

# Focusing on Equity After Newborn Screening

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# Disclosures: in the past 24 months

- PCORI
- CDC
- NIH
- HRSA -LEND
- PA Dept of Health –care coordination
- FISA –access to care
- ASTHO –health equity
- DOJ -Olmstead case expert

# Learner Objectives:

Define

Health equity, disparities and determinants of health

Review

Access to care

Consider

How we may engage with a health equity lens

# Health Equity

“Health equity means that everyone has a fair and just opportunity to be as healthy as possible. This requires removing obstacles to health such as poverty, discrimination, and their consequences, including powerlessness and lack of access to good jobs with fair pay, quality education and housing, safe environments, and health care.”

# Health Disparities

- Differences in health or its key determinants that adversely impact those marginalized
- Progress toward health equity is reduction in disparities

Poverty

Discrimination

Political and social determinants of health are maintained by mutually reinforcing systems of opportunity, housing, financing, employment, criminal justice... These systems are amenable to policy interventions.

**UPSTREAM**

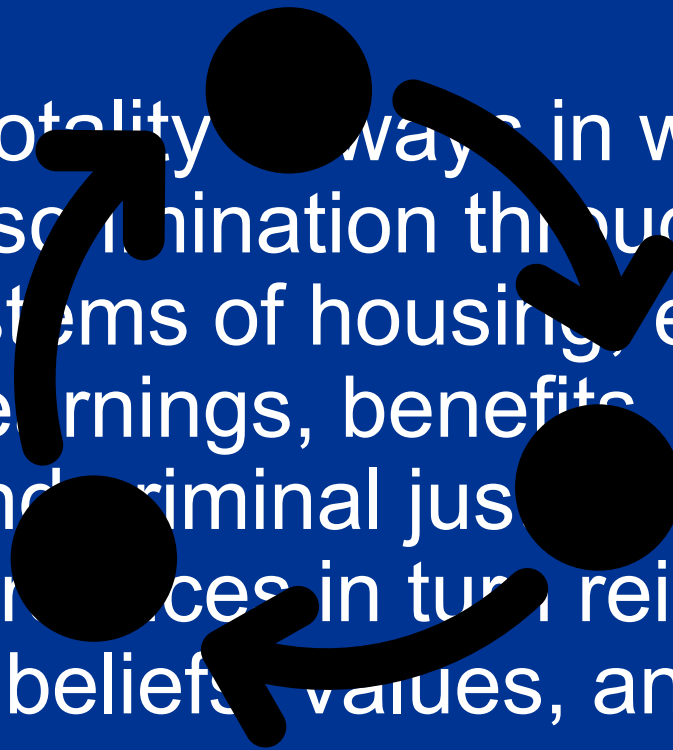
Housing instability  
Food insecurity  
Stable employment  
Poor quality education  
Lack of access to services and supports that promote health

**DOWNSTREAM**



# Structural Racism

- Refers to the totality of ways in which societies foster racial discrimination through mutually reinforcing systems of housing, education, employment, earnings, benefits, credit, media, health care, and criminal justice. These patterns and practices in turn reinforce discriminatory beliefs, values, and distribution of resources.



Structural racism and health inequities in the USA: evidence and interventions

Zinzi D Bailey ScD <sup>a</sup>, Prof Nancy Krieger PhD <sup>b</sup>, Madina Agénor ScD <sup>b</sup>, Jasmine Graves MPH <sup>c</sup>, Natalia Linos ScD <sup>a</sup>, Dr Mary T Bassett MD <sup>a</sup>  

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# Classism

*Classism is differential treatment based on social class or perceived social class. Classism is the systematic oppression of subordinated class groups to advantage and strengthen the dominant class groups. It's the systematic assignment of characteristics of worth and ability based on social class.*

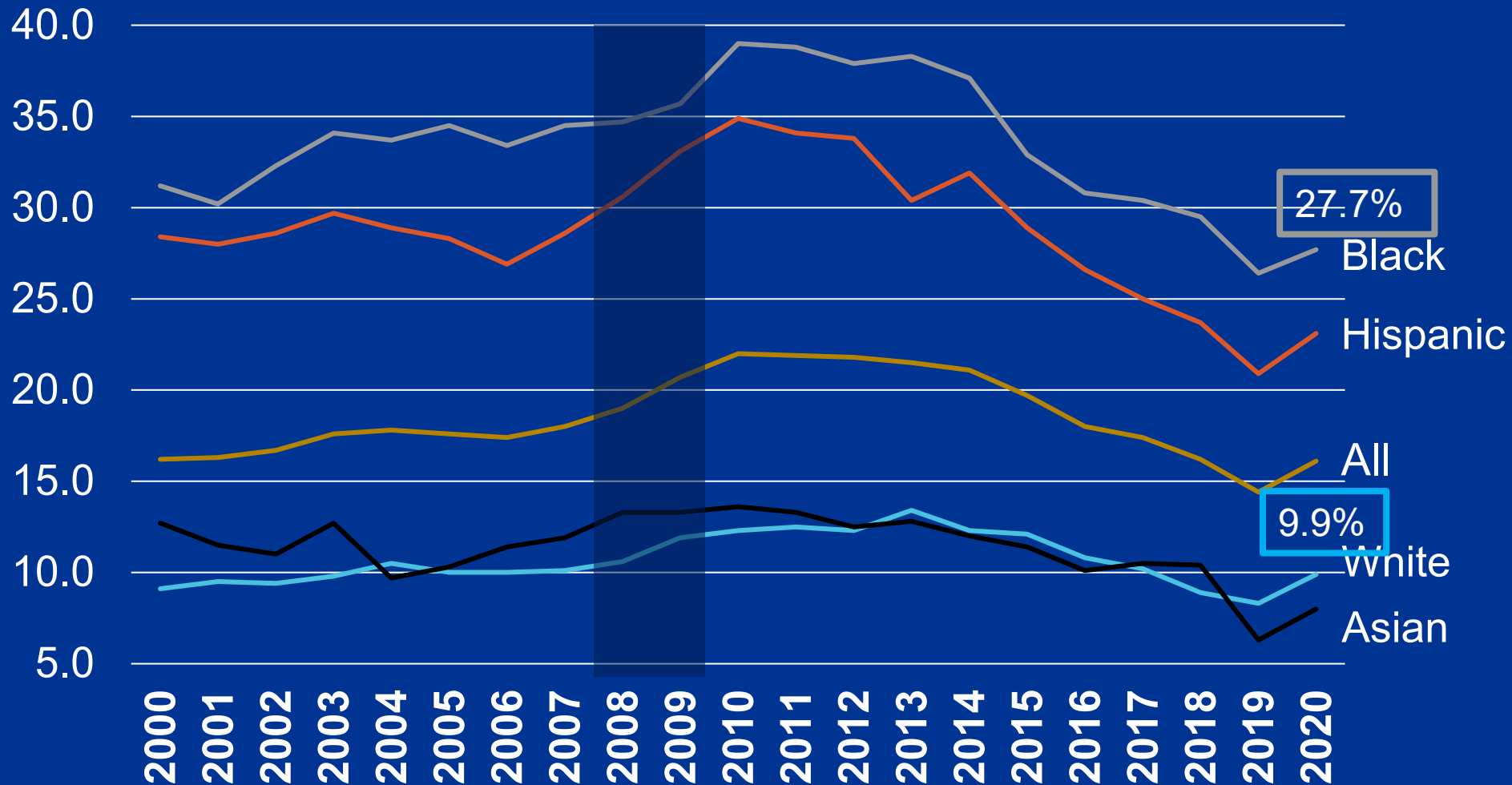
- individual attitudes and behaviors;
- systems of policies and practices that are set up to benefit the upper classes at the expense of the lower classes, resulting in drastic income and wealth inequality;
- the rationale that supports these systems and this unequal valuing; and
- the culture that perpetuates them

Classism is held in place by a system of beliefs and cultural attitudes that ranks people according to economic status, family lineage, job status, level of education, and other divisions.



