



Published in final edited form as:

*Cardiol Young*. 2023 December ; 33(12): 2539–2547. doi:10.1017/S1047951122004097.

## Racial and ethnic disparities in socio-economic status, access to care, and healthcare utilisation among children with heart conditions, National Survey of Children’s Health 2016–2019

Ashley S. Judge<sup>1,2</sup>, Karrie F. Downing<sup>1</sup>, Wendy N. Nembhard<sup>3</sup>, Matthew E. Oster<sup>1,4</sup>, Sherry L. Farr<sup>1</sup>

<sup>1</sup>Centers for Disease Control and Prevention, National Center on Birth Defects and Developmental Disabilities, Atlanta, GA, USA

<sup>2</sup>Oak Ridge Institute for Science and Education, Oak Ridge, TN, USA

<sup>3</sup>Department of Epidemiology, Fay W Boozman College of Public Health and the Arkansas Center for Birth Defects Research and Prevention, University of Arkansas for Medical Sciences, Little Rock, AR, USA

<sup>4</sup>Children’s Healthcare of Atlanta and Emory University School of Medicine, Atlanta, GA, USA

### Abstract

Among children with and without heart conditions of different race/ethnicities, upstream social determinants of health, such as socio-economic status, access to care, and healthcare utilisation, may vary. Using caregiver-reported data from the 2016–19 National Survey of Children’s Health, we calculated the prevalence of caregiver employment and education, child’s health insurance, usual place of medical care in the past 12 months, problems paying for child’s care, 2 emergency room visits, and unmet healthcare needs by heart condition status and race/ethnicity (Hispanic, non-Hispanic Black, and non-Hispanic White). For each outcome, we used multivariable logistic regression to generate adjusted prevalence ratios controlling for child’s age and sex. Of 2632 children with heart conditions and 104,841 without, 65.4% and 58.0% were non-Hispanic White and 52.0% and 51.1% were male, respectively. Children with heart conditions, compared to those without, were 1.7–2.6 times more likely to have problems paying for healthcare, have 2 emergency room visits, and have unmet healthcare needs. Hispanic and non-Hispanic Black children with heart conditions, compared to non-Hispanic White, were 1.5–3.2 times as likely to have caregivers employed <50 weeks in the past year and caregivers with high school education, public or no health insurance, no usual place of care, and 2 emergency room visits. Children with heart conditions, compared to those without, may have greater healthcare needs that more commonly go unmet. Among children with heart conditions, Hispanic and non-Hispanic

---

**Author for correspondence:** Sherry L. Farr, PhD, National Center on Birth Defects and Developmental, Disabilities, Centers for Disease Control and Prevention, 4770 Buford Hwy, MS 106-3, Atlanta, GA 30341, USA. Tel: +1 404 274 5638., sfarr@cdc.gov.

**Conflicts of interest.** None.

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

**Supplementary material.** To view supplementary material for this article, please visit <https://doi.org/10.1017/S1047951122004097>

Black children may experience lower socio-economic status and greater barriers to healthcare than non-Hispanic White children.

### Keywords

Racial/ethnic disparities; health care access; health care utilisation; CHD; paediatric; social determinants of health

---

An estimated 2.4% of United States children, or 1.7 million children, aged 0–17 years have a past or current heart condition.<sup>1</sup> Heart conditions may include congenital and acquired heart disease and syndromes affecting the heart. Compared to children without heart conditions, children with heart conditions, particularly those with congenital heart defects (CHDs), need life-long, specialty care.<sup>2</sup> Barriers to healthcare among children with heart conditions may include insufficient health insurance coverage, lack of proximity to healthcare providers with expertise in CHD, and unequal access to healthcare information related to CHD.<sup>3</sup> Racial disparities in health are caused by structural racism<sup>4,5</sup> – the conglomeration of mutually reinforcing, inequitable systems that reinforce discriminatory beliefs, values, and distributions of resources within a society.<sup>6</sup> Pathways through which structural racism affects health include economic injustice, social deprivation, and inadequate healthcare access and treatment.<sup>7</sup>

Despite advancements in medical care and increased survival of infants with heart conditions into adulthood, racial disparities in timing of diagnosis,<sup>8</sup> lapses in medical care,<sup>9</sup> preventive care utilisation,<sup>10</sup> quality of care,<sup>10</sup> and mortality<sup>11–14</sup> persist. Using Healthy People 2030's framework of social determinants of health,<sup>15</sup> identifying disparities in socio-economic status, education access and quality, and healthcare access and quality may provide insights into ways to improve the survival and overall health of all children with heart conditions. Thus, the objectives of this analysis were to (1) assess differences in socio-economic status, access to healthcare, and healthcare utilisation by presence of a heart condition and (2) assess differences in these outcomes by race/ethnicity among children with heart conditions.

## Materials and method

### National Survey of Children's Health

We performed a cross-sectional analysis of caregiver-reported data from the 2016–2019 National Survey of Children's Health, a population-based survey of the physical and emotional health of non-institutionalized United States children 17 years or younger. Households were randomly sampled from all 50 states and the District of Columbia. Among households identified with children, households with indicators of receipt of Supplemental Security Income or households living in areas of high poverty were sampled first. One child per household was selected. For households with multiple children, children aged 0–5 years and children with special healthcare needs were oversampled at a rate of 60 and 80%, respectively. National Survey of Children's Health oversamples children aged 0–5 and children with special healthcare needs to produce sufficient subgroup sizes to examine less common outcomes among them. Up to two primary caregivers were surveyed per child.

Surveys were offered in Spanish and English in web-based, paper, and telephone-assisted formats. From 2016 to 2019, the weighted overall response rate ranged from 37.4 to 43.1%. Data were weighted to account for non-response bias and to produce population-based estimates.

## Measures

All measures were caregiver-reported. Exposures of interest were child's heart condition status and race/ethnicity. Children were considered to have a heart condition if their caregiver answered "yes" to the following survey question: "Has a doctor or other healthcare provider EVER told you that this child has a heart condition?" Child's race/ethnicity was combined into the following categories: Hispanic, non-Hispanic White alone, and Non-Hispanic Black or African American alone. Non-Hispanic children of other race/ethnicities or multiple race/ethnicities were excluded due to low sample size among each group. (For non-Hispanic American Indian or Alaska Native, non-Hispanic Asian, non-Hispanic Native Hawaiian and Other Pacific Islander, non-Hispanic other, and non-Hispanic multiracial children, the total n was 15,562 [12.6%, range n = 273–7620] and among heart conditions was 327 [11%, range n = 8–187]) Missing data on race/ethnicity, representing <1% of children, were multiply imputed.

