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Educational Attainment and Employment Status of Adults Living With Congenital Heart Disease in the United States, CH STRONG 2016–2019

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Abstract

Background: Our objective was to characterize the education and employment history of young adults with congenital heart defects (CHD) living in the United States.

Methods: The 2016–2019 Congenital Heart Survey To Recognize Outcomes, Needs, and well-being collected data from young adults (ages 19–38) with CHD identified from active birth defect in Arkansas, Arizona, and Atlanta, Georgia. Educational attainment, employment history, and special education between kindergarten and 12th grade were self-/proxy-reported. Respondent percentages were standardized to the eligible population by CHD severity, birth year, site, sex, and maternal race/ethnicity and compared by CHD severity using *p* values from *Z*-scores. Log-binomial prevalence ratios (aPRs) assessed associations between respondent characteristics and

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Conflicts of Interest

The authors declare no conflicts of interest.

Disclosure

The authors have nothing to report.

Supporting Information

Additional supporting information can be found online in the Supporting Information section.

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. Analyses have been replicated by Justina Omari.

outcomes, adjusting for CHD severity, age group, sex, race/ethnicity, and site. Employment models also adjusted for education. Point estimates were compared to the 2018 American Community Survey (ACS) 5-year general population estimates.

Results: Among 1438 respondents, 28.3% attained $\geq$ bachelor's degree and 22.1% were unemployed for $\geq$ 12 months. Estimates were comparable by CHD severity (aPRs $\sim$ 1.0) and similar to general population estimates (in ACS, 21% attained $\geq$ bachelor's degree and 26% were unemployed). About 25.3% of adults with CHD received special education, more commonly adults with severe (32.9%) than nonsevere CHD (23.5%, $p = 0.01$).

Conclusions: Among young adults with CHD, educational attainment and employment did not substantially differ by CHD severity or from general population rates. One in four used special education between kindergarten and 12th grade. Clinical guidelines recommend ongoing educational and vocational support to individuals with CHD as needed so this population continues to thrive.

Keywords

adults with CHD; congenital heart defects; educational attainment; employment; special education; surveys and questionnaires; young adult

1 | Introduction

Congenital heart defects (CHD) are the most common structural birth defect and occur in approximately 1% of all live births (Reller et al. 2008). More than 80% of children born with CHD are expected to live to adulthood (Downing et al. 2023; Mandalenakis et al. 2017; Moons et al. 2010; Wauthy et al. 2011). As these children with CHD age, their parents express concerns regarding their children's future, including their education and employment opportunities in adulthood (Delaney et al. 2021). Researchers have estimated that, since 2010, there are more adults than children living with CHD in the United States (US) (Gilboa et al. 2016). Given the advancements in CHD care, they expect this gap will continue to grow as children age into adulthood and adults with CHD continue to live longer.

Adverse neurodevelopmental outcomes are common among children with CHD (Marino et al. 2012). Cognitive impairment and motor limitations can negatively impact their learning and concentration, communication, and gross and fine motor skills (Farr et al. 2018; Oster et al. 2017; Snookes et al. 2010), which may compromise future educational and employment outcomes. While a few studies have shown academic performance is worse in children with CHD compared to those without CHD (Bellinger et al. 2015; Lawley et al. 2019; Mulkey et al. 2016; Oster et al. 2017; Schaefer et al. 2016; Wotherspoon et al. 2020), similar studies of educational attainment in adults with CHD outside of the United States have had mixed results. These results have ranged from findings of lower educational attainment (Gong et al. 2020; Karsenty et al. 2015), to no difference (Bygstad et al. 2012; Raissadati et al. 2020; Schaefer et al. 2016; Vigl et al. 2011), to higher educational attainment among adults with CHD (Nieminen et al. 2003).

As in the general population, educational attainment is a predictor of employment status for adults with CHD (Sluman et al. 2019). However, similar to education, results from studies on employment among adults with CHD outside the United States are mixed, showing lower employment rates (Geyer et al. 2009), no difference (Kokkonen and Paavilainen 1992), or higher rates (Crossland et al. 2005) compared to adults without CHD. Among those with CHD, some studies have also found that employment rates decrease with increasing CHD severity (Crossland et al. 2005; Kamphuis et al. 2002).