# Percentage of Children Living in Poverty by Race

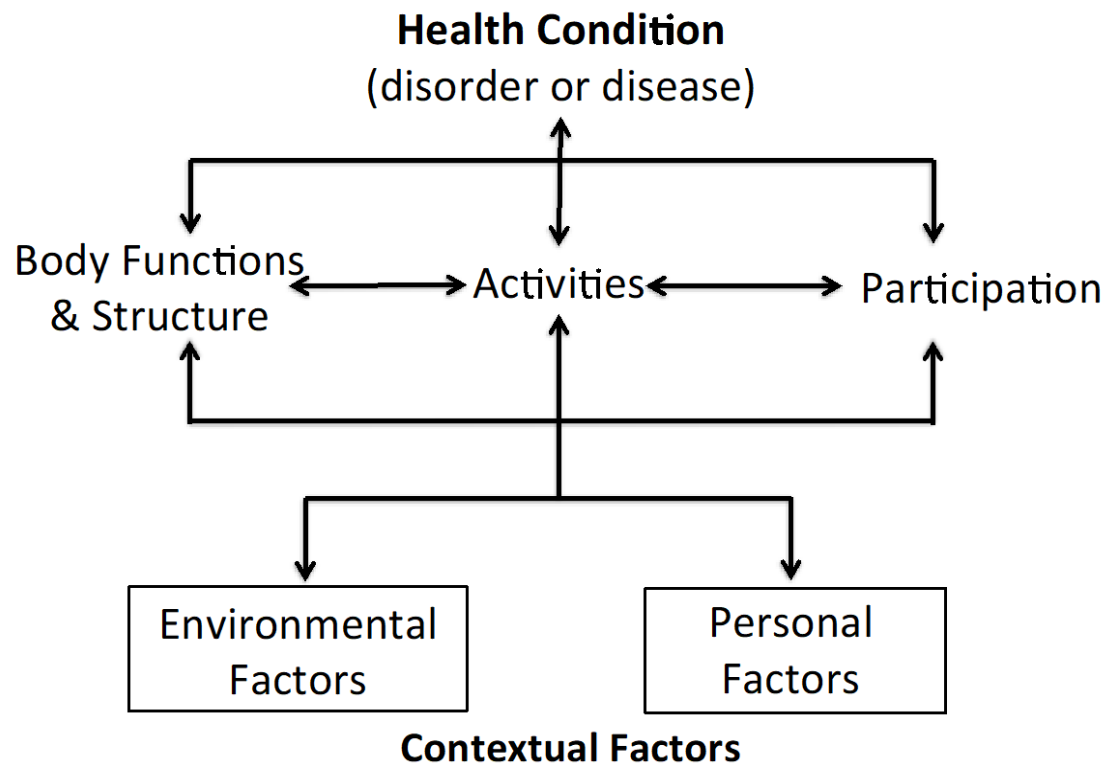
<https://www.census.gov/data/tables/time-series/demo/income-poverty/historical-poverty-people.html>



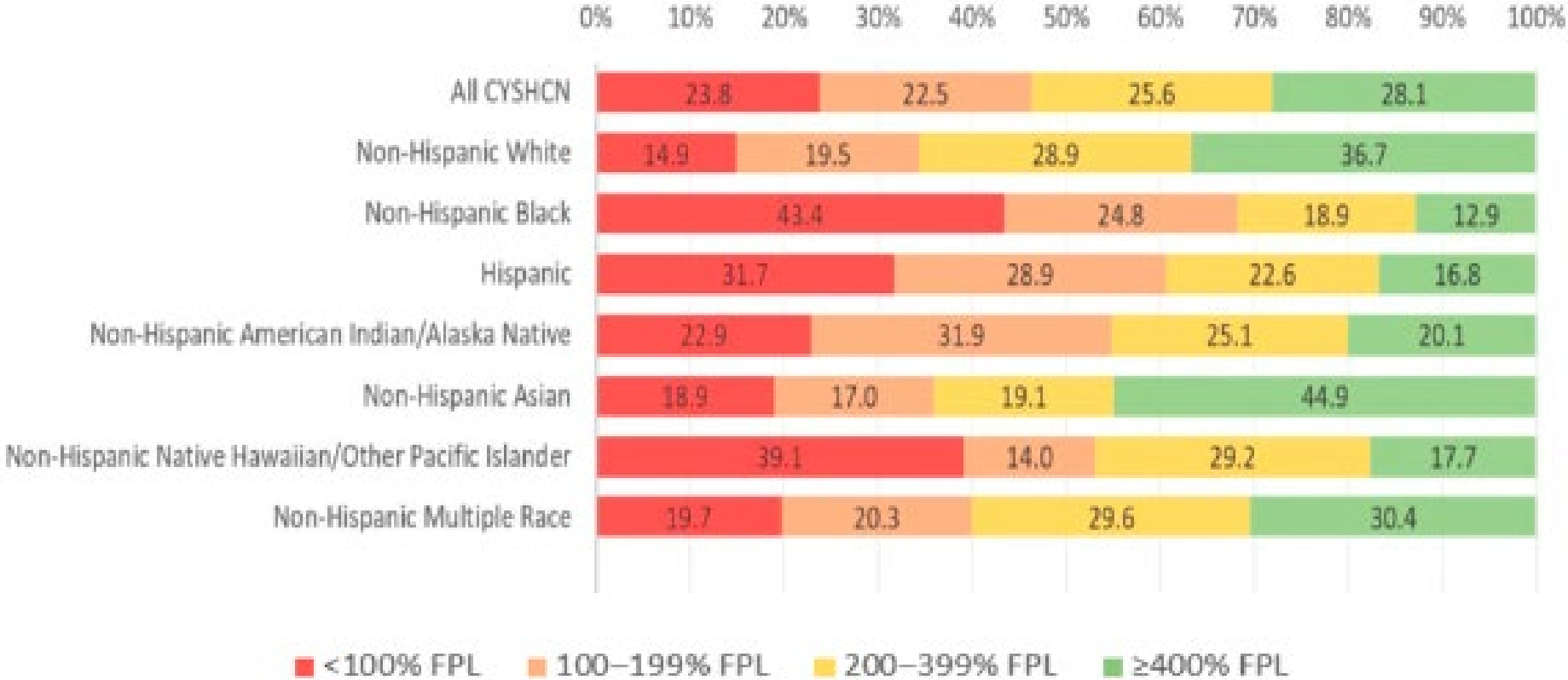
# Ableism

- Stereotyping, prejudice, discrimination and social oppression toward people with disabilities
- Disability cast as a diminished state of being based on the physical ideal

## Framing in neutral language -ICF



# CYSHCN more likely to be poor and more likely to be from minoritized background. (Schiff, 2022)



# Sickle Cell Disease

## Sickle Cell Disease in the U.S.

It is estimated that approximately:

**2,000,000**

Americans have sickle cell trait

**100,000**

are living with SCD

Sickle cell disease occurs in:

**1 in 365**

African-American births

**1 in 16,300**

Hispanic-American births

## Care and Treatment for Sickle Cell Disease

- Early entry into evidence-based care including specialty care from SCD specialists reduces complications, improves quality of life, and extends life expectancy for individuals living with SCD.
- Prevention and treatment options include:
  - » Lifestyle and behavior changes
  - » Medical screenings and interventions like vaccines
  - » Specific treatments such as Hydroxyurea to prevent SCD complications
- People living with SCD experience barriers to accessing care and treatment due to lack of access to SCD specialists, discrimination, racism and unmet social factors.