Covariates of interest included child's age and sex at birth. We grouped child's age into three categories: 0–6, 7–11, and 12–17 years. Child's sex at birth was defined as male or female. Missing data on age and sex were multiply imputed. We also examined primary language spoken at home, which was dichotomised as English and a language other than English.

The outcomes of this analysis broadly fall under three social determinants of health: socio-economic status, healthcare access, and healthcare utilisation. For socio-economic status, we examined caregiver's educational attainment and work status. We categorised educational attainment, based on information from up to two caregivers, as all surveyed caregivers having less than or equal to high school education and at least one having greater than high school education. Similarly, we defined caregiver's work status as "employed" if at least one caregiver indicated that he/she was employed at least 50 of the past 52 weeks, and "unemployed" if no caregivers were employed for at least 50 of the past 52 weeks.

For healthcare access, we examined child's insurance type, child's usual place of care, and whether the caregiver had problems paying for the child's healthcare in the past 12 months. We dichotomised child's health insurance type as any private (private only or public and private) and public, other, or no insurance. To determine child's usual place of care, caregivers were asked "Is there a place you or another caregiver USUALLY take this child when they are sick or you need advice about their health?" and "Where does this child USUALLY go first? ... Mark ONE only". Children whose reported usual place of care was a doctor's office or clinic/health centre were considered to have a usual place of care. Children who were usually taken to a place other than a doctor's office or clinic/health centre (e.g. an emergency room) or who had no usual place were considered not to have a usual place of care. The child's family was considered to have problems paying for healthcare if caregivers responded yes to the following question: "DURING THE PAST 12 MONTHS, did your family have problems paying for any of this child's medical or healthcare bills?" Caregivers

who answered “no” or who paid \$0 for their child’s healthcare in the past 12 months, and were therefore not asked the question on problems paying for care, were considered to have no problems paying for care.

For healthcare utilisation, we examined any preventive healthcare visits in the past 12 months, any specialty healthcare visits in the past 12 months, number of hospital emergency room visits in the past 12 months, and unmet need for care. Children who had no healthcare visits in the past 12 months were considered to have no preventive care or emergency room visits. To assess preventive healthcare in the past 12 months, caregivers were asked: “DURING THE PAST 12 MONTHS, how many times did this child visit a doctor, nurse, or other health care professional to receive a PREVENTIVE check-up? ... A preventive check-up is when this child was not sick or injured”. We dichotomised this variable as zero and one or more. To assess number of emergency visits, caregivers were asked “DURING THE PAST 12 MONTHS, how many times did this child visit a hospital emergency room?” We defined number of emergency room visits as 0, 1, or 2+ emergency room visits. To measure specialty care, caregivers were asked “DURING THE PAST 12 MONTHS, did this child see a specialist other than a mental health professional? ... Specialists are doctors like surgeons, heart doctors, allergy doctors, and others who specialize in one area of health care”. We defined needed specialty care as “Yes” and “No, but this child needed to see a specialist”. Children were considered to have unmet need for care if the parent answered “yes” to the following survey question: “DURING THE PAST 12 MONTHS, was there any time when this child needed health care but it was not received? ... Health care includes medical care, dental care, vision care, and mental health services”.

### Data analysis

We excluded children missing any variables of interest. Using chi square tests, we compared weighted prevalence of all social determinants of health outcomes, by heart condition status and race/ethnicity. Using the predicted marginal approach to multivariable logistic regression, adjusted for age and sex, we calculated adjusted prevalence ratios and 95% confidence intervals to examine the associations between heart condition status and each dichotomous outcome. For number of hospital emergency room visits, a three-level variable, we used the predicted marginal approach to multinomial logistic regression using a generalised logit link function. We also examined the associations between race/ethnicity and each outcome among children with and without heart conditions, separately. Among children with heart conditions, we examined effect modification in the association between race/ethnicity and outcomes by caregiver work status and educational attainment. As a sensitivity analysis, among children with heart conditions, we dichotomised Hispanic children into two groups: Hispanic children from primarily English-speaking households and Hispanic children from households primarily speaking a language other than English and compared outcomes between each group and non-Hispanic White children.

All analyses were conducted using SAS-callable SUDAAN. All estimates accounted for complex sampling and were weighted for non-response and to produce population-based national estimates. To create population-based estimates, the National Survey of Children’s Health assigns a weight for each child, comprised of the probability of the child’s

household being sampled, adjustment for non-response, and adjustments for demographic characteristics of the sampled children relative to the general US population (e.g. state, race, Hispanic ethnicity, sex, and age). More detailed information on sampling and weighting can be found in the National Survey of Children's Health Methodology Reports.<sup>16–19</sup> This analysis was exempt from human patients review due to the de-identified nature of this secondary dataset.

## Results

Of the 114,942 children of non-Hispanic White, non-Hispanic Black, or Hispanic race/ethnicity in the 2016–2019 National Survey of Children's Health, 359 children were excluded for missing information on heart condition status. Of the 2795 children with heart conditions and 111,788 without heart conditions, 163 (5.8%) and 6947 (6.2%), respectively, were excluded for missing data on other study variables. Our analytic sample comprised 104,841 children, 2632 with heart conditions, who were statistically weighted to represent 1.3 million United States children, or 2.2% of all United States children. Among children with heart conditions, children with missing data were more likely to have caregivers with a high school education or less and less likely to have problems paying for care (Supplementary Tables S1).

Non-Hispanic White children represented 65.4% and 58.0% of children with and without heart conditions, respectively (Table 1). Among children with heart conditions, 35.2% were 12–17 years old and 52.0% were male, compared to 34.3% and 51.1%, respectively, among children without heart conditions ( $p > 0.05$  for both). Among children with heart conditions, we observed no differences by race/ethnicity across age and sex strata; however, among children without heart conditions, we found that 37.4% of non-Hispanic Black children were 12–17 years old, compared to 33.8% of non-Hispanic White and Hispanic children, respectively ( $p < 0.001$ ).

