Racial Disparities and Social Determinants of Health in Pediatric Sickle Cell Disease

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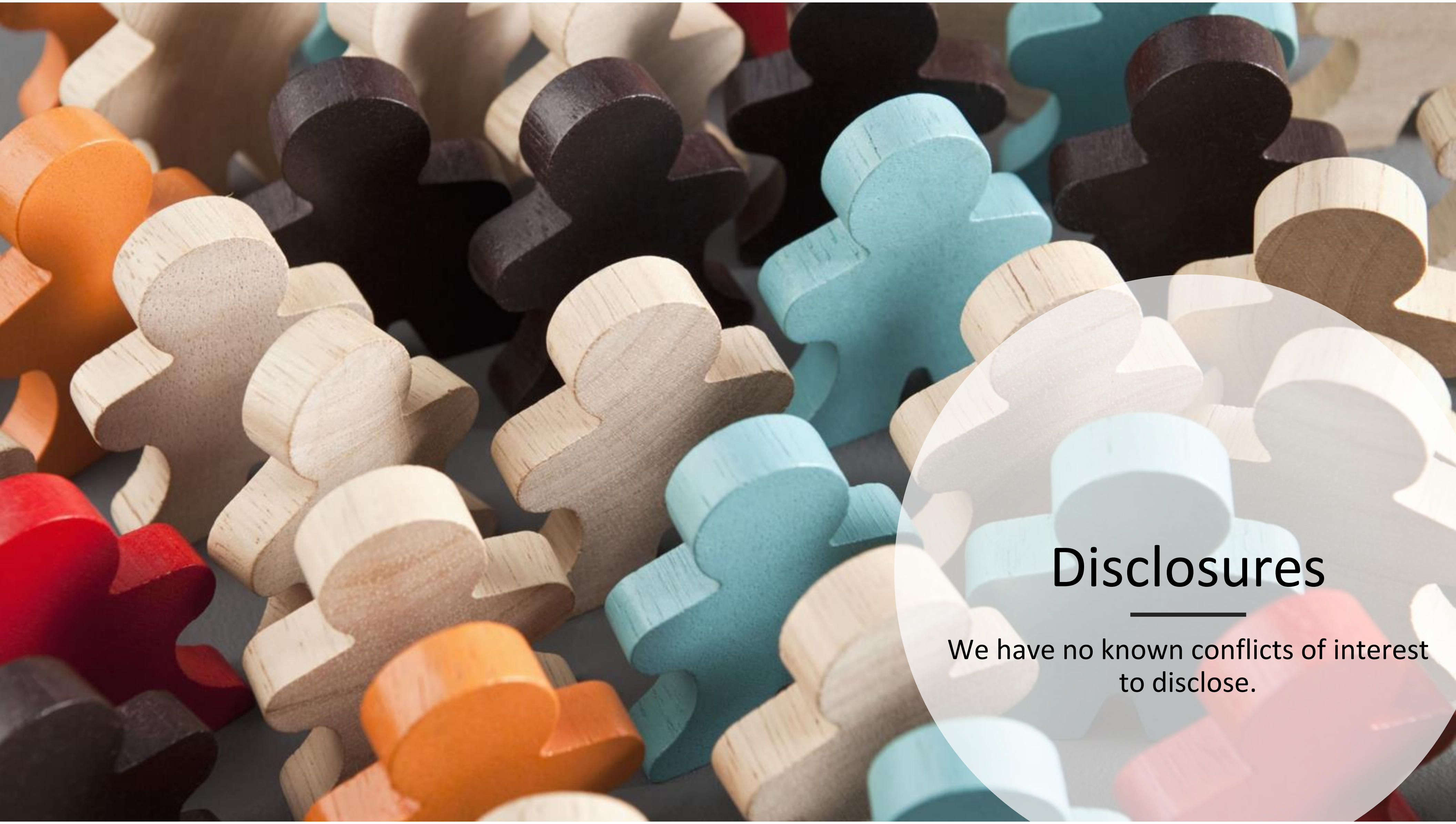


Disclosures

We have no known conflicts of interest to disclose.

Learning Objectives

Identify	Identify individual and systemic factors affecting racial disparities for children with sickle cell disease.
Explain	Explain the impact of socioeconomic factors and racism as determinants of health for children with sickle cell disease.
Discuss	Discuss the potential of social determinants of health screening within the delivery of pediatric hematology care for children with sickle cell disease.

"Of all the forms of inequality, injustice in health care is the most shocking and inhuman."
(Dr. Martin Luther King, Jr.)

Health Disparities

- Defined as differences in adverse health outcomes and health care utilization among social groups (Kim et al., 2020)

- Measured by differences in incidence, prevalence, mortality, burden of disease, and other adverse health conditions

- Racial disparites: differences are the result of one’s race or ethnicity

Race and Ethnicity

- Socially constructed categories created from prevailing social perceptions and historical policies and practices

- *“Solutions for health equity need to take into account the social, political, and historical context of race and ethnicity in this country.” (Communities in Action: Pathways to Health Equity, 2020)*

Racial Disparities in Children’s Health

PEDIATRICS®

OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

A statement of reaffirmation for this policy was published at **132(1):e281**

From the American Academy of Pediatrics Technical Report

Racial and Ethnic Disparities in the Health and Health Care of Children

Glenn Flores and THE COMMITTEE ON PEDIATRIC RESEARCH

Pediatrics April 2010, 125 (4) e979-e1020; DOI: https://doi.org/10.1542/peds.2010-0188

Racial Disparities

- In the U.S., health disparities for Black or African American youth include:
  - Mortality rates
  - Access and use of services
  - Quality of care
  - Prevention and population health
  - Adolescent health issues
  - Health status
  - Asthma prevalence
  - Special health care needs
  - Mental health care

(Flores, 2010)

Health Disparities in SCD

- Poor disease outcomes
- Limited access to specialized and disease-specific preventative care
- Barriers to effective pain treatment
- Higher mortality rate

(Lee et al., 2019)

Racial Disparities in SCD

Patients and families report that *race affects the quality of health care* for sickle cell patients (Nelson & Hackman, 2012)

Perceived racism predicts *depression, accelerated aging, and poorer quality of life* (Carter et al., 2019; Wakefield et al., 2017)

Pain management documented as *underestimated and undertreated* (Campbell et al., 2010)

25% longer wait times in ED *explained by African American race* (Haywood et al., 2013)

- 50% longer wait times compared to long bone fractures *after accounting for race*

Sources of Racial Disparities

Patient factors:

- Adherence, self-care, lifestyle
- Language and literacy
- Mistrust*

Provider factors:

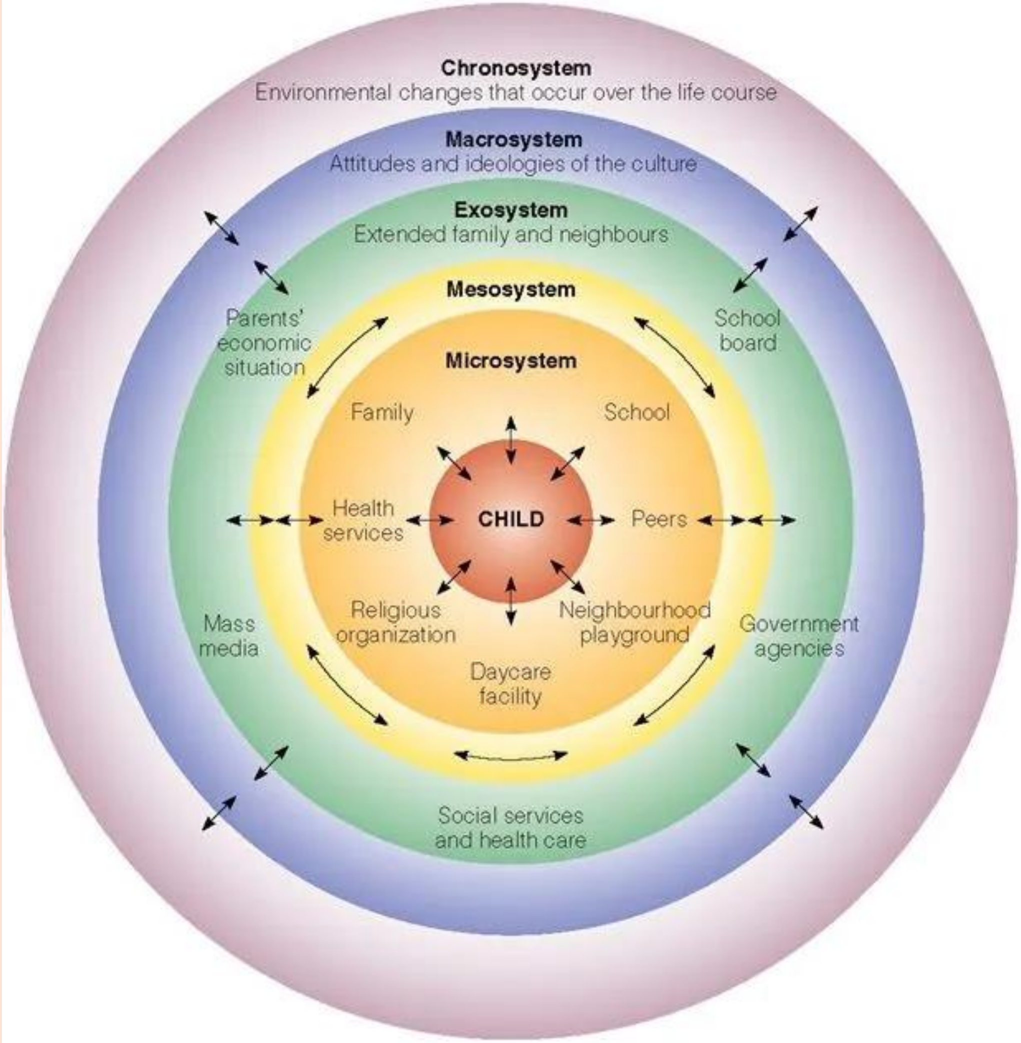
- Implicit bias
- Labeling of patients and language barriers
- Overt racism