Data are limited on education and employment outcomes of adults with CHD within the United States, though both are important contributors to quality of life and independence (Apers et al. 2016; Girouard and Kovacs 2020). Therefore, using population-based Congenital Heart Survey To Recognize Outcomes, Needs, and well-being (CH STRONG) data, we aimed to characterize educational attainment and employment history of young adults (19–38 years) with CHD in Arizona (AZ), Arkansas (AR), and metropolitan Atlanta, Georgia (GA) and to compare educational and employment outcomes across demographic and CHD-related characteristics.

2 | Methods

2.1 | CH STRONG Design and Population Description

CH STRONG was a Centers for Disease Control and Prevention (CDC)-funded project that used active case-finding methods in population-based birth defects surveillance systems in AZ, AR, and GA to identify young adults born with CHD between 1980 and 1997 and survey them on their longer-term outcomes, including educational attainment and employment. After using vital records to identify and exclude individuals who were deceased, a total of 9312 individuals with CHD were eligible to participate. Contact information collected at or around the time of birth by the birth defect surveillance systems was used to track and trace those eligible to their current address. Valid addresses were found for 6943 individuals. CH STRONG researchers then implemented established survey methods (Dillman 1978) (involving an introductory letter, a survey packet followed by a reminder postcard, and a replacement survey packet followed by reminder postcard, sent in established intervals) to recruit survey participants between 2016 and 2019 (i.e., when they were 19–38 years of age). Of those, 1656 completed the survey (response rates: 17.8% among all 9312 eligible; 23.9% among the 6943 who were sent a survey). To reduce sampling bias associated with nonresponse and adjust for differences in characteristics between respondents and nonrespondents, survey weights standardized the prevalence estimates from the analytic sample to the 9312 eligible individuals by site of birth, year of birth, sex, maternal race/ethnicity, and CHD severity. When results were stratified by CHD severity, standardization only involved site of birth, year of birth, sex, and maternal race/ethnicity. More detailed information has been published describing CH STRONG's methodology (Farr et al. 2020).

2.2 | CHD

CHD were diagnosed at birth or shortly thereafter and were identified from the birth defect surveillance systems using a 6-digit CDC-modified version of the British Pediatric

Association (CDC/BPA) codes between 745.000–746.860, 746.880–746.900, 747.100–747.400, and 747.900, excluding patent foramen ovale and other non-specific codes (Table S1) (Farr et al. 2020).

Information on anatomic severity of CHD (hereafter, referred to as CHD severity) was compiled from the CDC/BPA codes included in the respective site birth defects surveillance systems. Using a previously published categorization (Farr et al. 2020), CHD severity was identified as one of five different categories: severe, shunt and valve, shunt alone, valve alone, and other (Table S1). For this study, CHD severity status was further dichotomized into severe and nonsevere (which combines shunt and valve, shunt alone, valve alone, and other). All eligible cases were also assigned a primary CHD diagnosis, which we examined in supplemental analyses. For individuals with multiple types of CHD in different severity categories, the most severe defect was considered their primary diagnosis. If individuals had multiple types of CHD of similar severity, CH STRONG congenital cardiologists reviewed the CHD diagnosis codes and reached consensus on the primary diagnosis.

2.3 | Outcome Measures

CH STRONG participants were asked to report the highest school grade or postsecondary education they had completed. Responses were combined into four categories (less than high school, high school or equivalent, some college or associate degree, and bachelor's degree or higher) or two categories (high school or less, more than high school), depending on the analysis. On the survey, respondents reported if they participated in “special education” (not including “advanced placement” or “homebound education”) between kindergarten and 12th grade. The term “special education” on the survey was left to the interpretation of the participant and can include any specialized instruction designed to meet the unique needs of children with learning differences (U.S. Department of Education 2004). Those who reported participating in special education were further asked in which grade group they participated (kindergarten–3rd grade, 4th–6th grade, 7th–12th grade).