### Comparing children with and without heart conditions

Almost one in five (19.7%) children with heart conditions compared to 23.5% of children without heart conditions did not have a usual place of medical care ( $p = 0.02$ ; adjusted prevalence ratio [95% confidence interval]: 0.8 [0.7, 1.0]); less than one in ten children with heart conditions (9.9%) compared to 19.8% of children without heart conditions had not received preventive healthcare in the past 12 months ( $p < 0.001$ ; 0.5 [0.4, 0.6]). However, for 18.0% of children with heart conditions compared to 10.5% of those without heart conditions caregivers reported having problems paying for the child's medical care ( $p < 0.001$ ; 1.7 [1.5, 2.0]) (Fig 1). Children with heart conditions were more likely to have one (22.4% versus 15.1%; (1.5 [1.3, 1.7]) and two or more (10.6% versus 4.5%; (2.4 [1.9, 3.0]) emergency room visits in the past 12 months ( $p < 0.001$ ) and unmet need for healthcare (5.6% versus 2.9%;  $p < 0.001$ ; 1.9 [1.4, 2.5]). Among children with heart conditions, 2.2% reported needing medical care, 1.9% dental care, 0.9% vision care, 1.8% mental health services, and 1.1% another type of care; 1.8% reported needing two or more types of care. The most frequently reported reasons contributing to children with heart conditions not receiving needed health services were issues related to cost (60.1%), difficulties getting an

appointment (54.2%), ineligibility for services (27.5%), services unavailable in their area (24.4%), and transportation (16.3%).

Among the 1318 children with and 19,082 without heart conditions who needed to see a specialist, 5.3% of children with heart conditions and 11.2% of children without heart conditions did not receive specialty healthcare in the past 12 months ( $p < 0.001$ ; adjusted prevalence ratio = 0.5 [0.3, 0.8]). We found only 3.2% of children with heart conditions had no insurance; therefore, we combined this category with public or no insurance. We found no difference in caregiver educational attainment and work status, and child's health insurance type by heart condition status.

### **Racial/ethnic disparities in outcomes among children with heart conditions**

Among children with heart conditions, caregiver employment ( $p = 0.007$ ) and education ( $p = 0.048$ ) differed by race/ethnicity. Specifically, among children with heart conditions, Hispanic children, compared with non-Hispanic White children, were more likely to have no caregiver employed at least 50 of the past 52 weeks (15.4% versus 8.0%; 1.9 [1.0, 3.5]) and have caregiver(s) with a high school education or less (33.1% versus 22.7%; adjusted prevalence ratio [95% confidence interval]: 1.5 [1.0, 2.1]). Compared with non-Hispanic White children, non-Hispanic Black children were also more likely to have no caregiver employed at least 50 of the past 52 weeks (24.7% versus 8.0%; 3.2 [1.9, 5.2]) and have caregiver(s) with a high school education or less (35.7% versus 22.7%; 1.6 [1.1, 2.3]) (Fig 2; for exact estimates see supplemental materials).

Differences by race/ethnicity among children with heart conditions were also seen for insurance type ( $p < 0.001$ ) and having a usual place of care ( $p = 0.001$ ). Specifically, among children with heart conditions, Hispanic compared with non-Hispanic White children were more likely to have public or no insurance (54.8% versus 29.6%; adjusted prevalence ratio = 1.9 [1.5, 2.4]) and no usual place of medical care (26.3% versus 14.5%; 1.8 [1.2, 2.7]). Compared with non-Hispanic White children, non-Hispanic Black children were also more likely to have public or no insurance (62.1% versus 29.6%; 2.1 [1.7, 2.7]) and no usual place of medical care (33.9% versus 14.5%; 2.3 [1.6, 3.4]). Estimates for public insurance did not change substantially when 73 children with no insurance were removed from the model (Hispanic adjusted prevalence ratio = 2.0; non-Hispanic Black adjusted prevalence ratio = 2.3). There were no racial/ethnic disparities in having problems paying for child's medical care among children with and without heart conditions.

Among children with heart conditions, no racial/ethnic disparities were seen in receipt of preventive or specialty healthcare visits in the past 12 months or unmet need for healthcare in the past 12 months ( $p > 0.05$  for all). However, Hispanic and non-Hispanic Black children, compared with non-Hispanic White children, respectively, were more likely to have  $\geq 2$  emergency room visits in the past 12 months (14.1%, 18.3% versus 7.8%,  $p < 0.001$ ; 1.8 [1.0, 3.2] and 2.3 [1.3, 4.3]).

The racial/ethnic disparities seen in socio-economic status and healthcare access among children with heart conditions were also seen among children without heart conditions (Supplementary Tables S2 and S3).

Among 287 children of Hispanic ethnicity with heart conditions and information on language primarily spoken at home, 27.1% primarily spoke a language other than English at home (n = 10 (3.4%) missing data on language spoken at home). Hispanic children from households who primarily spoke a language other than English were more likely than non-Hispanic White children not to have received preventive (21.7% versus 8.8%; 2.5 (1.2, 5.2)) or specialty (16.5% versus 4.0%; 3.9 (1.1, 13.7)) healthcare in the past 12 months, although chi square p-values were not statistically significant, likely due to smaller sample size ( $p > 0.05$ ). No disparities were seen between Hispanic children from primarily English-speaking households and non-Hispanic White children in not receiving preventive (9.6% versus 8.8%; adjusted prevalence ratio 1.1 (0.5, 2.4)) or specialty (3.5% versus 4.0%; 0.8 (0.2, 2.8)) healthcare in the past 12 months. Associations between Hispanic ethnicity and other outcomes did not differ substantially by language spoken at home.