Systemic factors:

- Poor access, time constraints, hospital setting (public vs. private), lack of a diverse workforce and interpreters
- Poverty, discrimination, structural racism

(Gollust et al., 2018)

Bronfenbrenner Model (1979)



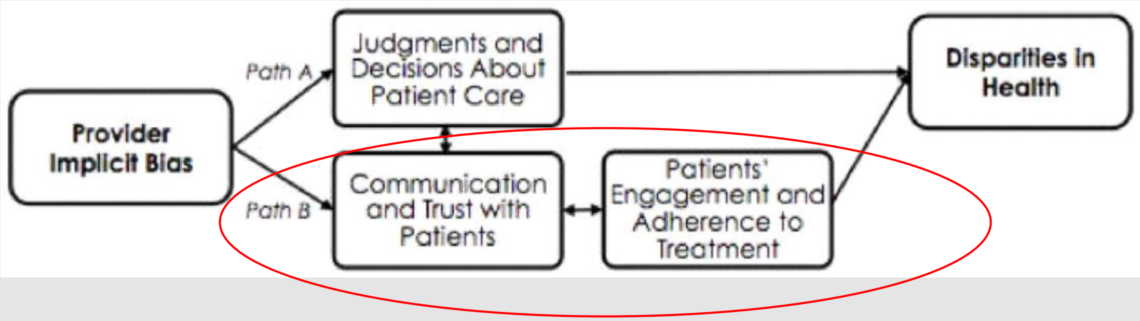
Individual Factors: Provider Implicit Bias

Identified by the Institute of Medicine as a source of health disparities among racial and ethnic minorities (Nelson, 2002).

Recent systematic and narrative reviews found that health care providers exhibit similar levels of implicit bias as the general population and clinical decision-making may be influenced by implicit bias (Maina et al., 2018).

These findings extend to pediatric health care and racial/ethnic minority youth (Raphael & Oyeku, 2020).

Proposed Pathway (Path B)



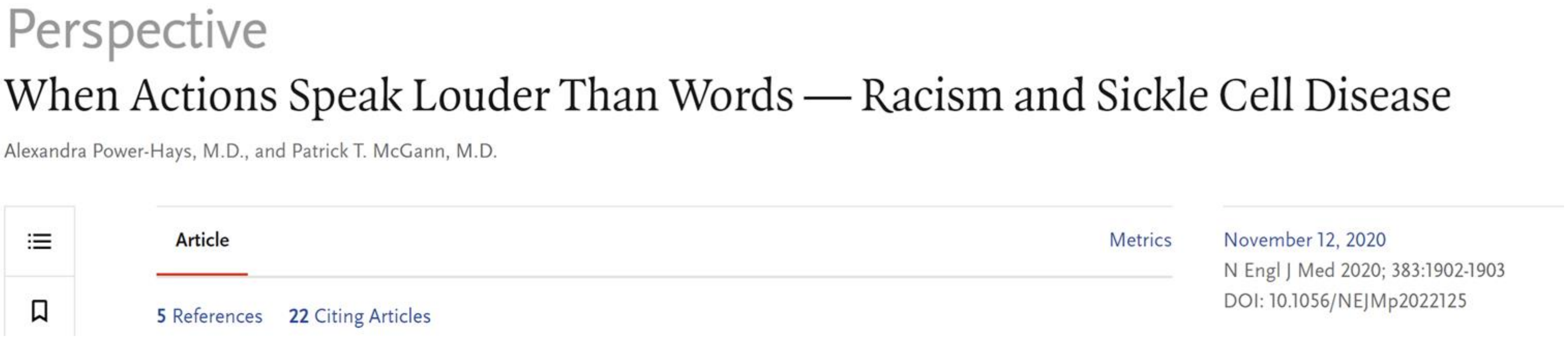
(Zestcott et al., 2016)

Interventions to Address Implicit Bias

- Individuation
- Perspective-taking
- Counter-steotyping
- Implicit Bias Reduction and Management and Transformative Learning Theory

(Javeed et al,, 2020; Zestcott et al., 2017)

Systemic Factors: Structural Racism



Perspective

When Actions Speak Louder Than Words — Racism and Sickle Cell Disease

Alexandra Power-Hays, M.D., and Patrick T. McGann, M.D.

Article

Metrics

5 References 22 Citing Articles

November 12, 2020
N Engl J Med 2020; 383:1902-1903
DOI: 10.1056/NEJMp2022125

“Although SCD was first described more than 100 years ago, the development of disease-modifying therapies has stagnated because of inadequate research funding, attributable at least in part to structural racism.” (Power-Hays & McGann, 2020)

Original Investigation | Health Policy

March 27, 2020

Comparison of US Federal and Foundation Funding of Research for Sickle Cell Disease and Cystic Fibrosis and Factors Associated With Research Productivity

Faheem Farooq, MD[1]; Peter J. Mogayzel, MD, PhD[2]; Sophie Lanzkron, MD[3]; et al

» Author Affiliations | Article Information

JAMA Netw Open. 2020;3(3):e201737. doi:10.1001/jamanetworkopen.2020.1737

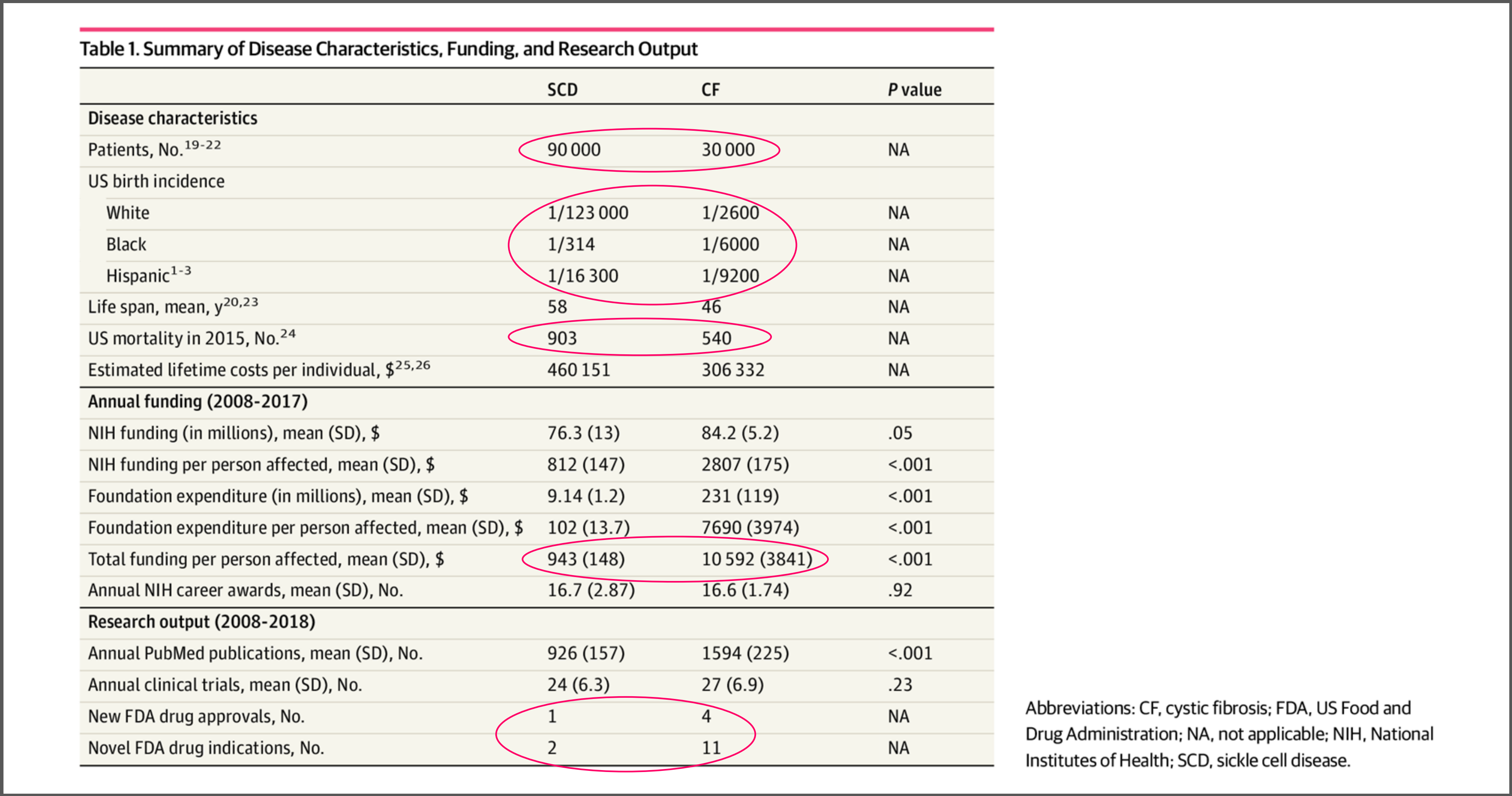


Table 1. Summary of Disease Characteristics, Funding, and Research Output

	SCD	CF	*P* value
Disease characteristics			
Patients, No.[19-22]	90 000	30 000	NA
US birth incidence			
White	1/123 000	1/2600	NA
Black	1/314	1/6000	NA
Hispanic[1-3]	1/16 300	1/9200	NA
Life span, mean, y[20,23]	58	46	NA
US mortality in 2015, No.[24]	903	540	NA
Estimated lifetime costs per individual, $[25,26]	460 151	306 332	NA
Annual funding (2008-2017)			
NIH funding (in millions), mean (SD), $	76.3 (13)	84.2 (5.2)	.05
NIH funding per person affected, mean (SD), $	812 (147)	2807 (175)	<.001
Foundation expenditure (in millions), mean (SD), $	9.14 (1.2)	231 (119)	<.001
Foundation expenditure per person affected, mean (SD), $	102 (13.7)	7690 (3974)	<.001
Total funding per person affected, mean (SD), $	943 (148)	10 592 (3841)	<.001
Annual NIH career awards, mean (SD), No.	16.7 (2.87)	16.6 (1.74)	.92
Research output (2008-2018)			
Annual PubMed publications, mean (SD), No.	926 (157)	1594 (225)	<.001
Annual clinical trials, mean (SD), No.	24 (6.3)	27 (6.9)	.23
New FDA drug approvals, No.	1	4	NA
Novel FDA drug indications, No.	2	11	NA

Abbreviations: CF, cystic fibrosis; FDA, US Food and Drug Administration; NA, not applicable; NIH, National Institutes of Health; SCD, sickle cell disease.