The employment history variables asked subjects to respond “full-time,” “part-time,” or “no” to the question “During the last 12 months, did you work for pay at any time at a job or business?” Subjects could select more than one response, and for this analysis the highest employment history response was used (e.g., if respondents answered “yes” to both working full- and part-time, the full-time response was analyzed).

2.4 | Covariates

Demographic characteristics included age group category in years (19–24, 25–30, 31–38), sex (male, female); self-reported race and ethnicity (categorized into non-Hispanic White, non-Hispanic Black, Hispanic, and non-Hispanic Other—including non-Hispanic American Indian or Alaskan Native, Asian, Native Hawaiian or Pacific Islander, or multi-racial); and site of birth (Arkansas [AR], Arizona [AZ], and Metro Atlanta, Georgia [GA]).

2.5 | Analytic Design

Individuals with genetic syndromes (e.g., Down syndrome) and individuals missing data on covariates, educational attainment, or the employment outcomes were excluded

from the analysis. Among the analytic sample, descriptive profiles (cell frequencies and unstandardized percentages) are presented for demographic characteristics by CHD severity. Chi-square tests of association (testing significance at $\alpha = 0.05$) were used to identify differences across CHD severity. Similar descriptive profiles (cell frequencies and unstandardized percentages) stratified by site of birth, rather than CHD severity, are included as supplemental analyses. Percentages of educational attainment, employment history, and special education participation are presented, standardized to the site of birth, year of birth, sex, maternal race/ethnicity, and CHD severity distribution of the 9312 eligible individuals in CH STRONG as collected from birth defect surveillance systems.

Percentages of educational attainment and employment history among the older age groups (i.e., 25–38) are included as supplemental analyses. Among all CH STRONG participants, comparisons between standardized percentages by CHD severity were assessed by calculating *Z*-scores and corresponding *p*-values.

To assess associations between respondent characteristics and outcomes, prevalence ratios (aPRs) were calculated using log-binomial regression models and adjusted for CHD severity, age, sex, self-reported race/ethnicity, and site of birth, with corresponding 95% confidence intervals (CIs). Models for employment outcomes also included educational attainment as a covariate. Supplemental analyses present standardized percentages of educational attainment and employment history by primary CHD diagnosis (for CHD types with > 25 observations).

All analyses were performed using SAS-callable SUDAAN. CH STRONG was approved by CDC's and University of Arkansas for Medical Sciences' Institutional Review Boards (IRB). The University of Arizona deferred to the CDC IRB.

3 | Results

Of 1656 CH STRONG survey respondents, 176 (10.6%) were excluded for having genetic syndromes, including Down syndrome. Of the remaining 1480, 42 (2.8%) were excluded for missing data on the education and work outcomes ($n = 35$) or race ($n = 7$). In total, 1438 CH STRONG respondents with no underlying comorbid genetic syndromes and complete responses to education and employment history questions were included in the analyses; of those, 486 (33.8%) had severe CHD and 952 (66.2%) had nonsevere CHD (Table 1). There was a higher proportion of males among those with severe CHD (54.5%) and a higher proportion of females among those with non-severe CHD (59.2%) ($p < 0.0001$). The distribution of self-reported race/ethnicity also differed by CHD severity ($p = 0.04$; e.g., 12.1% with severe CHD were Hispanic whereas 8.4% with nonsevere CHD were Hispanic) as did the site of birth ($p < 0.0001$; of those with severe CHD, 22.8% were born in AZ and 44.7% were born in AR).

Figure 1 presents standardized percentages and 95% CIs of educational attainment and employment history overall and by CHD severity. Educational attainment and employment outcomes by CHD severity were similar. The aPR assessing education attainment beyond high school by CHD severity was 1.00 (95% CI: 0.93–1.07), and the most common level of attainment for both severity groups was “some college education, no degree” (37.4%