Learn more at <https://mchb.hrsa.gov>

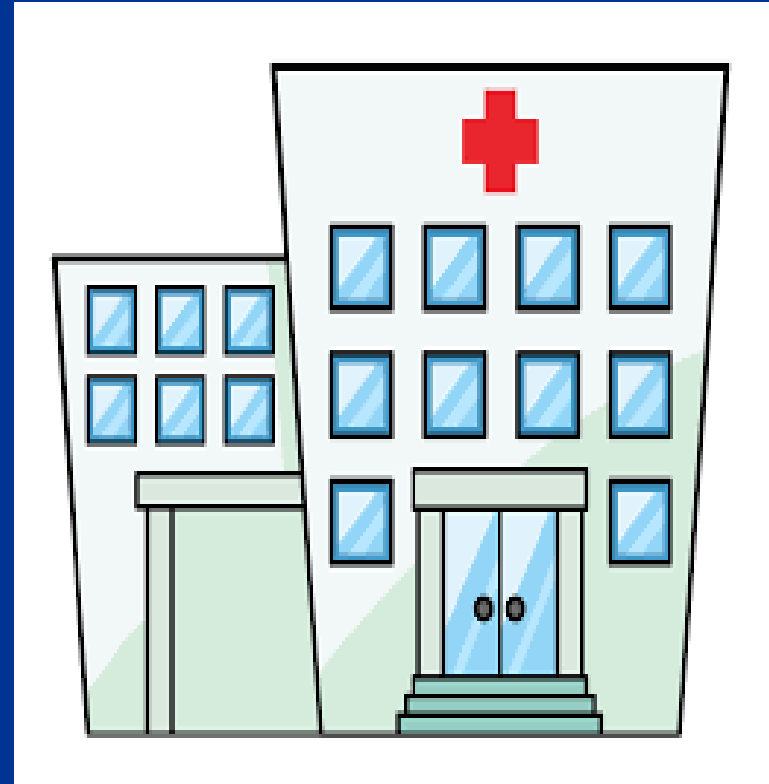
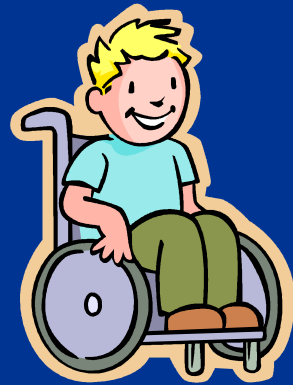
# Early Hearing Detection and Intervention

## Achievements

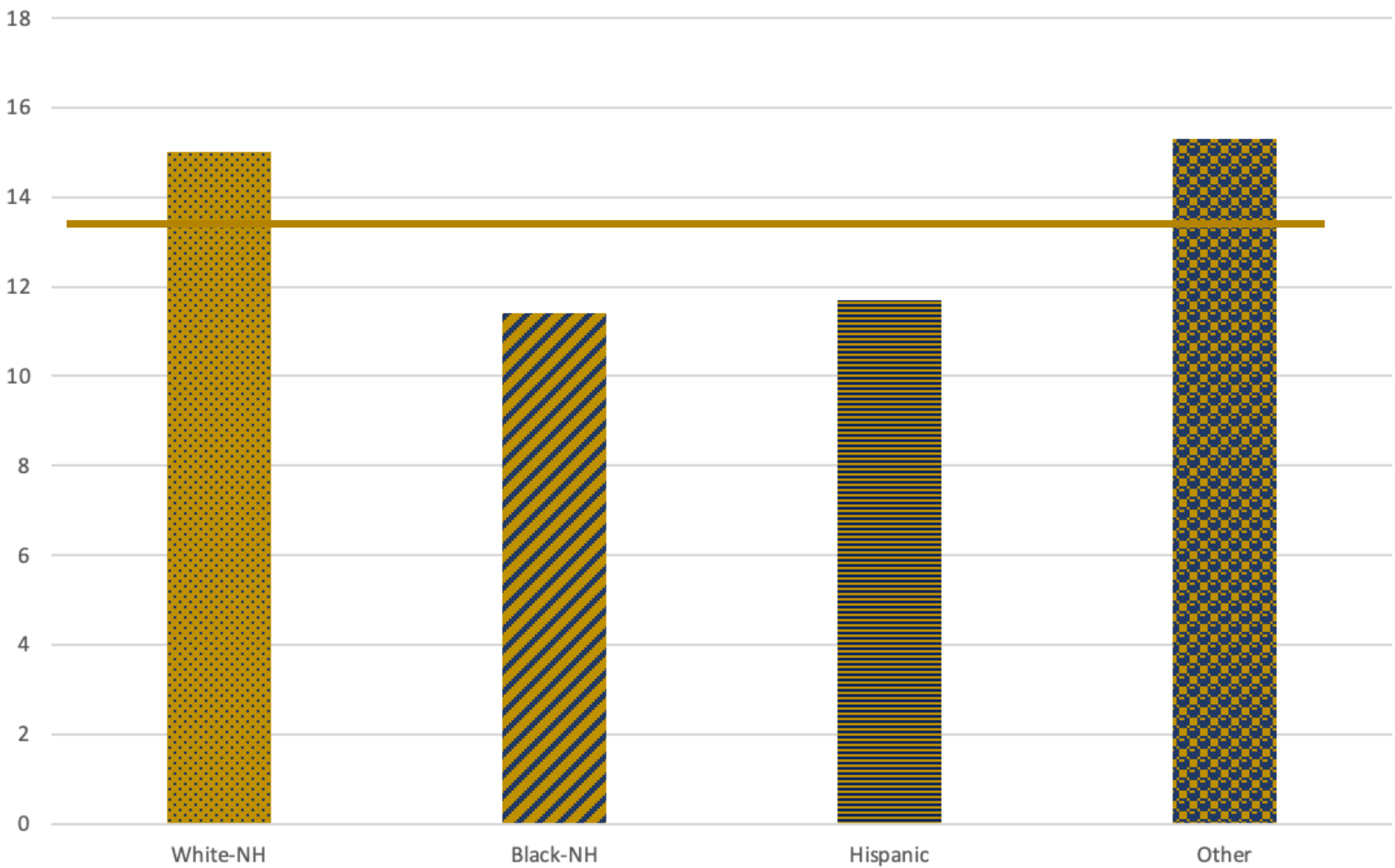
Before 1993, fewer than 1 in 10 newborns in the U.S. were screened for hearing loss, but now nearly all are screened. Since HRSA's Early Hearing Detection and Intervention program started, states and territories have had significant success identifying and getting services for newborns and infants with hearing loss. In 2018, data from CDC data told us that:

- 97% of all infants were screened prior to one month of age, and overall, 98.3% of all infants born in the U.S. had their hearing screened
- 77.1% of infants received audiological evaluations and a diagnosis by three months of age. Our system continues to work to increase the number of infants identified as deaf or hard of hearing at an early age.
- 70.1% of infants were enrolled in early intervention services before six months of age.