When limited to children with heart conditions whose caregiver(s) were employed throughout the year, differences by race/ethnicity were seen for emergency room visits ( $p = 0.006$ ). Specifically, compared to non-Hispanic White children, Hispanic children were 2.4 [1.3, 4.4] times more likely to have 2 emergency room visits in the past 12 months (14.8% versus 6.2%). Compared to non-Hispanic White children, non-Hispanic Black children were no more likely to have 2 emergency room visits in the past 12 months (6.8% versus 6.2%; 1.0 [0.5, 2.1]). When limited to children with heart conditions who have caregiver(s) with greater than a high school education, differences by race/ethnicity were seen for emergency room visits ( $p = 0.002$ ) and insurance type ( $p < 0.001$ ). Specifically, compared to non-Hispanic White children, Hispanic children were 2.8 [1.6, 5.2] times more likely to have 2 emergency room visits in the past 12 months (16.4% versus 6.1%) and 2.8 [2.0, 3.8] times more likely to have public or no insurance (46.4% versus 16.9%). Compared to non-Hispanic White children, non-Hispanic Black children were 2.0 [0.9, 4.6] times more likely to have 2 emergency room visits in the past 12 months (12.1% versus 6.1%) and 3.1 [2.3, 4.1] times more likely to have public or no insurance (51.4% versus 16.9%).

## Discussion

In this analysis of over 2600 United States children with heart conditions, we found that children with heart conditions were more likely than children without heart conditions to have parents reporting problems paying for child's medical care, unmet needs for healthcare, and need for emergency care. In addition, non-Hispanic Black and Hispanic children with heart conditions were more likely than their non-Hispanic White counterparts to have parents with less education and lower employment, to have public or no health insurance and no usual place of medical care, and to need more emergency care. For Hispanic children, associations were stronger for those from non-English speaking households. These findings show that children with heart conditions may have greater healthcare needs that more commonly go unmet compared to children without heart conditions, and non-Hispanic Black and Hispanic children with heart conditions may experience lower socio-economic status and even greater barriers to healthcare than non-Hispanic White children with heart conditions.

Among children with heart conditions, almost one in five had parents who reported trouble paying for care and over one in 20 had unmet healthcare needs, approximately twice the prevalence of children without heart conditions. Financial stress is prevalent among families of children with CHD, especially families of low socio-economic status or families with children who have severe CHD or special healthcare needs.<sup>20,21</sup> Financial difficulty has been associated with delayed care and adverse health outcomes among children with CHD.<sup>20,22</sup> In a nationally representative study of 188 United States families of children with CHD, a quarter who were unable to pay medical bills delayed or never received needed care for their child.<sup>20</sup> Delayed care may further result in the need for emergency care.<sup>23</sup> In this study, approximately one in five children with heart conditions had visited the emergency room once in the previous 12 months and one in ten had visited two or more times, around two to three times that of children without heart problems, respectively. Among children with heart conditions, reasons for higher emergency room use may be due to the need for urgent cardiac care determined by the family or treating physician. This disparity in emergency room use was most prominent among Hispanic and non-Hispanic Black children with heart conditions among whom one in six and one in seven visited the emergency room two or more times in the preceding 12 months.

This study found further disparities in socio-economic status and healthcare access and utilisation by race and ethnicity among children with heart conditions. Approximately one in three caregivers of non-Hispanic Black and Hispanic children had less than a high school education, compared to one in five caregivers of non-Hispanic White children. Previous studies found associations between caregiver educational attainment and poor outcomes among children with CHD.<sup>24–28</sup> Recent systematic reviews focused on children with CHD found that low parental education is associated with higher infant mortality, less access to care, increased risk of loss to follow up cardiology care, hospital re-admission, neurodevelopmental problems, and lower quality of life.<sup>29,30</sup> Caregiver education may also impact health-related knowledge, literacy, and problem-solving skills.<sup>31</sup> Caregivers with limited English proficiency may also face additional barriers navigating the healthcare system and accessing quality care.<sup>32,33</sup> Similarly, in this analysis, compared to non-Hispanic White children we found Hispanic children living in primarily non-English speaking households were more likely not to have had a preventive or specialty care visit in the past 12 months.

Additionally, the current study found larger percentages of caregivers of non-Hispanic Black and Hispanic children were unemployed, compared to non-Hispanic White children. Many studies have examined income or federal poverty status, rather than employment, finding racial/ethnic disparities in these measures of monetary resources. They further found associations between monetary resources and poor outcomes related to fetal diagnosis of CHD, CHD prevalence and incidence, infant mortality, post-surgical outcomes, access to care, loss to follow up, and hospital readmission among children with CHD.<sup>30</sup> In this study, we measured socio-economic status through consistency of employment, which is correlated with monetary resources, but also has implications for the child's health insurance.

We found additional racial and ethnic disparities among children with heart conditions in healthcare access and utilisation, specifically, differences in health insurance and having a



usual place of care. Among children with heart conditions, we found approximately half to two-thirds of non-Hispanic Black and Hispanic children only had public, other, or no health insurance and a quarter to a third of non-Hispanic Black and Hispanic children had no usual place of care, approximately twice that of non-Hispanic White children. Our finding is consistent with previous studies showing greater prevalence of public, Medicaid, or no insurance among non-White children compared to White children with CHD.<sup>9,28,31,34</sup> While public insurance provides healthcare access to children of lower income families and those with special healthcare needs, previous studies have found poorer outcomes among children with public insurance, such as lapses in cardiac care, hospital admission, mortality, number of emergency visits, and in hospital admission or mortality during an emergency room visit.<sup>29,30,35,36</sup> A study of 420,452 paediatric CHD-related emergency department visits, using 2006–2014 data from the nationwide emergency department sample, found two-thirds of CHD-related emergency department visits had government insurance as a primary payer, and that government insurance was a risk factor for inpatient hospital admission.<sup>35</sup> Racial and ethnic disparities have also been observed in emergency department visits among children with Kawasaki disease,<sup>37</sup> in mortality among children with cardiomyopathy and myocarditis,<sup>38</sup> and in treatment<sup>39</sup> and infant mortality<sup>40</sup> among infants with arrhythmias. Additionally, children with heart conditions of Hispanic ethnicity may be less likely than their non-Hispanic White counterparts to have a medical home,<sup>10</sup> and non-White children with CHD fall out of cardiac care earlier than White children.<sup>9</sup>

Several studies have found associations between race/ethnicity and poor outcomes,<sup>9,10,13,34</sup> and social determinants of health and poor outcomes,<sup>20–22,29,30,35</sup> yet few studies have examined the role of socio-economic indicators as potential mediators of the relationship between race/ethnicity and outcomes among children with CHD.<sup>28,31</sup> One such study found insurance status and maternal education mediated a quarter to a third of the relationship between Hispanic ethnicity and composite risk of mortality or unexpected hospital re-admissions in the first year of life.<sup>31</sup> Among children whose caregivers were employed or who had greater than a high school education, we found associations with 2 emergency room visits for Hispanic children strengthened and for non-Hispanic Black children attenuated slightly. While the current study shows associations between race/ethnicity and upstream social determinants of health, further research is needed to untangle the relationship between race/ethnicity, social determinants of health including insurance type and education, and poor outcomes.