CF and SCD

- Both are inherited, progressive, life-threatening disease associated with decreased quality of life and shortened life span

- CF:
  - ○ Primarily affects White Americans
  - ○ Affects one third **fewer** Americans than SCD
  - ○ Receives **7-11 times more research funding per patient** than SCD
  - ○ FDA approved **3** medications for SCD and **15** for CF

(Farooq et al., 2020)

POLICY STATEMENT Organizational Principles to Guide and Define the Child Health Care System and/or Improve the Health of all Children

American Academy of Pediatrics

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The Impact of Racism on Child and Adolescent Health

Maria Trent, MD, MPH, FAAP, FSAHM,[a] Danielle G. Dooley, MD, MPhil, FAAP,[b] Jacqueline Dougé, MD, MPH, FAAP,[c] SECTION ON ADOLESCENT HEALTH, COUNCIL ON COMMUNITY PEDIATRICS, COMMITTEE ON ADOLESCENCE

Racism

Racism is a core SDOH and driver of health inequity

Forms of Racism:

- Institutional/structural
- Personally mediated
- Internalized

Negative impact on health and well-being

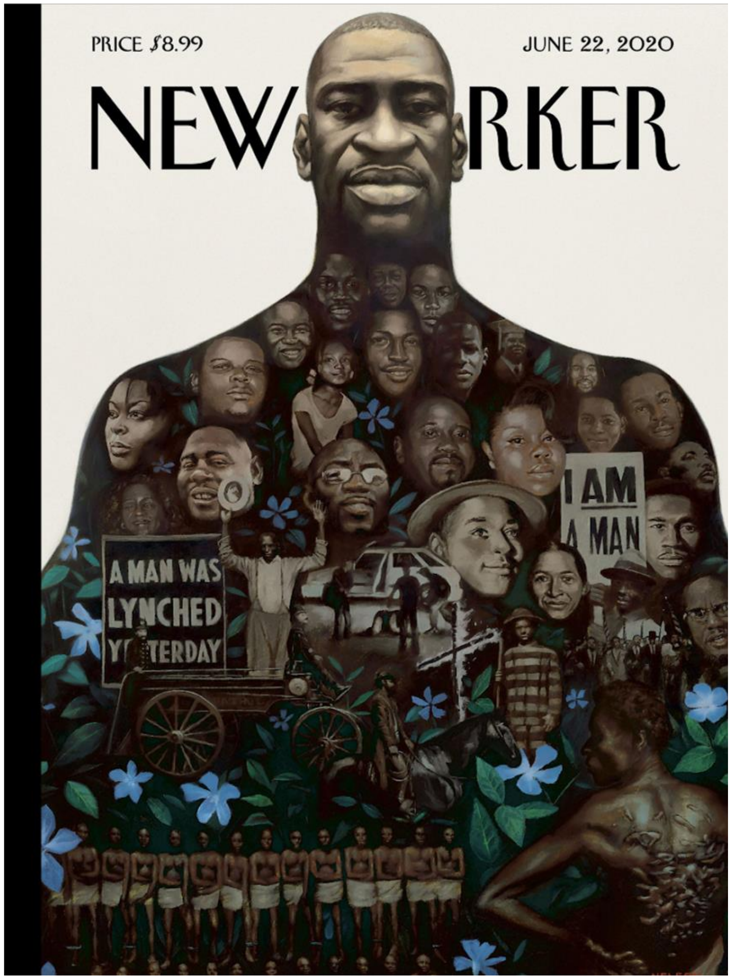
- e.g., birth disparities, detrimental mental health

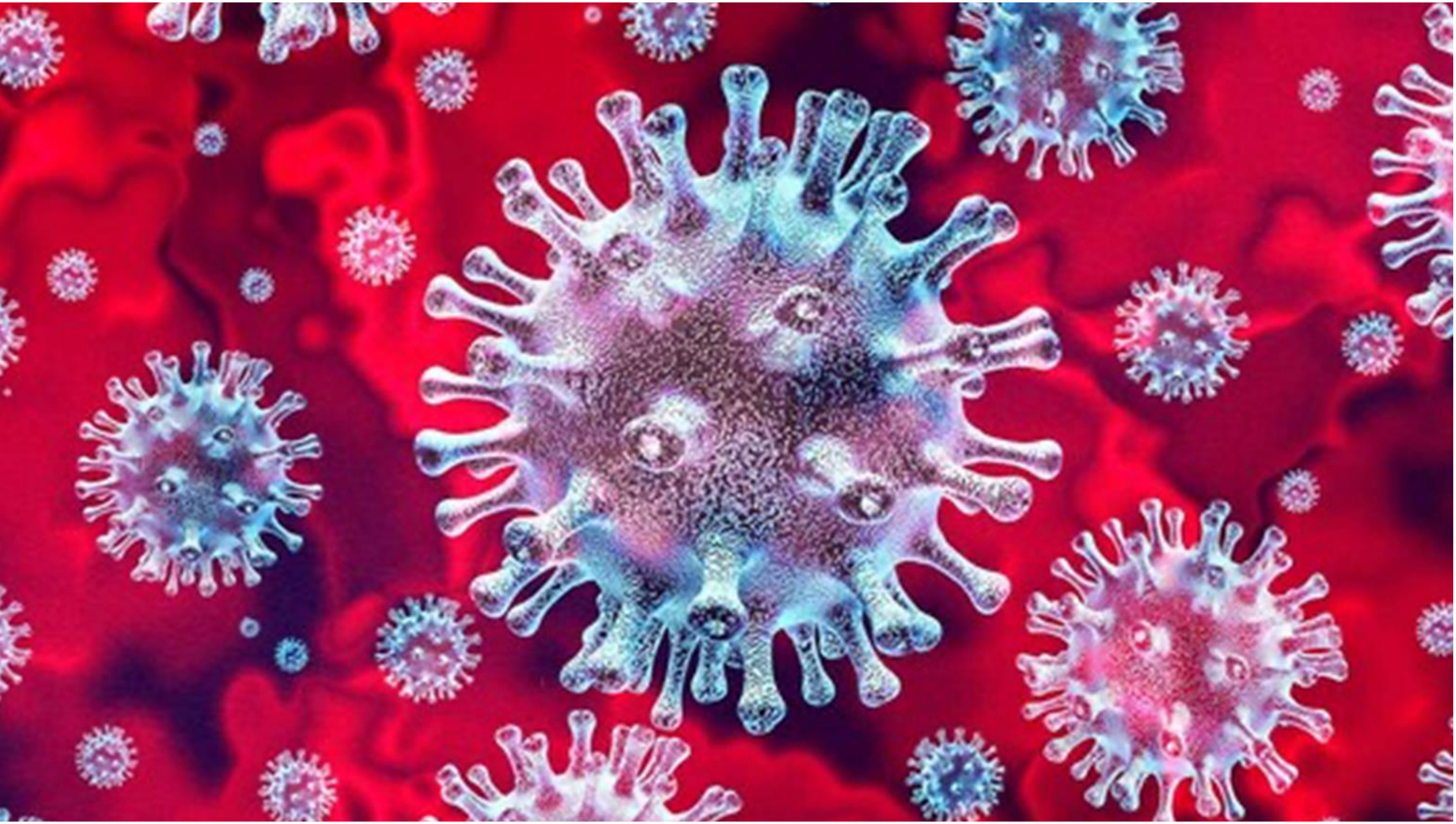
Source: Trent M et al. *Pediatrics*. 2019.