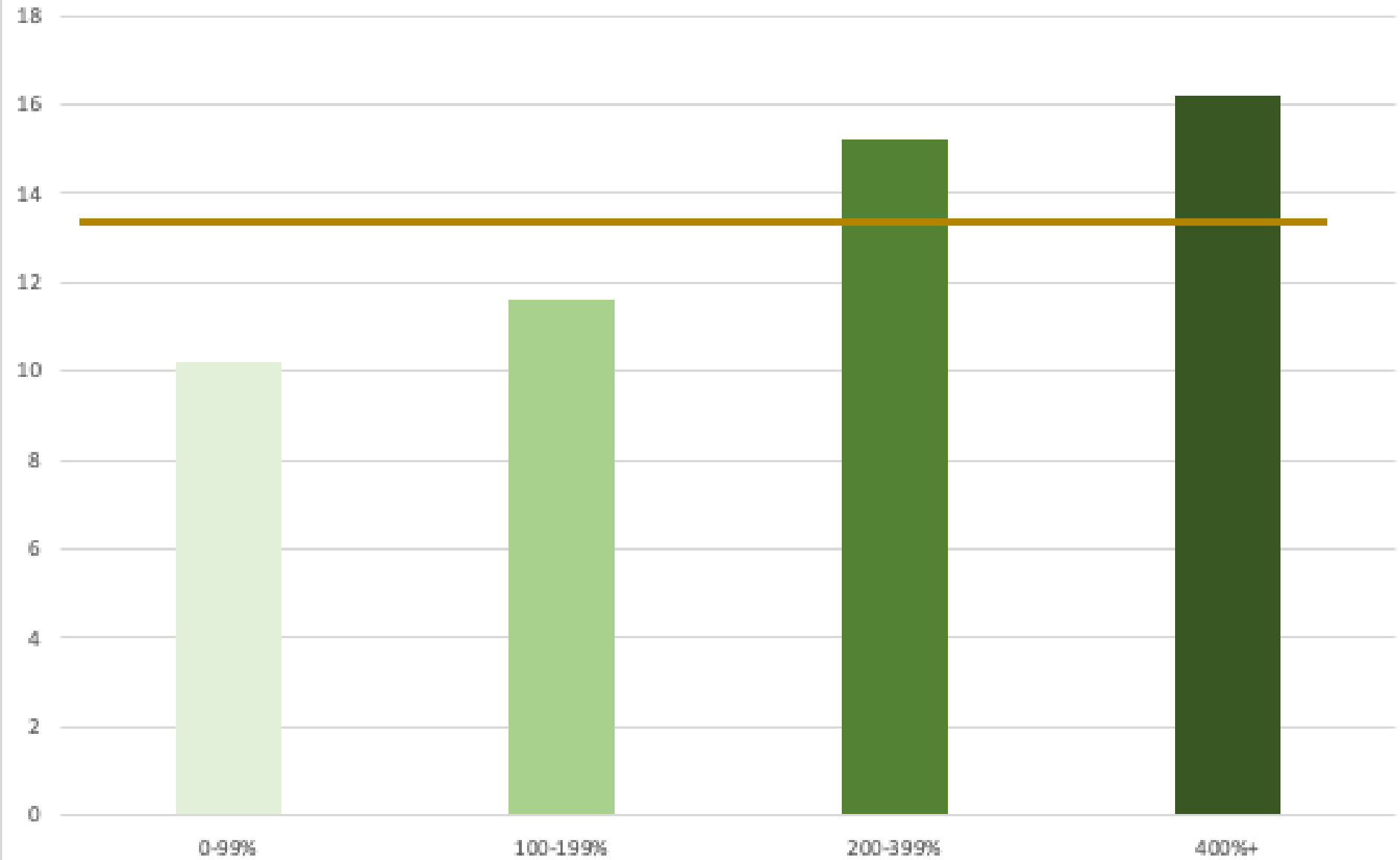
**In order to benefit from  
high quality health care,  
you need to be able  
access it**