The strengths of this analysis are in our use of a nationally representative data source and the large sample size of children with heart conditions. Yet, this study has some limitations. Of note, the National Survey of Children's Health is caregiver-reported and not otherwise validated. No information is available on what type of heart condition a child may have. Based on a CHD birth prevalence of about 1%<sup>41</sup> and given the 2.2% of children in our data have ever had a heart condition, less than half of children with heart problems in our sample may have CHD. Additionally, we were unable to examine other racial/ethnic groups or multiracial individuals due to low sample size within strata, and heterogeneity in results between these racial/ethnic groups prohibited their grouping. Compared to children included in this study, children missing data were more likely to have caregivers with a high school education or less and less likely to have problems paying for care, which may limit the

generalizability of our findings. Our measures for educational attainment and employment status were defined as a composite score of one or more caregivers. Thus, non-Hispanic Black children who are more likely to have one caregiver, rather than two, are necessarily more likely to have a higher percentage of caregivers not employed.<sup>34</sup> We were unable to distinguish between preventative primary care and preventative cardiology care in these data. Thus, for children with heart conditions, the prevalence of preventative care may be overestimated. The survey also does not specify the type of specialty care received. Finally, we could not link the upstream social determinants of health we examined to poor outcomes in these data.

Racial and ethnic disparities in social determinants of health, such as socio-economic status and healthcare access, are rooted in structural racism<sup>4</sup>; therefore, to achieve health equity in CHD, experts in the field have proposed interventions at the individual and population levels, such as diversifying the CHD workforce and implementing policies for lifelong insurance.<sup>42</sup> Additionally, interventions at the clinic and community level studied among other patient populations may have the potential to reduce these disparities. One such intervention is using parent mentors who themselves have children with CHD to facilitate and enhance communication between providers and families of children with CHD,<sup>30</sup> which has been shown to improve outcomes among children with asthma<sup>43</sup> and improve insurance rates, healthcare access, and parental satisfaction among uninsured children.<sup>44</sup> Other researchers have emphasised screening for social determinants of health at all healthcare visits, including specialty healthcare visits,<sup>42</sup> and utilising team-based care, including social workers to assist with barriers to care such as transportation and food insecurity.<sup>45</sup> Additionally, flags within medical records to identify children facing social complexities (e.g. parent or child mental illness, parent death, parent domestic violence, etc.) could help ensure they receive extra supports as needed.<sup>45</sup> Other researchers have suggested utilising medical interpreters for families of children with limited English language proficiency and providing community-based visitation programmes for new and pregnant mothers to ensure timely diagnosis of CHD and earlier treatment.<sup>34</sup>

In this analysis, we found barriers to care for children with heart conditions and racial/ethnic disparities in social determinants of health, such as socio-economic status and healthcare access and utilisation, among children with heart conditions. There is a need to identify families of children with CHD with unmet social or financial needs and to ensure equitable access to care for these children.<sup>46–49</sup> More understanding on ways in which social determinants of health, such as those examined in this analysis, modify the associations between race/ethnicity and poor outcomes may be beneficial. Additionally, further evaluation and implementation of successful strategies to improve social determinants of health may help decrease racial/ethnic disparities among children with heart conditions.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

## Acknowledgements.

This analysis was replicated by Brittany Wright.

### Financial support.

This research received no specific grant from any funding agency, commercial, or not-for-profit sectors.

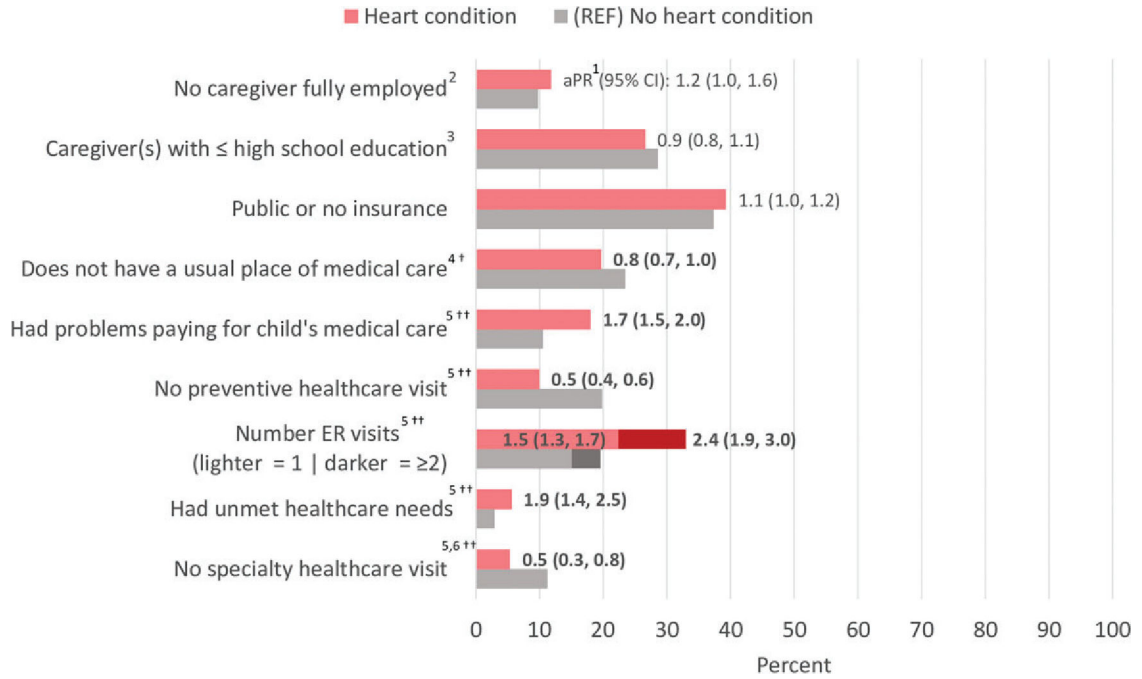
This project was supported in part by an appointment to the Research Participation Programme at the Centers for Disease Control and Prevention, administered by the Oak Ridge Institute for Science and Education through an interagency agreement between the US Department of Energy and CDC.