among severe CHD and 37.0% among non-severe CHD). Overall, more than a quarter (26.2% among severe CHD, 28.8% among nonsevere CHD) of the 19–38-year-olds with CHD in CH STRONG attained a bachelor's degree or higher. For employment history, 45.6% with severe CHD and 56.0% with non-severe CHD were employed full-time (aPR = 0.97, 95% CI: 0.91–1.02), and 27.8% and 23.1% worked part-time (aPR = 1.02, 95% CI: 0.92–1.14) during the 12 months before the survey. Additionally, 26.6% with severe CHD and 20.9% with non-severe CHD were unemployed during the 12 months before the survey. Table S2 presents demographics and outcomes by CH STRONG site of birth, with observed differences across all sites for all variables (all $p < 0.05$) except employment history ($p = 0.06$). Figure S1 highlights attainment of education beyond high school (Panel A) and full or part-time employment history (Panel B) by primary CHD diagnosis (for CHD types with > 25 observations). Figure S2 highlights attainment of education beyond high school (Panel A) and full or part-time employment history (Panel B) among the older age groups (i.e., CH STRONG participants ages 25–38); in this supplemental analysis, the most common level of attainment was bachelor's degree or higher (38.6% overall, 40.5% among severe CHD, 38.2% among nonsevere CHD).

Figure 2 presents standardized percentages and 95% CIs of participation in special education among young adults with any CHD, severe CHD, and nonsevere CHD that occurred between kindergarten and 12th grade. Overall, 25.3% of adults with CHD had ever participated in a special education program during grade school, and 14.9% participated in special education during all three grade categories (i.e., kindergarten–3rd grade, 4th–6th grade, 7th–12th grade). Participation in special education differed by CHD severity; adults with severe CHD (32.9%) were more likely to participate in special education between kindergarten and 12th grade, compared to those with nonsevere CHD (23.5%) ($p = 0.01$). More specifically, differences by severity were observed between 4th and 6th grade ($p = 0.02$) and 7th–12th grade ($p = 0.01$).

Table 2 presents percentages and aPRs for educational attainment and employment history outcomes by characteristics. Education and employment increased with increasing age, such that percentages with more than a high school education ranged from 62.8% among 19–24-year-olds to 75.0% among 31–38-year-olds, and percentages with full-time employment ranged from 41.9% to 66.9%. Compared with males, females were more likely to attain more than a high school education (aPR = 1.11, 95% CI: 1.04–1.19). Compared with non-Hispanic White respondents, fewer non-Hispanic Black (aPR = 0.80, 95% CI: 0.71–0.90) and Hispanic (aPR = 0.83, 95% CI: 0.71–0.97) respondents attained more than a high school education. Compared with individuals born in Metro Atlanta, those born in Arizona and Arkansas were less likely to have more than a high school education (AZ aPR = 0.84, 95% CI: 0.77–0.92; AR aPR = 0.86, 95% CI: 0.79–0.92). For employment history, compared with no employment, participants 31–38 years were less likely to be employed part-time only (aPR = 0.79, 95% CI: 0.66–0.94). Compared with those with at least a bachelor's degree, those with less education were less likely to be employed, either part-time (aPRs increased from 0.57 for $< HS$ to 0.87 for some college) or full-time (aPRs increased from 0.63 for $< HS$ to 0.90 for some college). Females were slightly less likely to have full-time employment compared to males (aPR = 0.94, 95% CI: 0.90–0.99).

4 | Discussion

Two out of three young adults with CHD had attained education beyond high school, and over three quarters had worked at least part-time in the 12 months prior to completing the survey. We did not observe substantial differences in educational attainment and employment outcomes by CHD severity. It was interesting to note that more than a quarter of young adults with CHD participated in a special education program by 12th grade, and these participation rates differed by CHD severity. A third of those with severe CHD had participated in special education compared with one in four with nonsevere CHD.