# Care in a well-functioning system

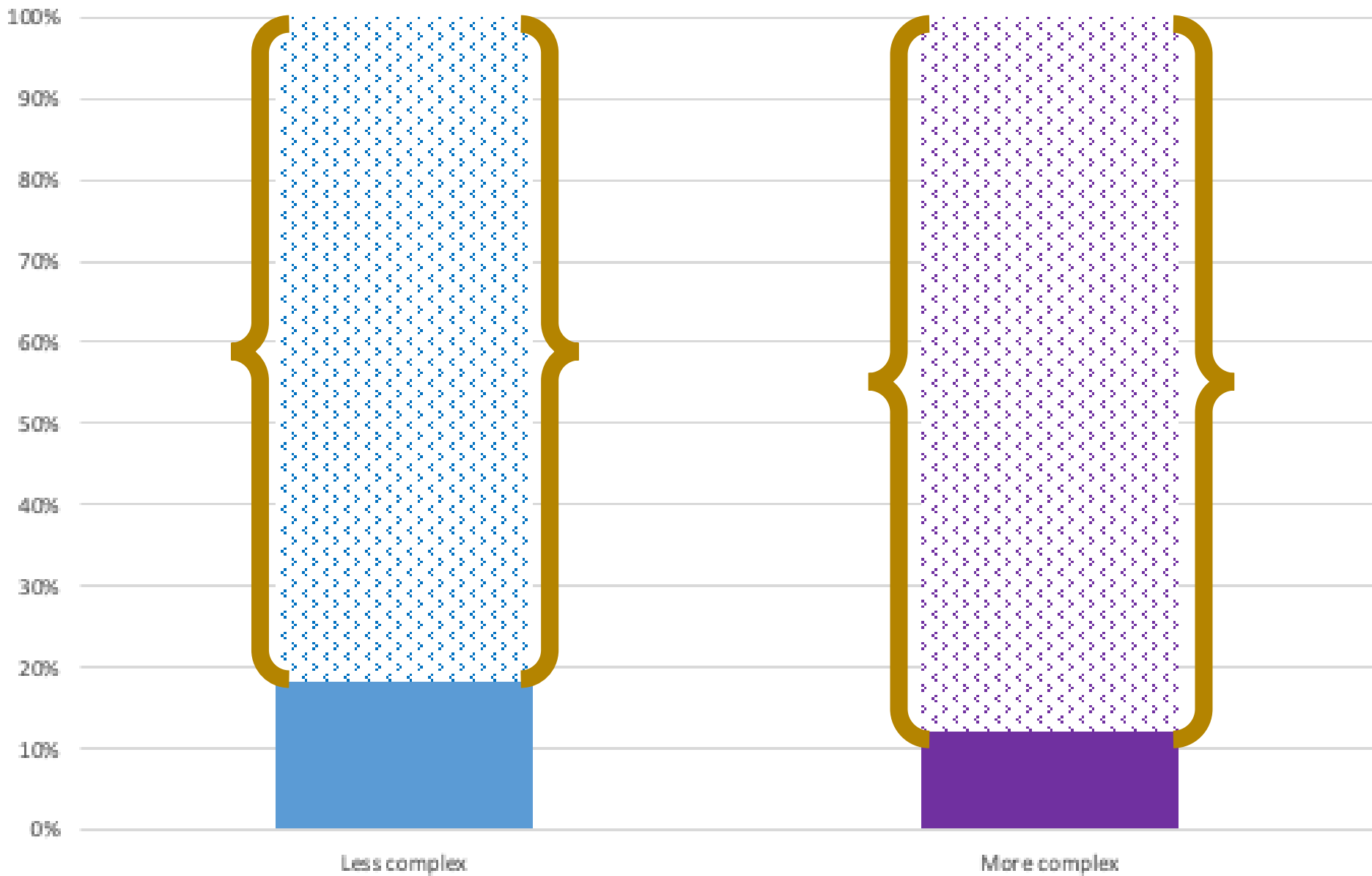


## Care in a well-functioning system

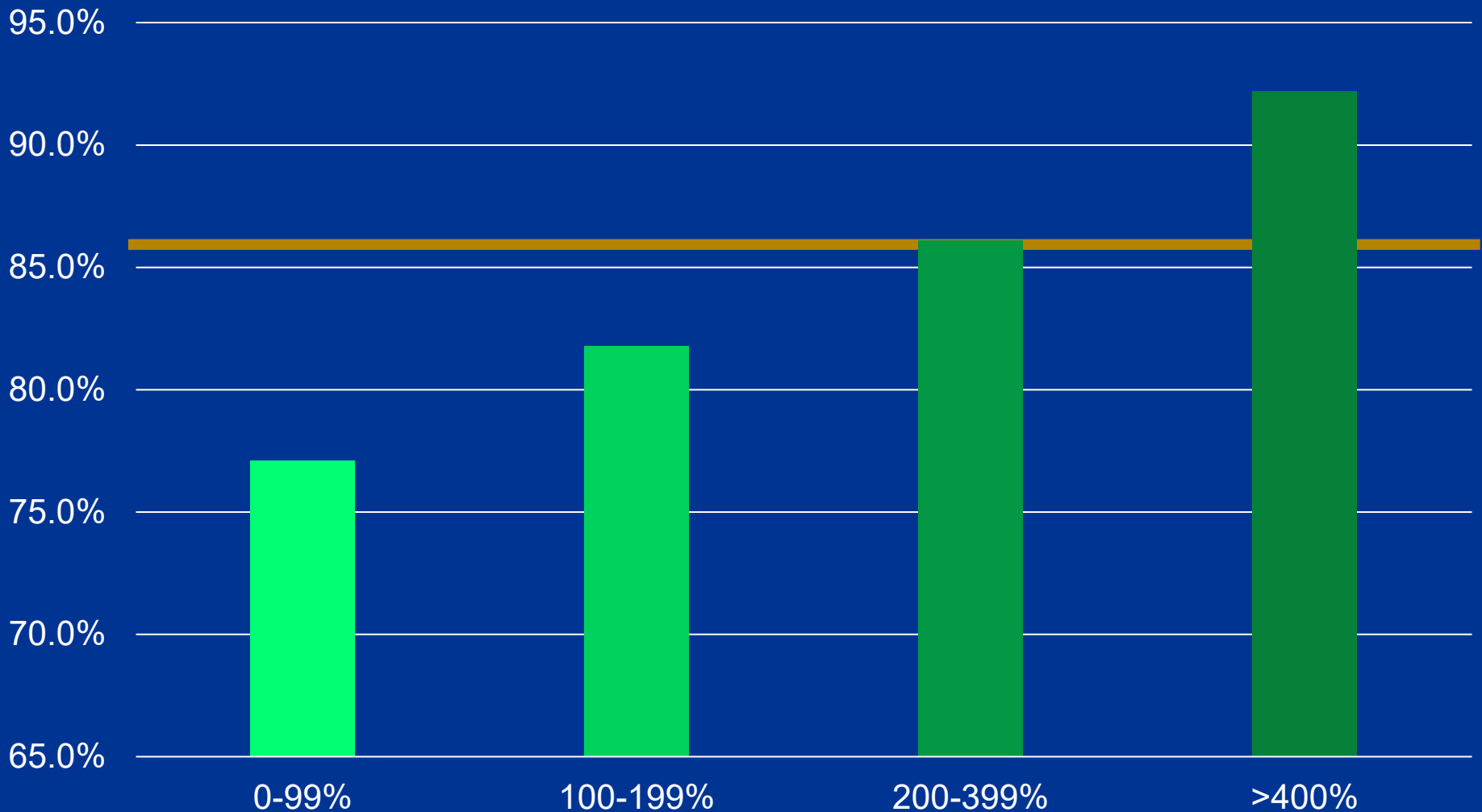




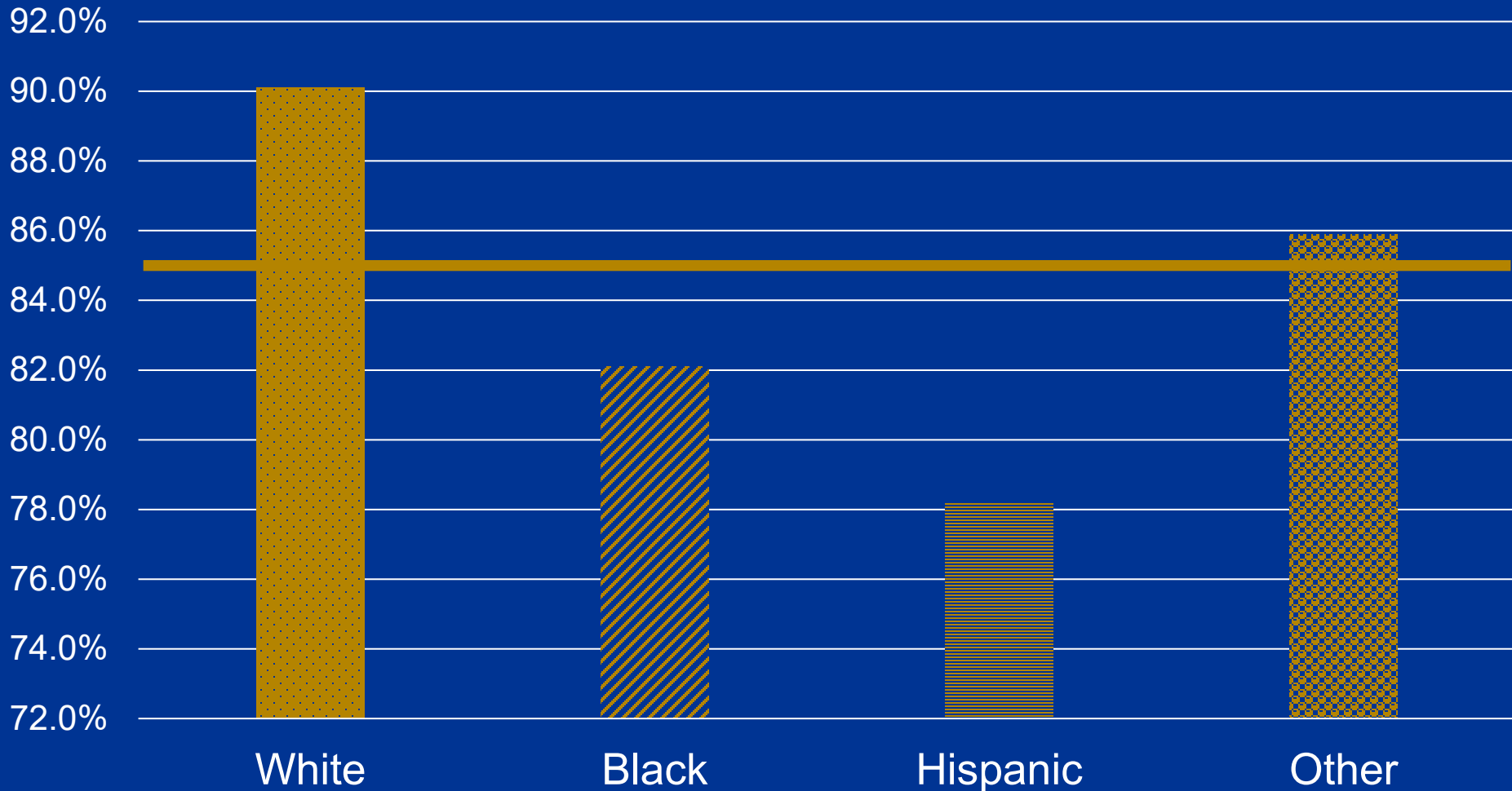