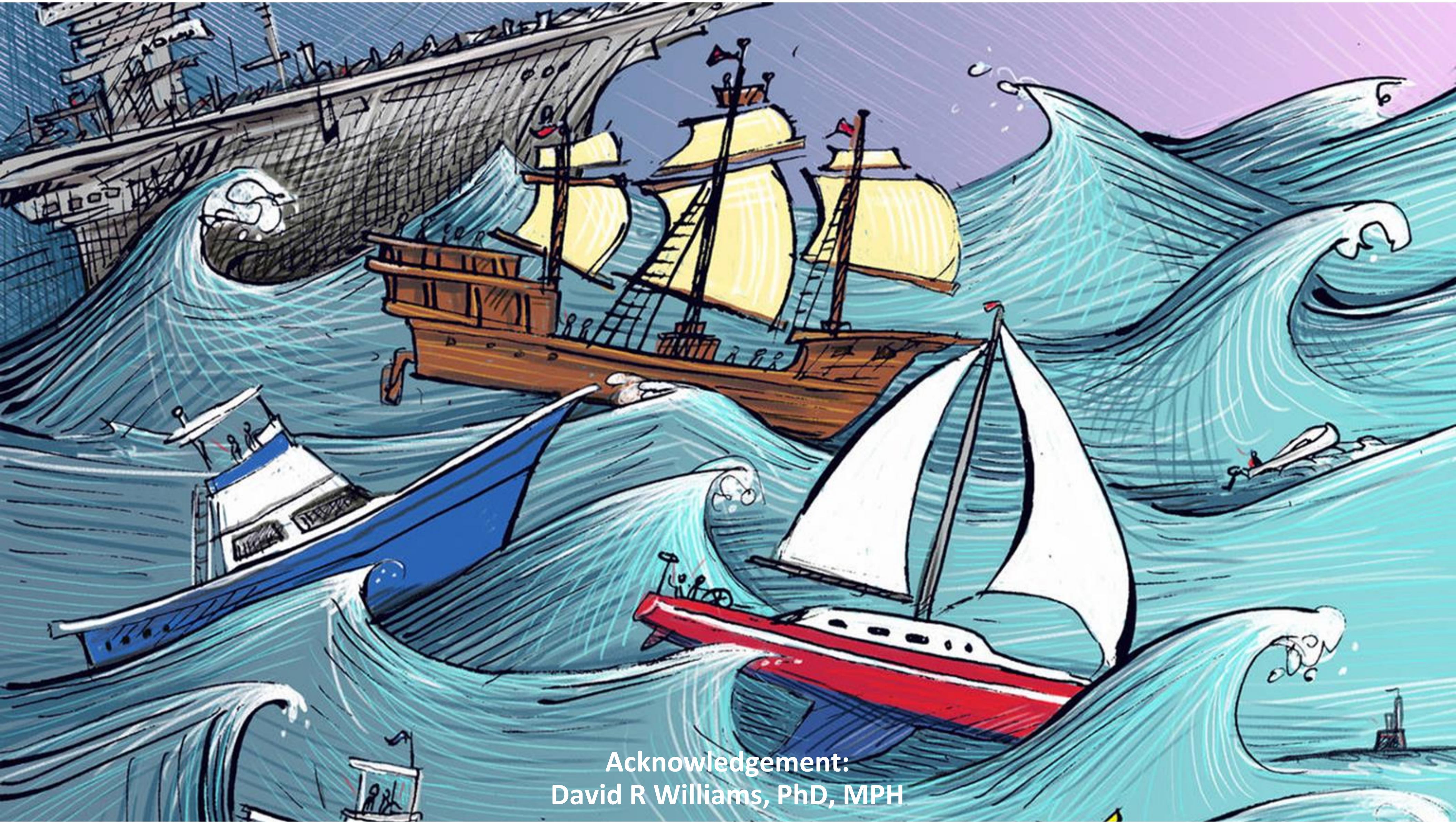
Racial and Social Injustice

“We must act now to strengthen the immunity of our societies against the virus of hate.”

- United Nations Secretary-General Antonio Guterres





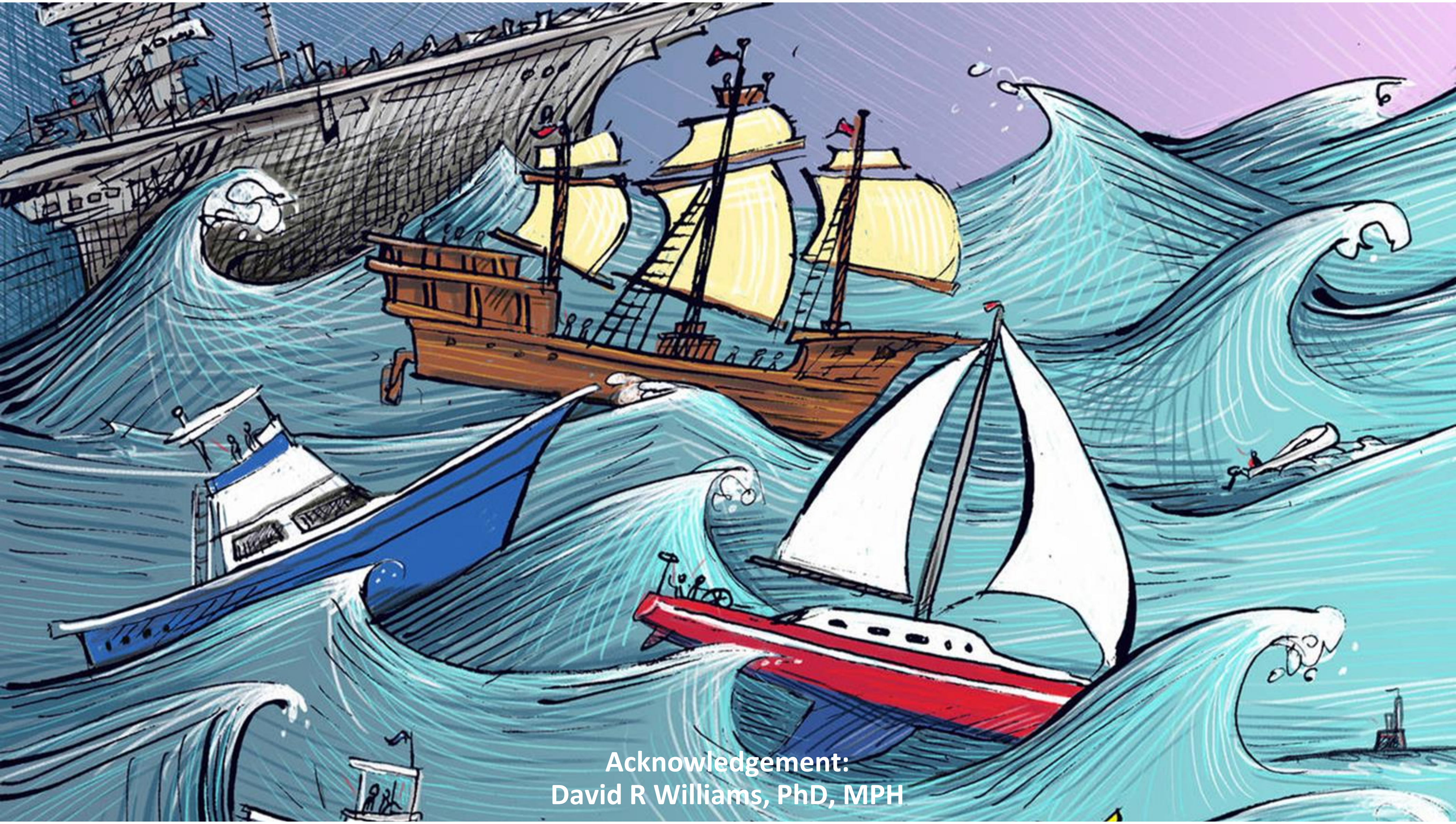


Acknowledgement:
David R Williams, PhD, MPH

COVID-19: Socioeconomic and Racial Disparities among Children

Child Economic Status/Race	Percent (%)	AOR
Low-income	**38%**	**2.1**
High-income	**9%**	**ref**
Hispanic	**46%**	**1.9**
Black	**30%**	**2.3**
White	**7%**	**ref**

Source: Goyal MK et al. *Pediatrics*. 2020. Aug 5.



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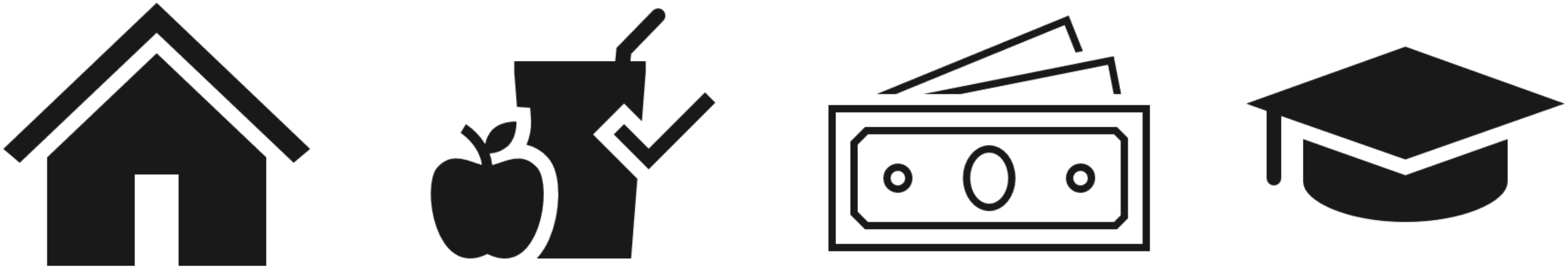


Sturdiness of Boats

=

Social Determinants of Health

Social Determinants of Health

The circumstances in which people are born, grow, live, work and age. These circumstances are shaped by the distribution of money, power, and resources at global, national, and local levels.