In previous literature, children with CHD experienced difficulties with learning and concentration, communication, and gross and fine motor skills that impacted their academic achievement (Farr et al. 2018; Oster et al. 2017; Snookes et al. 2010). For example, children with CHD, compared with children without CHD, perform lower on standardized educational tests and other tests based on questionnaire-administered items and scales (Bellinger et al. 2015; Glinianaia et al. 2021; Lawley et al. 2019; Mulkey et al. 2016; Oster et al. 2017; Schaefer et al. 2016; Wotherspoon et al. 2020). Our study focused on the educational attainment of young adults with CHD, but we found that one in four had participated in special education between kindergarten and 12th grade, and 19%–21% participated in special education across specific grade levels. These percentages from CH STRONG are higher than the reported 11%–14% special education enrollment among all U.S. public school students during the 1990–1991 and 2004–2005 school years, when many CH STRONG respondents would have been of school age (National Center for Education Statistics 2015). Riehle-Colarusso et al. found that children with CHD (and no other syndromes or birth defects) were 50% more likely to receive special education than children without birth defects (Riehle-Colarusso et al. 2015). The special educational needs of those children with CHD fell particularly within the categories of intellectual disability, sensory impairment, significant developmental delay, and specific learning disability services.

In CH STRONG, more than a quarter of the 19–38-year-olds with CHD attained a bachelor's degree or higher. As a comparison with general population, the American Community Survey estimated educational attainment among 18–34-year-olds in the United States and found that a similar percentage (21%) attained a bachelor's degree or higher (U.S. Census Bureau 2018a). To further compare educational attainment among those with CHD to those without CHD, a recent systematic review and meta-analysis identified 11 published studies (including one U.S. study, published in 2003 using data on 124 patients of an outpatient cardiology clinic in a Northeastern U.S. city) that specifically examined university education across comparative CHD and non-CHD populations (Cocomello et al. 2021). Across all studies in their analysis, those with CHD were 38% less likely to obtain a university degree compared with those without CHD; however, those authors concluded that the educational attainment of those with CHD could be higher or lower than that of their peers given the sparsity of studies as well as the lack of adjustment for confounders and heterogeneity of included studies. Furthermore, findings from this predominantly European systematic review, given differences in education systems, may be less generalizable to the United States.

Unemployment in the prior 12 months among CH STRONG participants aged 19–38 years (22.1%), especially those with severe CHD (26.6%), was also similar to unemployment among the 16–64-year-old general population (26%) based on American Community Survey estimates (U.S. Census Bureau 2018b). In previous literature, one study on employment of CHD patients in 6 cardiology clinics across the United States similarly found that about 30% were unemployed (including unemployment due to disability, homemaking, or academic study) (Sluman et al. 2019). Additionally, several European studies have explored employment among adults with CHD. Geyer and colleagues observed that full-time employment rates were lower among German males (but not female) adults with CHD than those without CHD, and rates decreased as CHD severity increased (Geyer et al. 2009). A study in the Netherlands also found that employment rates were lower as the severity of CHD increased (Kamphuis et al. 2002). Conversely, a Finnish study found no difference in employment rates between matched CHD and non-CHD populations (Kokkonen and Paavilainen 1992). Further, a matched CHD and non-CHD cohort study from the United Kingdom found that those with CHD had significantly higher rates of unemployment, regardless of severity (Crossland et al. 2005). However, employment rates can vary by country and over time, so results from non-U.S. studies may not be comparable to a U.S.-based population.

As previously observed among the CHD population and the general population (National Center for Education Statistics 2020; Sluman et al. 2019), we found that educational attainment was a predictor of employment status for adults with CHD. Compared with those with at least a bachelor's degree, those in CH STRONG with less than a high school diploma were the least likely to report part-time and full-time employment, followed by those with a high school diploma and those with some college education. Also reflective of the general population (U.S. Census Bureau 2018a, 2018b), site was associated with education in CH STRONG, such that individuals from Arizona and Arkansas had lower educational attainment compared with metro Atlanta, and sex was associated with employment, such that females were slightly less likely to be employed full-time compared with males.