# Care in a well-functioning system



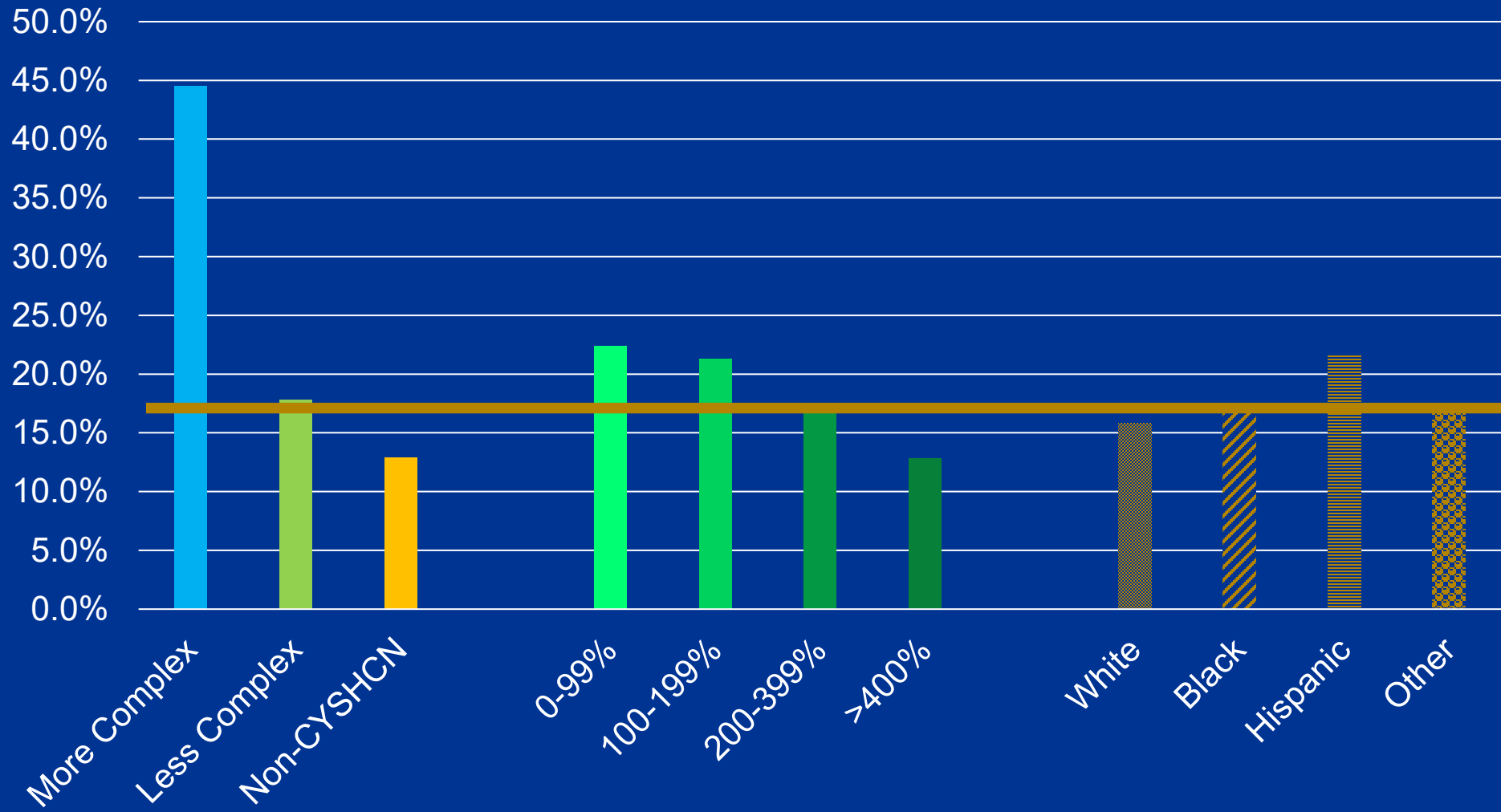
# Family-Centered Care by Income (NSCH 2019-2020)



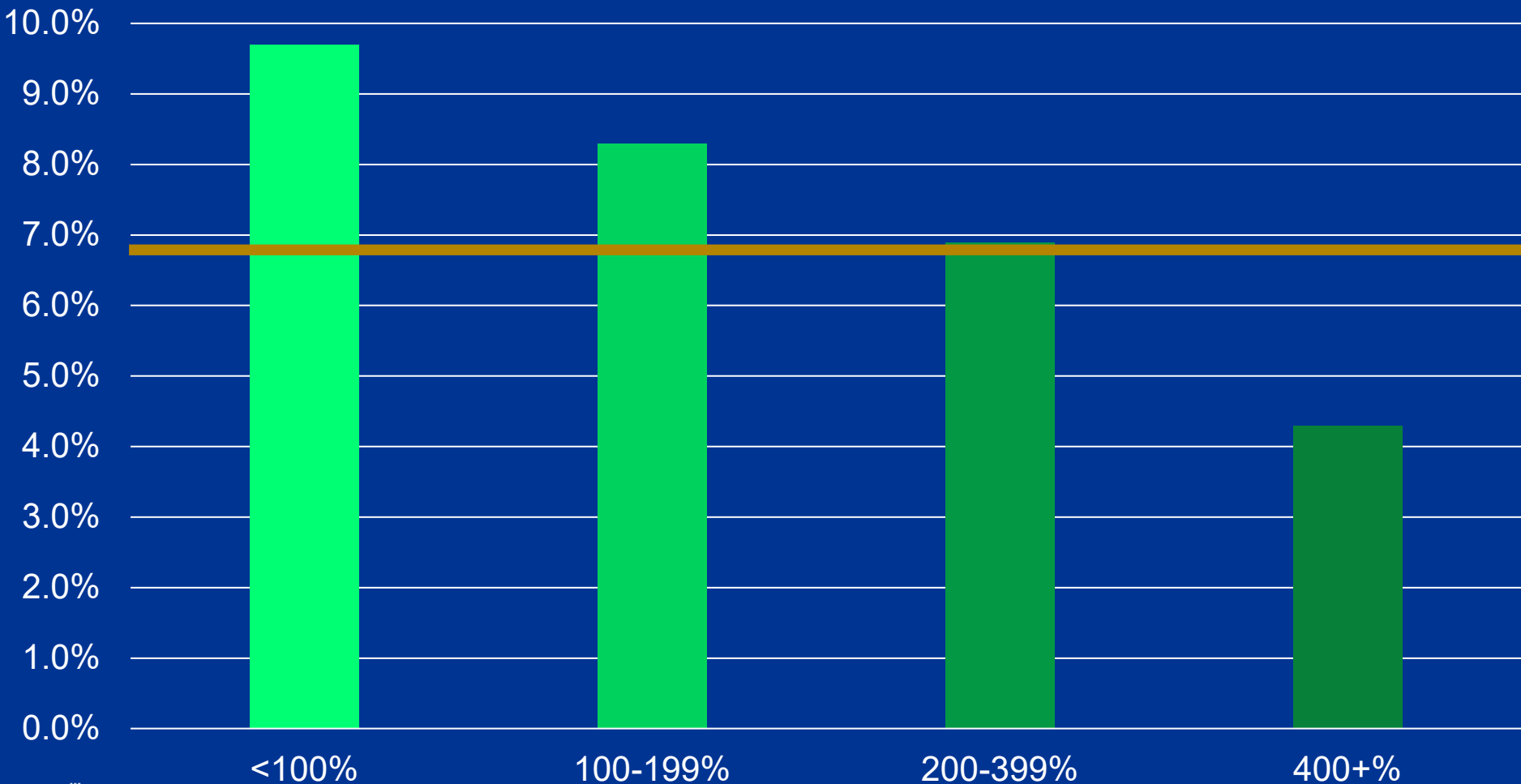
# Family-Centered Care by Minorization (NSCH 2019-2020)



