change, which is challenging
- Many org strategies are complex and expensive

Policy Changes to Address Disparities

Medicaid Waivers

- Medicaid is single largest payer for behavioral health care for autistic children
- Waivers allow states to:
  - Enroll people who otherwise wouldn't be eligible
  - Provide services not included in the state plan
- 11 states have autism-specific waivers

EFFECTS OF WAIVERS AND WAIVER GENEROSITY ON ODDS OF REPORTING UNMET HEALTH CARE NEED



Pros and cons of systems approaches

Pros

- May result in even more lasting change to practitioner behavior and child outcomes
- Organizations can be creative in responding, leading to new models of care

Cons

- Requires the most political will and capital
- Must be very targeted (or else gameable)
- Results may come slowly

If we want to improve care and reduce disparities we need to...

- Use a multi-pronged approach that includes families, practitioners, organizations and policy makers
- Address environmental racism
- Find partners across disability groups
- Recognize that disparities in autism care are part of a larger legacy of disparities in health care and education.

Thank You

David.mandell@pennmedicine.upenn.edu

THE SCHOOL DISTRICT OF PHILADELPHIA

NIH National Institute of Mental Health