Educational attainment and the ability to obtain and maintain employment contribute to quality of life and independence for adults living with CHD (Apers et al. 2016; Girouard and Kovacs 2020). Further, unemployment among adults with CHD has been associated with worse self-reported health, more symptoms of depression and anxiety, and more health-risk behaviors (Moons et al. 2018). Kovacs and Bellinger have suggested clinical strategies to optimize the educational achievement and employment of adults with CHD (Kovacs and Bellinger 2020), especially those with cognitive disabilities who constitute more than a quarter of all adults with CHD (Downing et al. 2021). Strategies that healthcare providers can implement include supporting their patients' academic and employment pursuits commensurate with neurocognitive abilities/strengths, advocating for appropriate accommodations in academic and employment settings, and encouraging the use of available academic resources and community employment services. Before patients reach adulthood, guidelines from the American Heart Association suggest that pediatric patients with CHD be screened to identify those at high risk for neurodevelopmental concerns and referred for formal evaluation and early intervention if high risk (Marino et al. 2012; Sood et al. 2024). Additionally, vocational planning early in adolescence may be beneficial so that appropriate

educational options can be pursued before entering the workforce (Kamphuis et al. 2002; Marino et al. 2012).

In addition to healthcare providers' individual efforts, Chowdhury et al. published a 2020 Call to Action describing the need for legislation that supports collaboration between health and school systems and bolsters access to high-quality coordinated care and early intervention for people with CHD, such that concerns can be identified and interventions implemented early, but also so that realistic expectations for education and career goals can be set (Chowdhury et al. 2021).

4.1 | Limitations

CH STRONG is limited to participants born in three regional sites in the US South and Southwest, and as such, descriptive and multivariable adjusted findings from this study may be difficult to generalize to a representative population of young adults with CHD in the United States. However, our individual site populations are demographically heterogeneous and exhibit diversity in findings across each of the three sites, which in the aggregate may be more reflective of a broader population. The CH STRONG overall response rate was 17.8%. As previously mentioned, we presented prevalence estimates standardized by CHD severity, birth year, site of birth, sex, and maternal race/ethnicity to the CH STRONG eligible population to minimize non-response bias and improve comparability across surveys. Nevertheless, we did not have information on parental education or employment among non-respondents, so we cannot estimate potential response bias associated with these variables.

All education and employment outcomes were self-reported and not administratively confirmed. School enrollment at the time of the survey was not collected; some participants may have reported less employment because they were enrolled in school full-time. However, we provided prevalence estimates for each age group and a prevalence ratio for high school educational attainment, which the surveyed age range would typically have had the opportunity to complete. Furthermore, the ACS general population estimates assess these outcomes among a similar (18–34) or expanded (16–64) age range, subject to these same limitations.

We were only able to identify educational level milestones and employment status. Though unavailable for this analysis, incorporating a measure of performance (e.g., standardized test scores or grade point average) and collecting additional details on the type of fields of academic study, the type of employment they pursue, and associated income would improve our understanding of how to tailor academic programs to individuals with CHD.

4.2 | Conclusions

Overall, young adults with CHD living in three different regions in the United States attained similar education and employment outcomes as their peers in the general population. Educational and employment outcomes did not substantially differ by CHD severity. Moreover, individuals with severe CHD were more likely to have participated in special education between kindergarten and 12th grade than those with nonsevere CHD. To ensure this population continues to thrive, clinical guidelines recommend healthcare providers of adults with CHD offer support and encouragement as patients pursue their

education and employment goals, promote relevant services, and connect their patients to resources as needed (Girouard and Kovacs 2020; Sable et al. 2011). Findings from this analysis may inform resource allocation at the state and local level.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Data Availability Statement

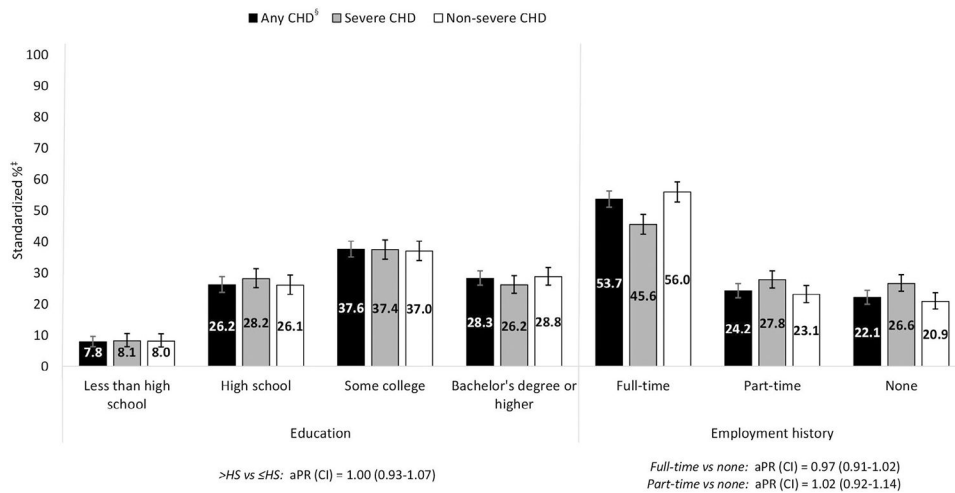
Requests to access the data set from qualified researchers trained in human subject confidentiality protocols may be sent to the Centers for Disease Control and Prevention (CDC) at chstrong@cdc.gov.