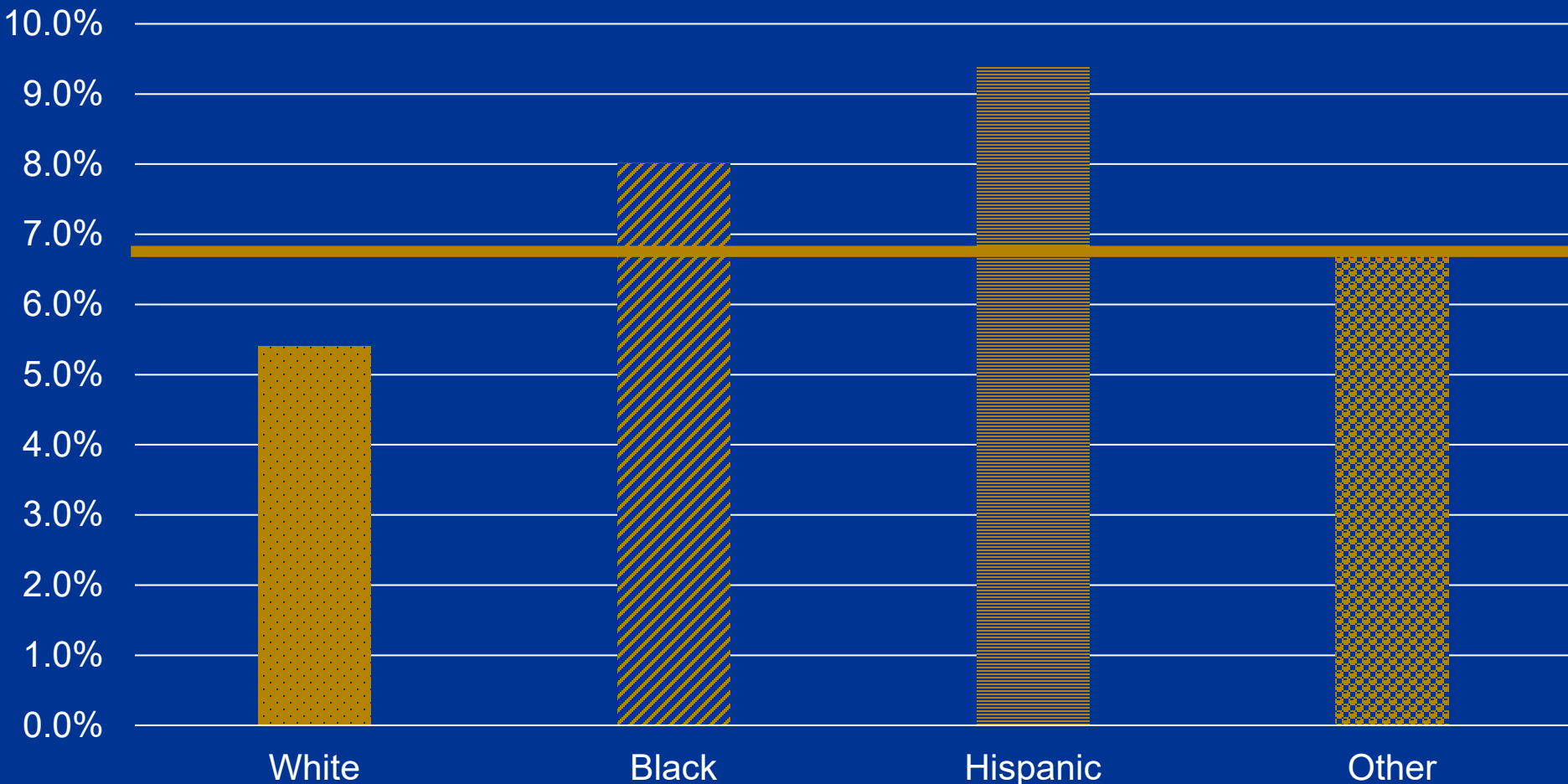
# Frustration getting care (NSCH 2019-2020)



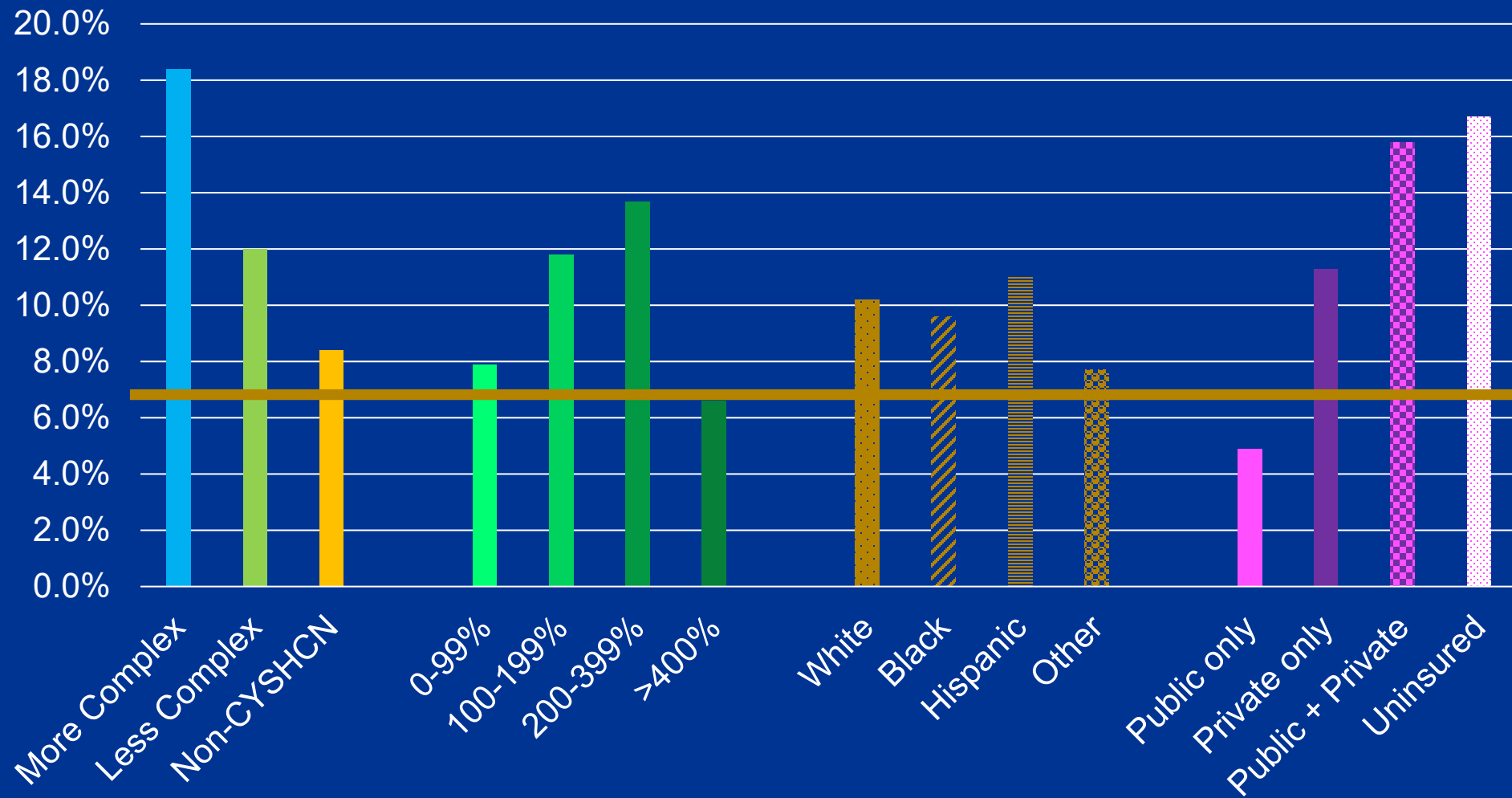
# Stopping or Cutting Back on Work Due to Child's Health by Income (NSCH 2019-2020)