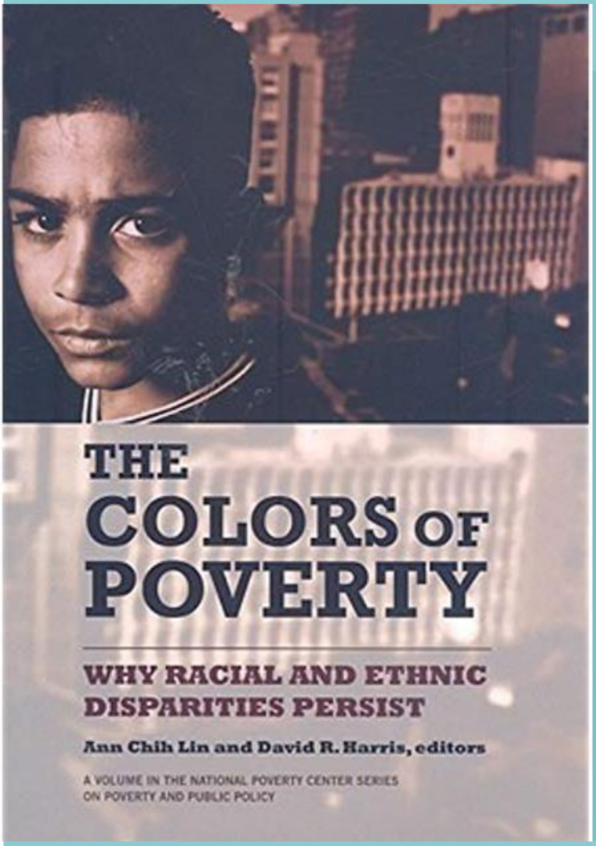
World Health Organization

Structural Racism: The Root Cause of the Social Determinants of Health

September 22, 2020 The Petrie-Flom Center Staff Blog Symposia, Criminal Law, Doctor-Patient Relationship, Featured, Health Law Policy, History, Medical Quality, Patient Care, Public Health, Race, Social Determinants of Health, Understanding the Role of Race in Health

Racial/Ethnic Disparities Persist

- Disparities in resources and educational opportunities
- Public policies (e.g., housing, education, crime)
- Ethos of rugged individualism in U.S. erodes support for anti-poverty programs



THE
COLORS OF
POVERTY

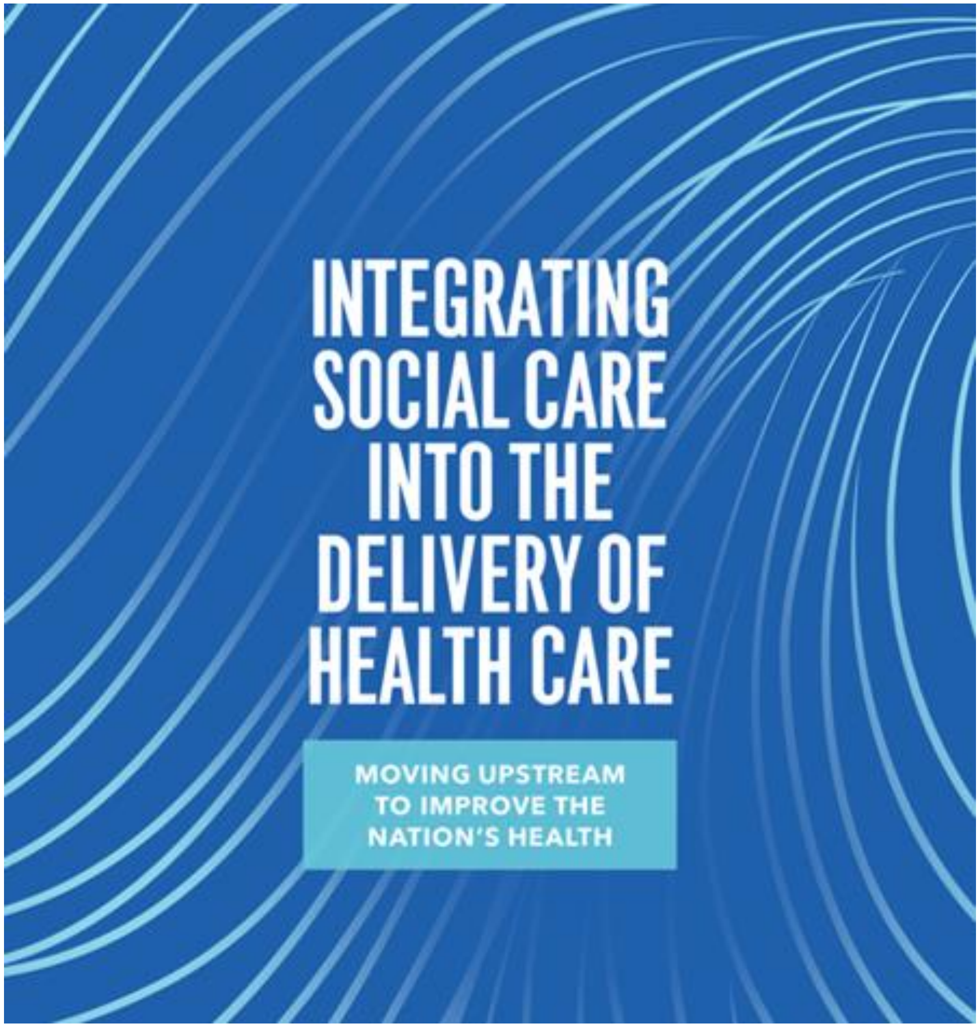
WHY RACIAL AND ETHNIC
DISPARITIES PERSIST

Ann Chih Lin and David R. Harris, editors

A VOLUME IN THE NATIONAL POVERTY CENTER SERIES
ON POVERTY AND PUBLIC POLICY

Integrate Effective Empathetic Social Care into HealthCare

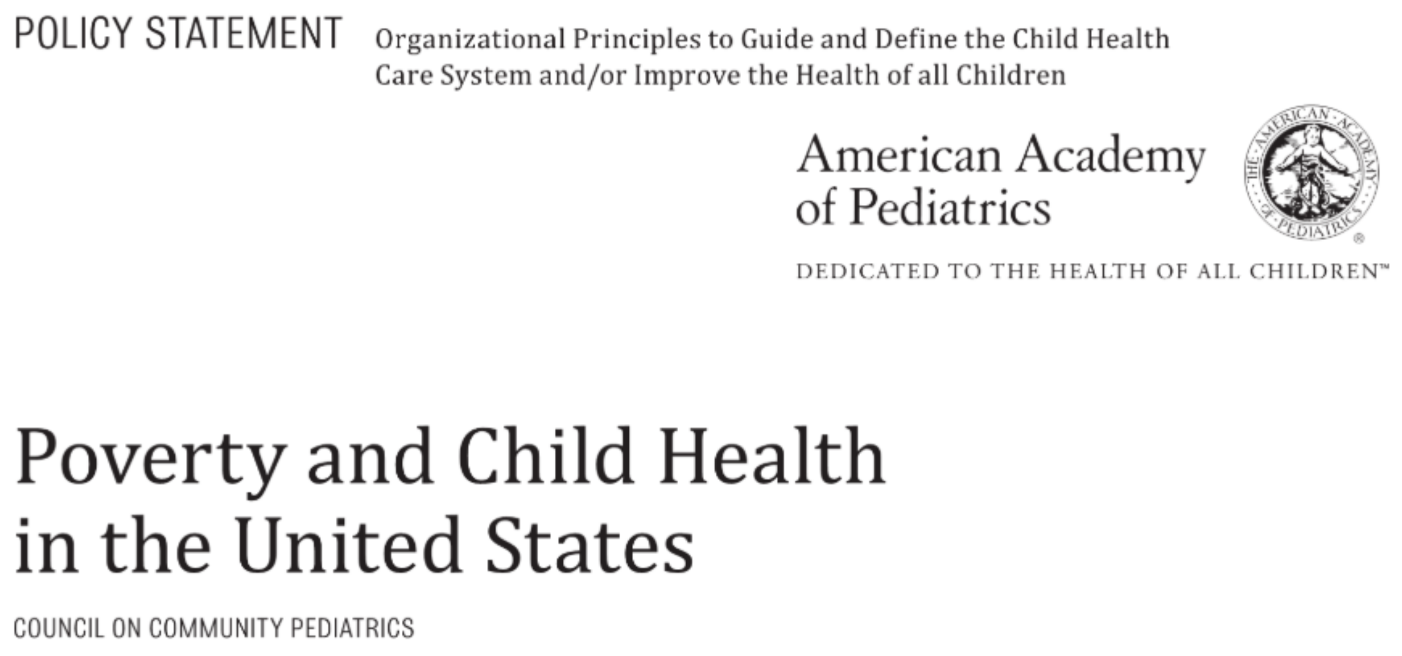
Source: Poverty and Child Health in the United States. Council on Community Pediatrics. *Pediatrics*. 2016.



INTEGRATING SOCIAL CARE INTO THE DELIVERY OF HEALTH CARE

MOVING UPSTREAM TO IMPROVE THE NATION'S HEALTH

AAP Recommendations on SDoH Screening



POLICY STATEMENT Organizational Principles to Guide and Define the Child Health Care System and/or Improve the Health of all Children

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Poverty and Child Health in the United States

COUNCIL ON COMMUNITY PEDIATRICS

AAP Recommendations

- Screen for risk factors within **social determinants of health** during patient encounters
- Either brief written screener or verbally ask family member questions about their basic needs
- As patient-centered medical homes develop, care coordinators may connect families in poverty with resources

Poverty and Child Health in the United States.
Council on Community Pediatrics. *Pediatrics*. 2016.

Medicaid SDOH Policies

Managed Care Organizations in 30 states

- Encouraging screening for social needs and providing social services referrals

Medicaid ACOs

- Requiring SDOH intervention (e.g., housing)
- Health-related social needs screening as a quality measure

Well Childcare Visits

Evaluation

Community Resources

Advocacy

Referral

Education

My Fellowship Study

- **WE CARE** intervention increased the discussion and referral **(51% vs 12%)** of adverse social determinants of health at low-income children’s WCC visits

Source: Garg A et al. *Pediatrics*. 2007;120;547-558. Funded by: The Commonwealth Fund

Cluster RCT

Study Design: Cluster randomized controlled trial (RCT)

Setting: 8 health centers (CHCs) in Boston

Garg A et al. *Pediatrics*. 2015;132(2);e296-304.