## References

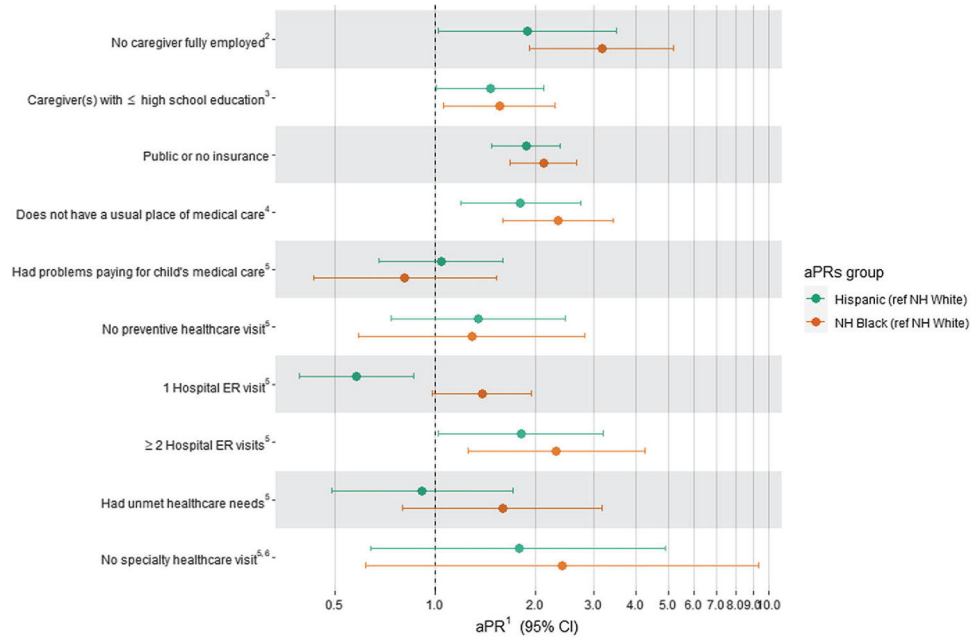
1. Chen M, Riehle-Colarusso T, Yeung LF, Smith C, Farr SL. Children with heart conditions and their special health care needs — United States, 2016. *Morb Mortal Week Rep* 2018; 67: 1045–1049.
2. Stout KK, Daniels CJ, Aboulhosn JA, et al. 2018 AHA/ACC guideline for the management of adults with congenital heart disease: a report of the American College of Cardiology/American Heart Association Task Force on Clinical Practice Guidelines. *Circulation* 2018; 139.
3. Jenkins KJ, Botto LD, Correa A, et al. Public health approach to improve outcomes for congenital heart disease across the life span. *J Am Heart Assoc* 2019; 8: e009450. [PubMed: 30982389]
4. Churchwell K, Elkind MSV, Benjamin RM, et al. Call to action: structural racism as a fundamental driver of health disparities: a presidential advisory from the American Heart Association. *Circulation* 2020; 142: e454–e468. [PubMed: 33170755]
5. Williams DR, Cooper LA. Reducing racial inequities in health: using what we already know to take action. *Int J Environ Res Public Health* 2019; 16: 606. [PubMed: 30791452]
6. Krieger N. Discrimination and health inequities. *Int J Health Serv* 2014; 44: 643–710. [PubMed: 25626224]
7. Bailey ZD, Krieger N, Agénor M, Graves J, Linos N, Bassett MT. Structural racism and health inequities in the USA: evidence and interventions. *Lancet* 2017; 389: 1453–1463. [PubMed: 28402827]
8. Krishnan A, Jacobs MB, Morris SA, et al. Impact of socioeconomic status, race and ethnicity, and geography on prenatal detection of hypoplastic left heart syndrome and transposition of the great arteries. *Circulation* 2021; 143: 2049–2060. [PubMed: 33993718]
9. Jackson JL, Morack J, Harris M, DeSalvo J, Daniels CJ, Chisolm DJ. Racial disparities in clinic follow-up early in life among survivors of congenital heart disease. *Congenit Heart Dis* 2019; 14: 305–310. [PubMed: 30561880]
10. Broughton A, Riehle-Colarusso T, Nehl E, Riser AP, Farr SL. Preventive care and medical homes among US children with heart conditions. *Cardiol Young* 2021; 31: 114–120. [PubMed: 33161934]
11. Boneva RS, Botto LD, Moore CA, Yang Q, Correa A, Erickson JD. Mortality associated with congenital heart defects in the United States: trends and racial disparities, 1979–1997. *Circulation* 2001; 103: 2376–2381. [PubMed: 11352887]
12. Gilboa SM, Salemi JL, Nembhard WN, Fixler DE, Correa A. Mortality resulting from congenital heart disease among children and adults in the United States, 1999 to 2006. *Circulation* 2010; 122: 2254–2263. [PubMed: 21098447]
13. Lopez KN, Morris SA, Sexson Tejtel SK, Espaillat A, Salemi JL. US mortality attributable to congenital heart disease across the lifespan from 1999 through 2017 exposes persistent racial/ethnic disparities. *Circulation* 2020; 142: 1132–1147. [PubMed: 32795094]
14. Oster ME, Strickland MJ, Mahle WT. Impact of prior hospital mortality versus surgical volume on mortality following surgery for congenital heart disease. *J Thorac Cardiovasc Surg* 2011; 142: 882–886. [PubMed: 21571324]
15. Office of Disease Prevention and Health Promotion. *Social Determinants of Health: U.S. Department of Health and Human Services*, 2020.