# Stopping or Cutting Back on Work Due to Child's Health by Minoritization (NSCH 2019-2020)

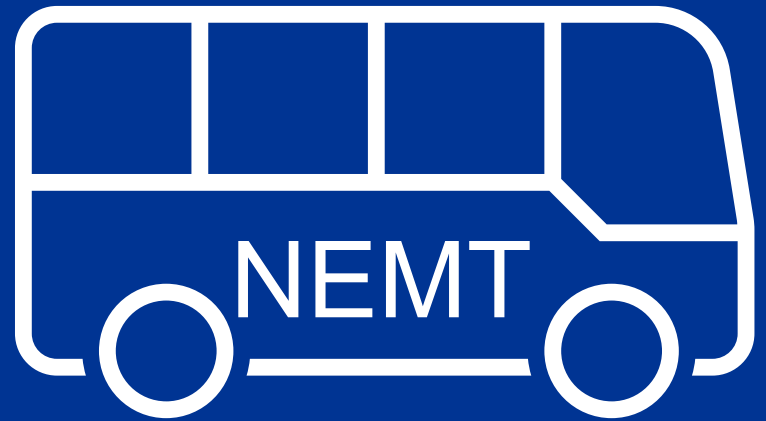


# Trouble pay medical bills (NSCH 2019-2020)



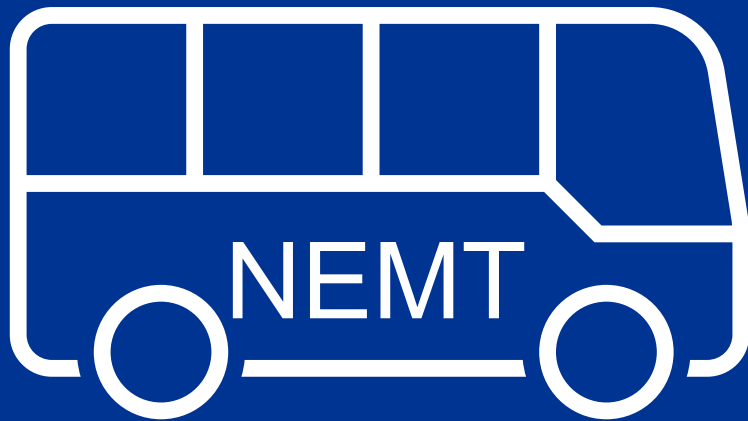
# Attendance policies

- Imagine you are the parent of a child with medical complexity reliant on non-emergency medical transportation services for your child to attend therapy appointments





# Attendance policies



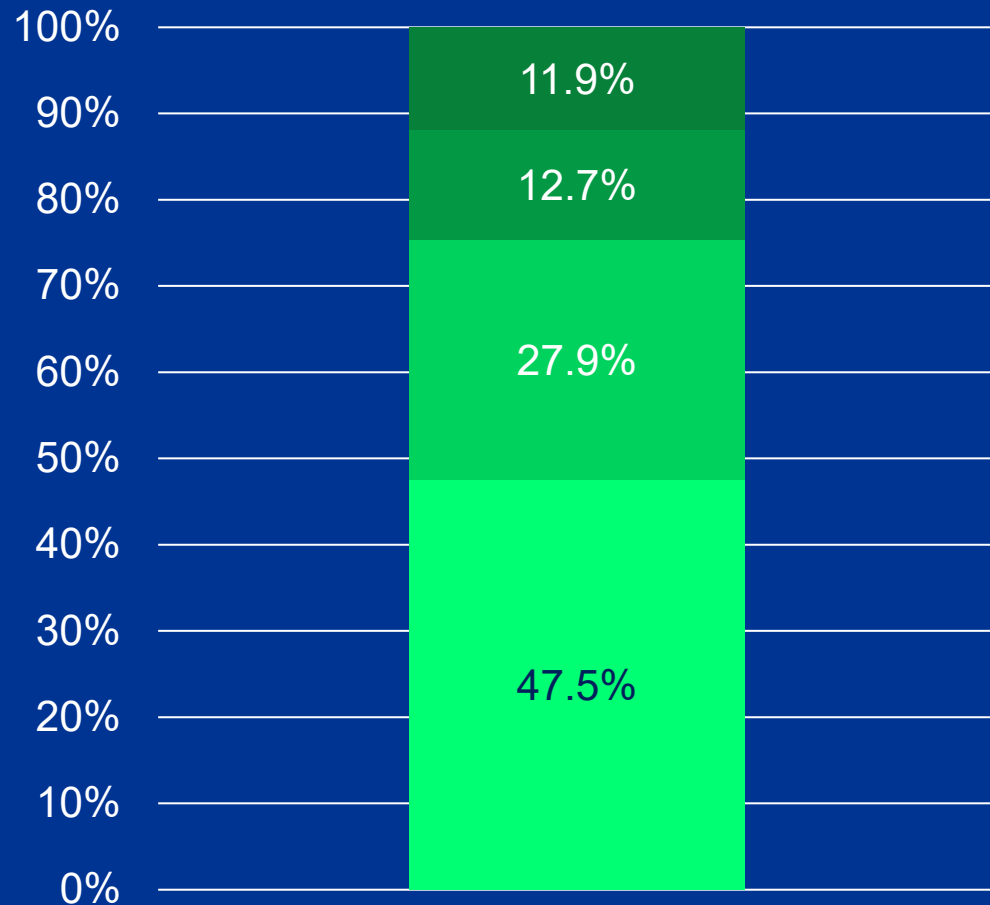
- NEMT provides a two-hour window for the pickup time
- Is frequently late
- Occasionally cancels at the last minute

# Attendance policies



# Who does this impact? (NSCH 2019-2020)

- When care is forgone and transportation is a problem, who does this impact?
  - Kids with medical complexity
  - Kids from minoritized backgrounds
  - Kids who live in households with fewer financial resources





**“Of all the forms of inequality, injustice in health care is the most shocking and inhumane.”**

**Dr Martin Luther King, Jr**