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**FIGURE 1 |.**

Educational attainment and employment history among young adults born in Arizona, Arkansas, and Atlanta, Georgia, with severe and nonsevere CHD[†], CH STRONG 2016–2019. [†]CHD severity was categorized as severe CHD if the person had one or more 6-digit CDC/BPA severe CHD codes defined in Table S1. Otherwise, CHD severity was considered non-severe since the person had only shunt and valve, shunt alone, valve alone, and other nonsevere CHD codes as defined in Table S1. [‡]Standardized to the CH STRONG eligible sample ($n = 9312$ individuals with CHD in birth defect surveillance systems who were not deceased or incarcerated at time of survey) by site of birth and sex, maternal race/ethnicity, and birth year.[§]Also standardized by CHD severity. aPR = prevalence ratio comparing severe to nonsevere CHD, adjusted for age group, sex, self-reported race/ethnicity, and site of birth; CH STRONG = Congenital Heart Survey To Recognize Outcomes, Needs, and well-being; CHD = congenital heart defects; CI = 95% confidence interval; HS = high school.

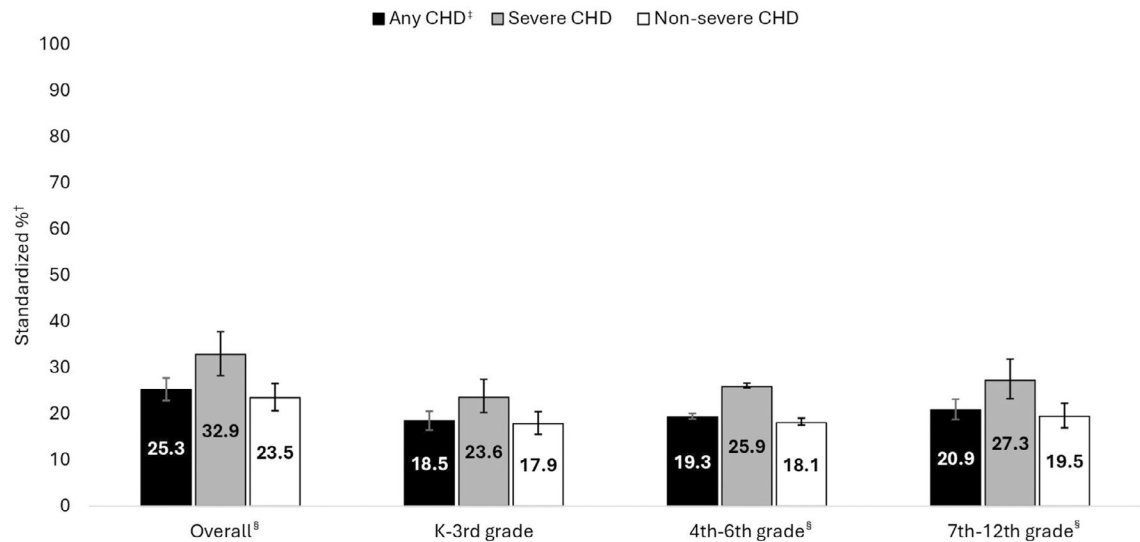


FIGURE 2 |.