16. U.S. Census Bureau. 2016 National Survey of Children's Health Methodology Report. U.S. Department of Commerce, 2018.
17. U.S. Census Bureau. 2017 National Survey of Children's Health Methodology Report. U.S. Department of Commerce, 2018.
18. U.S. Census Bureau. 2018 National Survey of Children's Health Methodology Report. U.S. Department of Commerce, 2018. 2019
19. U.S. Census Bureau. 2019 National Survey of Children's Health Methodology Report. U.S. Department of Commerce, 2020.
20. Ludomirsky AB, Bucholz EM, Newburger JW. Association of financial hardship because of medical bills with adverse outcomes among families of children with congenital heart disease. *JAMA Cardiol* 2021; 6: 713–717. [PubMed: 33325991]
21. Connor JA, Kline NE, Mott S, Harris SK, Jenkins KJ. The meaning of cost for families of children with congenital heart disease. *J Pediatr Health Care* 2010; 24: 318–325. [PubMed: 20804952]
22. McClung N, Glidewell J, Farr SL. Financial burdens and mental health needs in families of children with congenital heart disease. *Congenit Heart Dis* 2018; 13: 554–562. [PubMed: 29624879]
23. Gurvitz M, Valente AM, Broberg C, et al. Prevalence and predictors of gaps in care among adult congenital heart disease patients: HEART-ACHD (The Health, Education, and Access Research Trial). *J Am Coll Cardiol* 2013; 61: 2180–2184. [PubMed: 23542112]
24. Kucik JE, Nembhard WN, Donohue P, et al. Community socioeconomic disadvantage and the survival of infants with congenital heart defects. *Am J Public Health* 2014; 104: e150–e157. [PubMed: 25211743]
25. Loccoh EC, Yu S, Donohue J, et al. Prevalence and risk factors associated with non-attendance in neurodevelopmental follow-up clinic among infants with CHD. *Cardiol Young* 2018; 28: 554–560. [PubMed: 29357956]
26. Majnemer A, Limperopoulos C, Shevell M, Rohlicek C, Rosenblatt B, Tchervenkov C. Developmental and functional outcomes at school entry in children with congenital heart defects. *J Pediatr* 2008; 153: 55–60. [PubMed: 18571536]
27. Mulkey SB, Bai S, Luo C, et al. School-age test proficiency and special education after congenital heart disease surgery in infancy. *J Pediatr* 2016; 178: 47–54.e41. [PubMed: 27453376]
28. Kucik JE, Cassell CH, Alverson CJ, et al. Role of health insurance on the survival of infants with congenital heart defects. *Am J Public Health* 2014; 104: e62–70.
29. Best KE, Vieira R, Glinianaia SV, Rankin J. Socio-economic inequalities in mortality in children with congenital heart disease: a systematic review and meta-analysis. *Paediatr Perinat Epidemiol* 2019; 33: 291–309. [PubMed: 31347722]
30. Davey B, Sinha R, Lee JH, Gauthier M, Flores G. Social determinants of health and outcomes for children and adults with congenital heart disease: a systematic review. *Pediatr Res* 2021; 89: 275–294. [PubMed: 33069160]
31. Peyvandi S, Baer RJ, Moon-Grady AJ, et al. Socioeconomic mediators of racial and ethnic disparities in congenital heart disease outcomes: a population-based study in California. *J Am Heart Assoc* 2018; 7: e010342. [PubMed: 30371284]
32. Eneriz-Wiemer M, Sanders LM, Barr DA, Mendoza FS. Parental limited English proficiency and health outcomes for children with special health care needs: a systematic review. *Acad Pediatr* 2014; 14: 128–136. [PubMed: 24602575]
33. Gulati RK, Hur K. Association between limited english proficiency and healthcare access and utilization in California. *J Immigr Minor Health* 2022; 24: 95–101. [PubMed: 34097162]
34. Peterson JK, Catton KG, Setty SP. Healthcare disparities in outcomes of a metropolitan congenital heart surgery center: the effect of clinical and socioeconomic factors. *J Racial Ethn Health Disparities* 2018; 5: 410–421. [PubMed: 28849382]
35. Edelson JB, Rossano JW, Griffis H, et al. Emergency department visits by children with congenital heart disease. *J Am Coll Cardiol* 2018; 72: 1817–1825. [PubMed: 30286926]
36. Skinner AC, Mayer ML. Effects of insurance status on children's access to specialty care: a systematic review of the literature. *BMC Health Serv Res* 2007; 7: 194. [PubMed: 18045482]

37. Lo J, Gauvreau K, Baker AL, et al. Multiple emergency department visits for a diagnosis of Kawasaki disease: an examination of risk factors and outcomes. *J Pediatr* 2021; 232: 127–132.e123. [PubMed: 33453202]
38. Olsen J, Tjoeng YL, Friedland-Little J, Chan T. Racial disparities in hospital mortality among pediatric cardiomyopathy and myocarditis patients. *Pediatr Cardiol* 2021; 42: 59–71. [PubMed: 33025028]
39. Sooy-Mossey M, Neufeld T, Hughes TL, et al. Health disparities in the treatment of supraventricular tachycardia in pediatric patients. *Pediatr Cardiol* 2022; 43: 1857–1863. [PubMed: 35536424]
40. Well A, Fenrich A, Shmorhun D, et al. Arrhythmias requiring ECMO in infants without structural congenital heart disease. *Pediatr Cardiol* 2022; 43: 914–921. [PubMed: 35037091]
41. Reller MD, Strickland MJ, Riehle-Colarusso T, Mahle WT, Correa A. Prevalence of congenital heart defects in metropolitan Atlanta, 1998–2005. *J Pediatr* 2008; 153: 807–813. [PubMed: 18657826]
42. Lopez KN, Baker-Smith C, Flores G, et al. Addressing social determinants of health and mitigating health disparities across the lifespan in congenital heart disease: a scientific statement from the American Heart Association. *J Am Heart Assoc* 2022; 11: e025358. [PubMed: 35389228]
43. Flores G, Bridon C, Torres S, et al. Improving asthma outcomes in minority children: a randomized, controlled trial of parent mentors. *Pediatrics* 2009; 124: 1522–1532. [PubMed: 19948624]
44. Flores G, Lin H, Walker C, et al. Parent mentors and insuring uninsured children: a randomized controlled trial. *Pediatrics* 2016; 137: e20153519. [PubMed: 27244706]
45. Arthur KC, Lucenko BA, Sharkova IV, Xing J, Mangione-Smith R. Using state administrative data to identify social complexity risk factors for children. *Ann Fam Med* 2018; 16: 62–69. [PubMed: 29311178]
46. Council On Community P. Poverty and child health in the United States. *Pediatrics* 2016; 137.
47. Cheng TL, Goodman E, Bogue CW, et al. Race, ethnicity, and socioeconomic status in research on child health. *Pediatrics* 2015; 135: e225–237. [PubMed: 25548336]
48. Chowdhury D, Johnson JN, Baker-Smith CM, et al. Health care policy and congenital heart disease: 2020 focus on our 2030 future. *J Am Heart Assoc* 2021; 10: e020605. [PubMed: 34622676]
49. Parker MG, Garg A, Brochier A, et al. Approaches to addressing social determinants of health in the NICU: a mixed methods study. *J Perinatol* 2021; 41: 1983–1991. [PubMed: 33128013]