Funded by: NICHD

Grant no. R00HD056160

Intervention Components: WE CARE

- Survey Instrument
- Family Resource Book
- Provider Training
- Follow Up

Component 1: WE CARE Survey

- ✓ Completed prior to WCC visits
- Self-report
- Screened for 6 basic needs

Childcare

Education
(<high school)

Employment

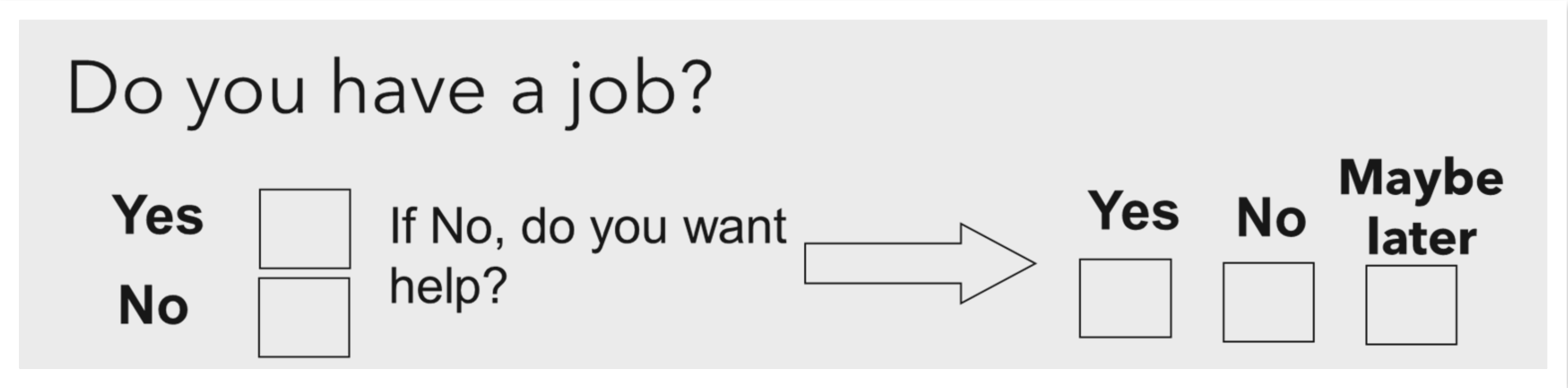
Food Security

Household heat

Housing

WE CARE Survey Instrument

- Self-report
- **Each topic:** 2 questions to screen for problem and identify motivation to address it
  - **Example:** Unemployment



Do you have a job?

Yes ☐

No ☐

If No, do you want help? ⇨

Yes	**No**	**Maybe later**
☐	☐	☐

Component 2:
Family Resource Book

CONTAINED 1 PAGE TEAR-OUT INFORMATION SHEETS FOR EACH BASIC NEED

LISTS 2-4 COMMUNITY RESOURCES AND CONTACT INFORMATION

AVAILABLE IN ALL EXAM ROOMS

Unmet Basic Needs at Baseline

Of all families (n=336):

≥1 need

90%

≥2 needs

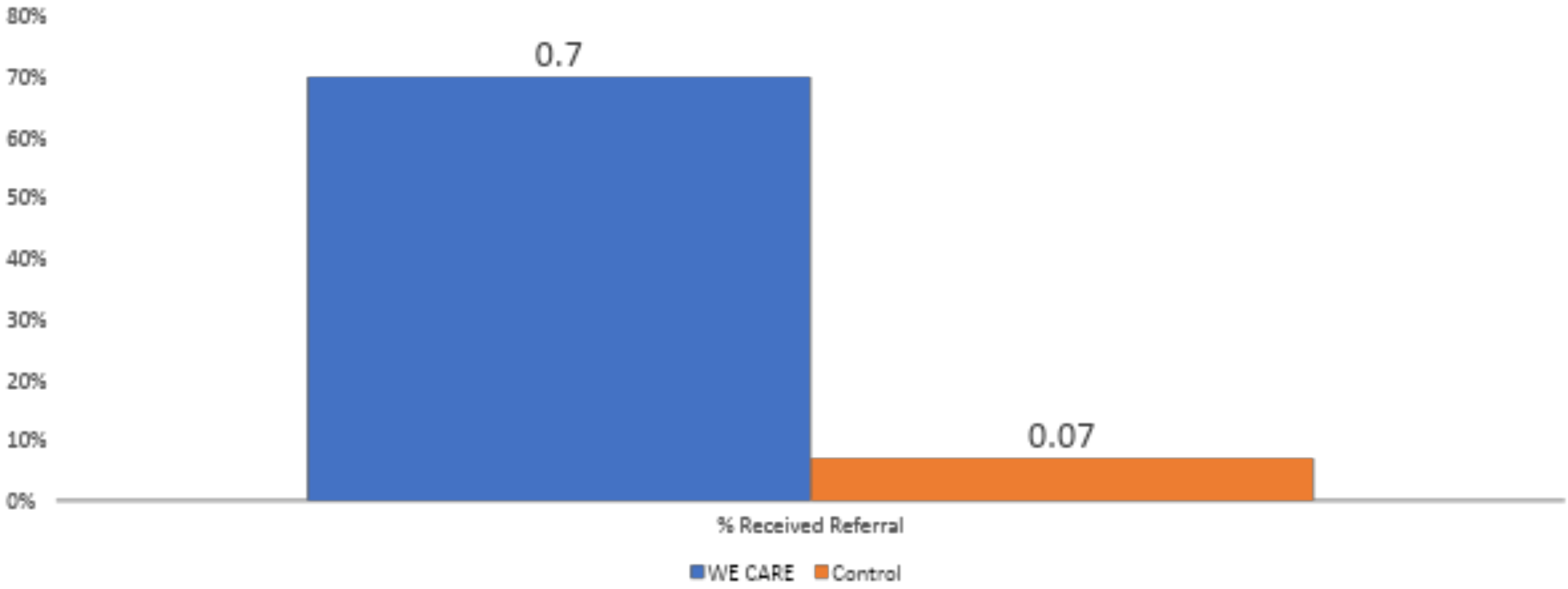
68%

≥3 needs

39%

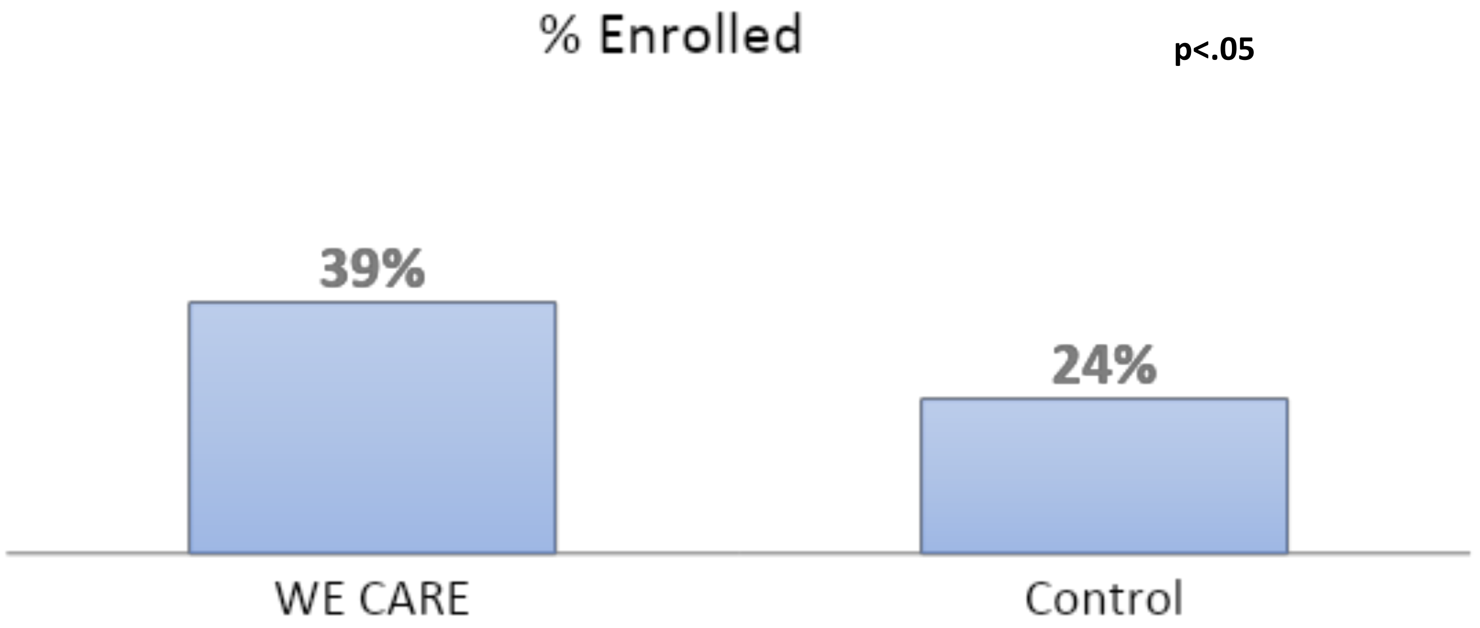
Source: Garg, Arvin, et al. “Addressing social determinants of health at well child care visits: a cluster RCT.” *Pediatrics* 135.2 (2015): e296-e304.

Referrals Received at WCC Visit



Source: Garg, Arvin, et al. 2015. 135.2: e296-e304.

Enrollment in Resources at F/U



Source: Garg, Arvin, et al. “Addressing social determinants of health at well child care visits: a cluster RCT.” *Pediatrics* 135.2 (2015): e296-e304.

Enrollment in Resources

Resources	WE CARE (n=136)	Control (n=135)	aOR (95% CI)
Any new resource	39%	24%	1.6 (1.1-2.5)
Childcare	15%	7%	3.3 (1.1-9.3)
Food assistance	11%	9%	0.8 (0.4-1.7)
GED degree	2%	1%	2.0 (0.5-8.8)
Employment/job training	8%	2%	7.9 (1.3-49.7)
Fuel assistance	7%	1%	11.1 (1.6-75.4)
Homeless shelter	2%	5%	0.3 (0.1-0.7)
Rental assistance	4%	7%	0.7 (0.3-1.3)

Adjusted for race, marital status, and maternal employment
Adjusted ICC <0.001

Source: Garg, A., et al. *Pediatrics* 135.2 (2015): e296-e304.