**Figure 1.** Prevalence and adjusted prevalence ratios of indicators of family socioeconomic status, health care access, and health care utilization among U.S. children with and without heart conditions, National Survey of Children’s Health 2016–19 aPR: adjusted prevalence ratio; CI: confidence interval; ER: emergency room; Bolded aPRs: statistically significant; <sup>1</sup>Adjusted for age, sex; <sup>2</sup>No caregiver(s) are employed at least 50 of the past 52 weeks; <sup>3</sup>All caregiver(s) have a high school education or less; <sup>4</sup>Those who did not receive their usual care at a doctor’s office received care at a hospital ER or OD, retail store clinic or ‘Minute Clinic,’ school, some other place, or no place; <sup>5</sup>in past 12 months; <sup>6</sup>Among 1,318 and 19,082 children with and without heart conditions, respectively, who needed a specialty healthcare visit; †=p<0.05; ††=p<0.01.



**Figure 2.** Adjusted prevalence ratios of indicators of family socioeconomic status, health care access, and health care utilization by race/ethnicity among U.S. children with heart conditions, National Survey of Children’s Health 2016–19 aPRs: adjusted prevalence ratios; CI: confidence interval; ER: emergency room; <sup>1</sup>Adjusted for age, sex; <sup>2</sup>No caregiver(s) are employed at least 50 of the past 52 weeks; <sup>3</sup>All caregiver(s) have a high school education or less; <sup>4</sup>Those who did not receive their usual care at a doctor’s office received care at a hospital ER or OD, retail store clinic or ‘Minute Clinic,’ school, some other place, or no place; <sup>5</sup>in past 12 months; <sup>6</sup>Among 1,318 and 19,082 children with and without heart conditions, respectively, who needed a specialty healthcare visit.

**Table 1.** Demographic characteristics of children with and without heart conditions, National Survey of Children’s Health 2016–19.

	Among children with heart conditions										Among children without heart conditions										Chi-Square P value <sup>2</sup>	Chi-Square P value <sup>3</sup>	
	All children with heart conditions					Non-Hispanic White					Hispanic					Non-Hispanic Black							
	Total N	Total weighted % (95% CI)	Weighted % (95% CI)	N	Chi-square P value <sup>1</sup>	Total N	Total weighted % (95% CI)	Weighted % (95% CI)	N	Chi-square P value <sup>1</sup>	Total N	Total weighted % (95% CI)	Weighted % (95% CI)	N	Chi-square P value <sup>1</sup>	Total N	Total weighted % (95% CI)	Weighted % (95% CI)	N	Chi-square P value <sup>1</sup>			
Total	2,632	2.2 (2.1, 2.4)	65.4 (61.2, 69.3)	2,162	297	20.8 (17.3, 24.8)	173	13.8 (11.2, 16.9)	104,841	97.8 (97.6, 97.9)	84,275	58.0 (57.3, 58.8)	13,546	27.6 (26.9, 28.4)	7,020	14.3 (13.8, 14.8)							
Age (years)																							
6	801	34.8 (31.2, 38.6)	35.2 (31.2, 39.4)	654	97	33.8 (24.7, 44.2)	50	34.8 (24.7, 46.5)	34,403	37.2 (36.6, 37.9)	27,755	38.3 (37.7, 39.0)	4,562	37.0 (35.2, 38.8)	2,086	33.3 (31.4, 35.3)							0.454
11	672	29.9 (26.2, 33.9)	30.9 (26.6, 35.6)	544	80	26.5 (18.1, 37.0)	48	30.5 (21.3, 41.6)	28.4 (27.8, 29.1)	21,265	27.8 (27.3, 28.4)	3,700	3.700	29.2	1,911	29.3 (27.5, 31.1)							
17	1,159	35.2 (31.8, 38.9)	33.9 (30.4, 37.7)	964	120	39.7 (29.8, 50.7)	75	34.7 (25.4, 45.3)	34.3 (33.7, 35.0)	35,255	33.8 (33.2, 34.4)	5,284	5.284	33.8	3,023	37.4 (35.5, 39.4)							
Male	1,448	52.0 (48.1, 56.0)	50.2 (45.9, 54.5)	1,170	167	51.2 (40.6, 61.8)	111	62.0 (50.7, 72.1)	54,356	51.1 (50.4, 51.8)	43,741	51.2 (50.6, 51.9)	6,977	50.9 (49.1, 52.8)	3,638	50.8 (48.8, 52.8)							0.886
Female	1,184	48.0 (44.0, 51.9)	49.8 (45.5, 54.1)	992	130	48.8 (38.2, 59.4)	62	38.0 (27.9, 49.3)	48.9 (48.2, 49.6)	40,534	48.8 (48.1, 49.4)	6,569	6.569	49.1	3,382	49.2 (47.2, 51.2)							

<sup>1</sup> Comparing characteristics by race/ethnicity among children with heart conditions.

<sup>2</sup> Comparing characteristics by race/ethnicity among children without heart conditions.

<sup>3</sup> Comparing characteristics by heart status among all children.

CI = confidence interval.