Other Social Needs RCT Studies

Written resource handouts vs. patient navigation for parents with needs

2 safety-net pediatric urban clinics

- Both arms found **decrease in social risks** 6-month follow-up
- Both arms found **improved child and parent heath** 6-month follow-up
- In-person navigation arm, **fewer hospitalizations** 12-month follow-up (hazard ratio, 0.59; 05% CI, 0.38-0.94)

Sources: Pantell MS et al. JAMA Netw Open 2020. Gottlieb LM et al. JAMA Netw Open. 2020.

Unintended Consequences of SDOH Screening on Doctor-Patient Relationship

VIEWPOINT

Avoiding the Unintended Consequences of Screening for Social Determinants of Health

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Screening for social determinants of health, which are the health-related social circumstances (eg, food insecurity and inadequate or unstable housing) in which people live and work, has gained momentum as evidenced by the recent Centers for Medicare & Medicaid Services innovation initiative of $157 million toward creation of accountable health communities.[1] Funding will allow grantees to test a novel model of health care that includes identifying and addressing social determinants of health for Centers for Medicare & Medicaid Services beneficiaries. The initiative promotes collaboration between the clinical realm and the community through screening of beneficiaries to (1) identify unmet health-related social needs and (2) assist high-risk beneficiaries (ie, >2 emergency department visits and a health-related social need) with accessing available community services.

Some health policy makers have embraced screening of social determinants as the next hope for achieving the triple aim of better health, improved health care delivery, and reduced costs because social and environmental factors are thought to contribute half of the modifiable factors that influence health.[2] Examples of policy statements supporting screening for social determinants include the Institute of Medicine's *Capturing Social and Behavioral Domains and Measures in Electronic Health Records*[3] and the American Academy of Pediatrics' *Poverty and Child Health in the United States*.[4]

> Screening for any condition in isolation without the capacity to ensure referral and linkage to appropriate treatment is ineffective and, arguably, unethical.

ment) requires effective care coordination and cross-sector collaboration. The relatively few exemplary, evidence-based models (eg, WE CARE, Health Leads, Project DULCE, Safe Environment for Every Kid, Help Me Grow) that use such strategies are limited in scope and reach and must be expanded to address the needs of diverse patient populations.[6]

The sensitive nature of such issues as food insecurity, unemployment, and interpersonal violence also poses unique challenges. Physicians may be uncomfortable routinely inquiring about adverse social circumstances, given their lack of personal experience with such needs and inadequate training on how to respectfully elicit and respond to patients' concerns. In addition, the absence of available services means that needs are often difficult to address, given the tenuous capacity of community resources such as affordable housing, behavioral health services, workforce development and employment, and public transportation.

Thus, despite the potential benefits of identifying and addressing adverse social determinants, there is the potential for unintended harm. Such screening could yield expectations that, if unfulfilled, could lead to frustration for patients and physicians alike. Furthermore, patients' perceptions of physicians as judgmental, presumptuous, or even callous could erode the patient-physician relationship. However, several key principles could guide physicians on how to effectively incorporate screening for social determinants into their practice.

Ensure Patient- and Family-Centered Screening for Social Determinants of Health

Many validated screening tools for unmet material needs, such as food and housing, were created for

Source: Garg A et al. *JAMA*. 2016.

Guiding Principles for SDOH Screening

- Ensure screening is **Family-Centered**
- **Integrate** screening with referrals and linkage to community-based resources
- **Shared Decision Making**
- Use a **Strength-based Approach**
- **Do not** limit screening practices on apparent social status

Source: Garg A et al. JAMA. 2016.

Suburban Families' Experience with Food Insecurity (FI) Screening: Qualitative Study

Suburban parents were overall **comfortable** discussing FI with their pediatrician

Parents expressed **initial surprise** at screening **followed by comfort** discussing their unmet food needs

Important for pediatricians to clarify that screening was **to offer support and acknowledge parents' feeling of shame** that accompany FI

Source: Palakshappa D et al. Pediatrics. 2017.

Adverse SDOH for Families with Children with SCD

- Multicenter clinical trial found that children with SCA live in households with a median income of $6,250 (n=536).
- Data from Boston Medical Center (BMC) and Boston Children's Hospital demonstrated that > 90% of families of children with SCD have at least one unmet material need.
- 59% families (n=101) presented to ED had housing, utility and/or food insecurity

King AA, et al. *Am J Hematol.* 2014;89(10):E188-E192.
Sonik RA et al. *Child Youth Serv Rev*. 2018;84:76-81.
Power-Hays A et al. *Pediatr Blood Cancer*. 2020;67(10):E28587.
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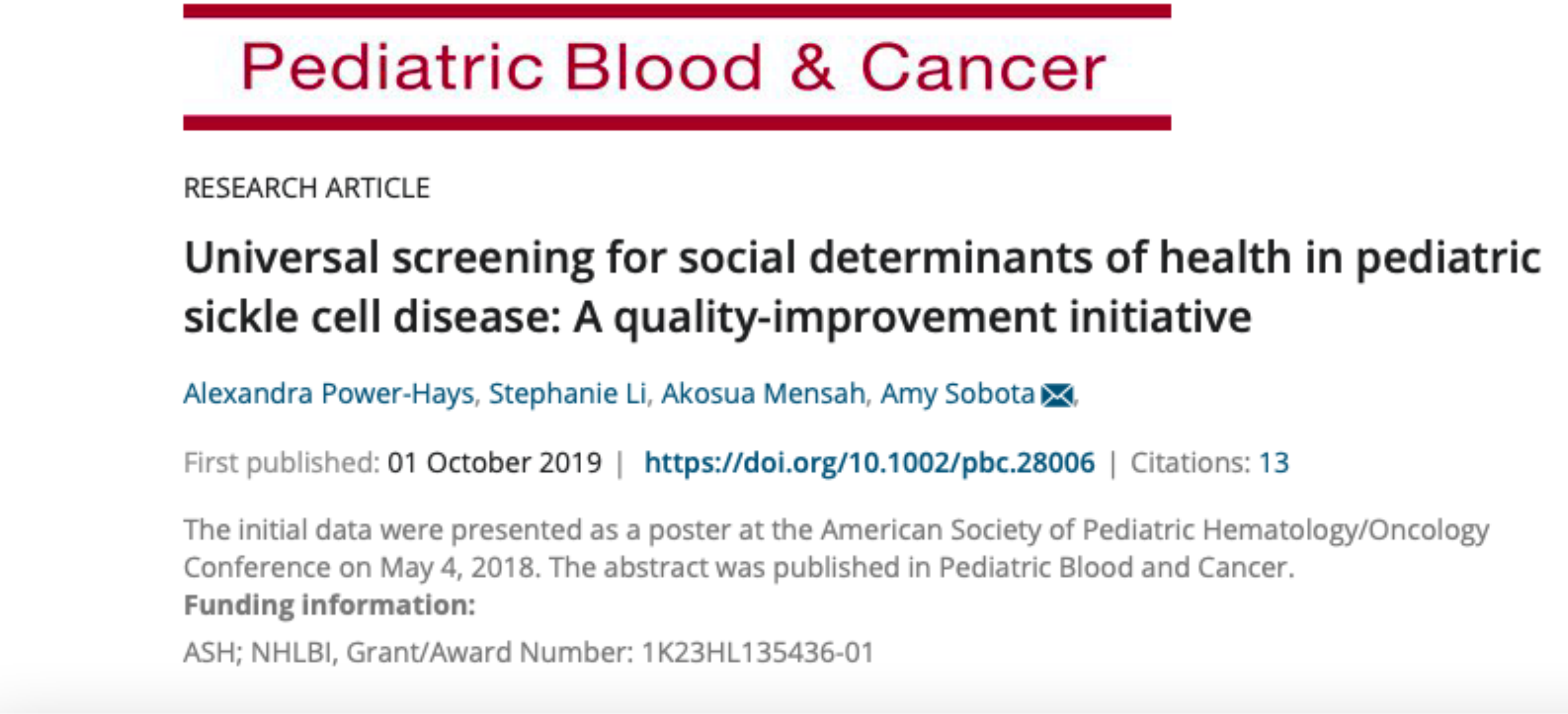


Pediatric Blood & Cancer

RESEARCH ARTICLE

Universal screening for social determinants of health in pediatric sickle cell disease: A quality-improvement initiative

Alexandra Power-Hays, Stephanie Li, Akosua Mensah, Amy Sobota ✉,

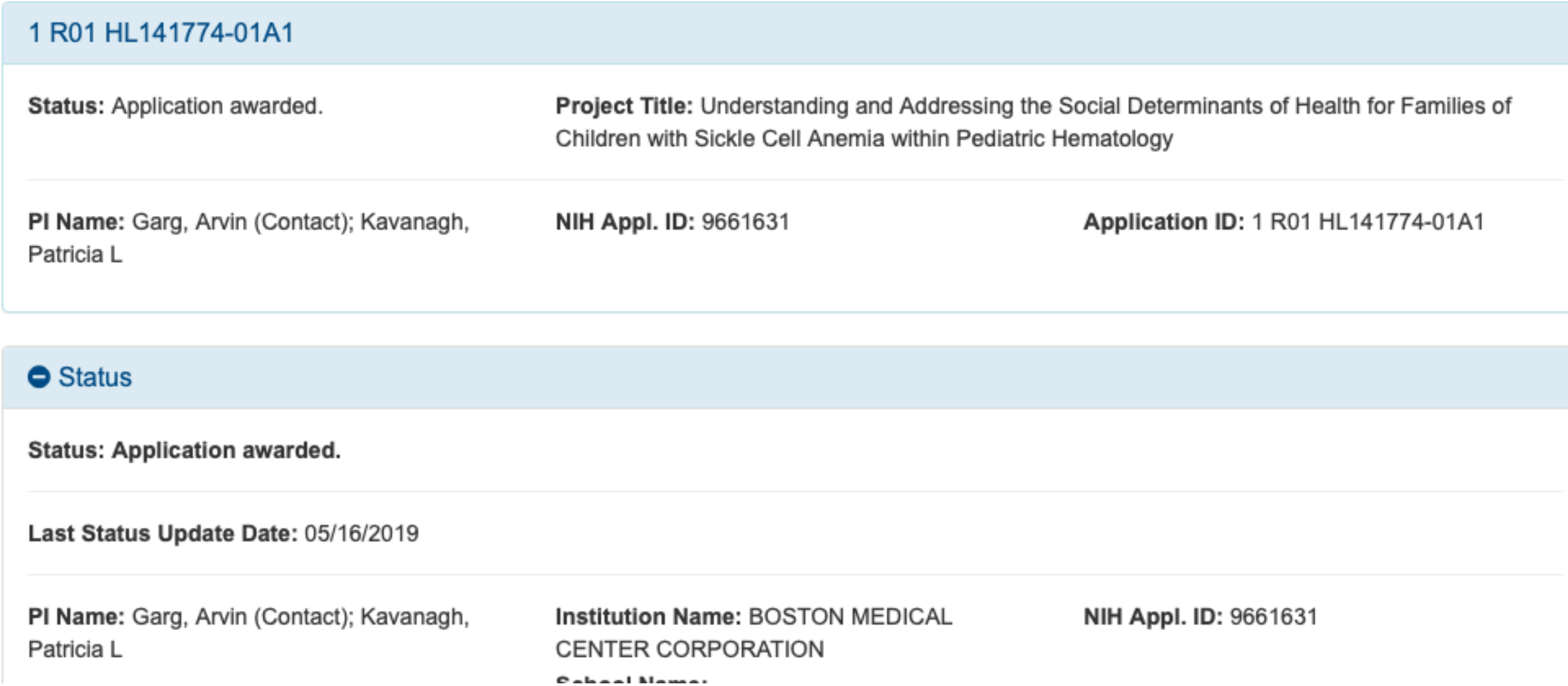
First published: 01 October 2019 | https://doi.org/10.1002/pbc.28006 | Citations: 13

The initial data were presented as a poster at the American Society of Pediatric Hematology/Oncology Conference on May 4, 2018. The abstract was published in Pediatric Blood and Cancer.
Funding information:

ASH; NHLBI, Grant/Award Number: 1K23HL135436-01

Study Results: August 2017-Nov 2018

- **156 screeners** distributed
- **66% families** > 1 need
- **80% of families with needs** received referrals
- **45% families with needs reached out** to community resources



1 R01 HL141774-01A1

Status: Application awarded.

Project Title: Understanding and Addressing the Social Determinants of Health for Families of Children with Sickle Cell Anemia within Pediatric Hematology

PI Name: Garg, Arvin (Contact); Kavanagh, Patricia L

NIH Appl. ID: 9661631

Application ID: 1 R01 HL141774-01A1

Status

Status: Application awarded.

Last Status Update Date: 05/16/2019

PI Name: Garg, Arvin (Contact); Kavanagh, Patricia L

Institution Name: BOSTON MEDICAL CENTER CORPORATION

School Name:

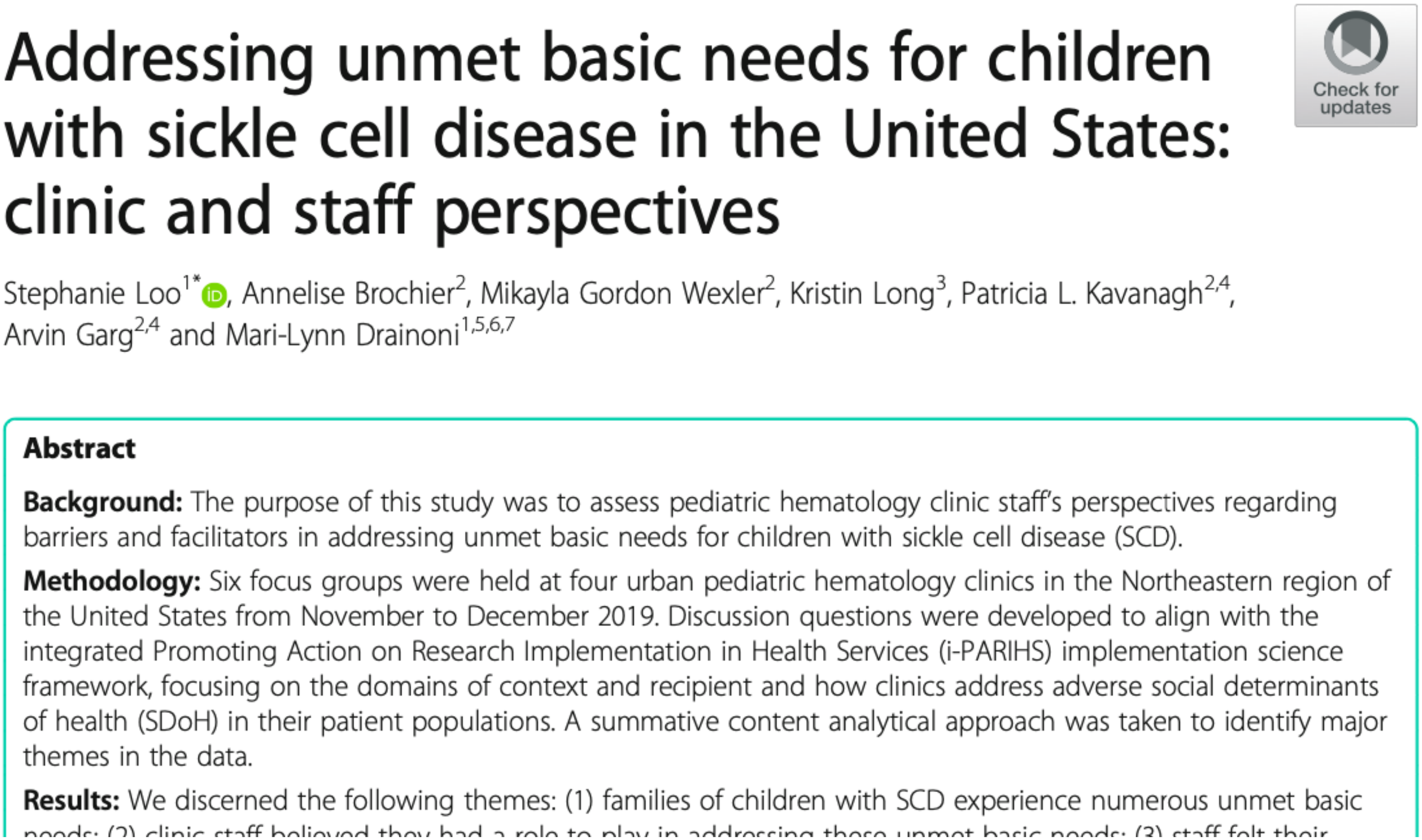
NIH Appl. ID: 9661631

Study Aims

- **Examine the implementation** of WE CARE in pediatric hematology clinics using mixed-methods to assess feasibility and acceptability and identify adaptations to meet the needs of this population
- Field test key study logistics and obtain population-specific empirical estimates of study parameters to plan a pragmatic cluster RCT evaluating the impact of WE CARE by **conducting a pilot trial**
- **Assess the family contextual factors** that promote or prevent effective SCA management by parents of children with SCA in the setting of unmet material needs, such as food or housing.

Participating Institutions

- Boston Children’s Hospital
- Connecticut Children’s Medical Center
- Hasbro Children’s Hospital
- Yale New Haven Children’s Hospital



Addressing unmet basic needs for children with sickle cell disease in the United States: clinic and staff perspectives

Stephanie Loo[1*], Annelise Brochier[2], Mikayla Gordon Wexler[2], Kristin Long[3], Patricia L. Kavanagh[2,4],
Arvin Garg[2,4] and Mari-Lynn Drainoni[1,5,6,7]

Abstract

Background: The purpose of this study was to assess pediatric hematology clinic staff's perspectives regarding barriers and facilitators in addressing unmet basic needs for children with sickle cell disease (SCD).

Methodology: Six focus groups were held at four urban pediatric hematology clinics in the Northeastern region of the United States from November to December 2019. Discussion questions were developed to align with the integrated Promoting Action on Research Implementation in Health Services (i-PARIHS) implementation science framework, focusing on the domains of context and recipient and how clinics address adverse social determinants of health (SDoH) in their patient populations. A summative content analytical approach was taken to identify major themes in the data.

Results: We discerned the following themes: (1) families of children with SCD experience numerous unmet basic needs; (2) clinic staff believed they had a role to play in addressing these unmet basic needs; (3) staff felt their

Themes from Providers & Staff

- Families of children with SCD experience numerous unmet material needs
- Clinic staff believed they had a role to play in addressing these unmet needs
- Staff felt their ability to address families’ unmet material needs depended upon caregivers’ capacity to act on staff’s recommendations
- Clinic staff’s ability to address these needs was limited by organizational and systemic factors beyond their control

Piloting WE CARE in 2 Study Sites

- **>60% families (n=225)** received and completed WE CARE screener at visits
- **54% families** reported >1 need wanted help with
- Most common needs were food, education, utilities and employment
- Majority of families who wanted help received community resource information

Summary

- Racial disparities persist in healthcare and outcomes particularly for children with SCD
- Racism and SDOH are drivers of health outcomes and inequities
- There is an opportunity to empathetically assist families with their unmet material needs at pediatric hematology clinics
- Much more work needs to be done to integrate social care into medical care and to partner with community stakeholders

Acknowledgements:

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