Participation in K–12th grade special education among young adults with severe and nonsevere CHD, overall and by grade group, CH STRONG 2016–2019. [†]Standardized to the CH STRONG eligible sample ($n = 9312$ individuals with CHD in birth defect surveillance systems who were not deceased or incarcerated at time of survey) by site of birth, sex, maternal race/ethnicity, and birth year. [‡]Also standardized by CHD severity. [§]Z-score $p = 0.01$ overall, $p = 0.02$ for 4th–6th grade, and $p = 0.01$ for 7th–12th grade. CH STRONG = Congenital Heart Survey To Recognize Outcomes, Needs, and well-being; CHD = congenital heart defects; CI = 95% confidence interval.

TABLE 1 |

Characteristics of young adults born in Arizona, Arkansas, and Atlanta, Georgia, with congenital heart defects (CHD) by CHD severity^a, CH STRONG 2016–2019.

	CHD severity				Chi square <i>p</i>
	Severe CHD		Nonsevere CHD		
	<i>N</i>	%	<i>N</i>	%	
All	486	33.8	952	66.2	
Age in years					0.23
19–24	202	41.6	414	43.5	
25–30	208	42.8	366	38.4	
31–38	76	15.6	172	18.1	
Sex at birth					< 0.0001
Female	221	45.5	564	59.2	
Male	265	54.5	388	40.8	
Race/ethnicity					0.04
NH White	336	69.1	659	69.2	
NH Black	55	11.3	145	15.2	
Hispanic	59	12.1	80	8.4	
NH other	36	7.4	68	7.1	
Site of birth					< 0.0001
Arizona	111	22.8	434	45.6	
Arkansas	217	44.7	210	22.1	
Metro Atlanta, GA	158	32.5	308	32.4	

Abbreviations: CH STRONG = Congenital Heart Survey To Recognize Outcomes, Needs, and well-beinG; CHD = congenital heart defects GA = Georgia; NH = non-Hispanic.

^a CHD severity was categorized as severe CHD if the person had one or more 6-digit CDC/BPA severe CHD codes defined in Table S1. Otherwise, CHD severity was considered nonsevere since the person had only shunt and valve, shunt alone, valve alone, and other nonsevere CHD codes as defined in Table S1.

TABLE 2 |

Associations between characteristics and educational attainment, and employment history among young adults born in Arizona, Arkansas, and Atlanta, Georgia with CHD, CH STRONG 2016–2019.

	More than a high school education, compared to high school or less			Type of work in past 12 months, compared to none					
				Part-time only			Any full-time		
	N	%	aPR ^a (95% CI)	N	%	aPR ^{a,b} (95% CI)	N	%	aPR ^{a,b} (95% CI)
Age in years									
19–24	387	62.8	Reference	216	35.1	Reference	258	41.9	Reference
25–30	418	72.8	1.13 (1.05, 1.22)	103	17.9	0.90 (0.80, 1.01)	367	63.9	1.04 (0.98, 1.11)
31–38	186	75.0	1.12 (1.02, 1.23)	33	13.3	0.79 (0.66, 0.94)	166	66.9	1.03 (0.96, 1.10)
Sex at birth									
Female	566	72.1	1.11 (1.04, 1.19)	203	25.9	0.98 (0.89, 1.08)	409	52.1	0.94 (0.90, 0.99)
Male	425	65.1	Reference	149	22.8	Reference	382	58.5	Reference
Race/ethnicity									
NH White	720	72.4	Reference	234	23.5	Reference	572	57.5	Reference
NH Black	122	61.0	0.80 (0.71, 0.90)	53	26.5	1.05 (0.91, 1.21)	101	50.5	1.03 (0.95, 1.12)
Hispanic	77	55.4	0.83 (0.71, 0.97)	51	36.7	1.12 (0.96, 1.31)	63	45.3	1.06 (0.95, 1.17)
NH other	72	69.2	1.03 (0.90, 1.17)	14	13.5	0.73 (0.56, 0.94)	55	52.9	0.94 (0.85, 1.03)
Site of birth									
Arizona	273	63.9	0.84 (0.77, 0.92)	117	27.4	0.97 (0.84, 1.12)	217	50.8	1.00 (0.93, 1.07)
Arkansas	359	65.9	0.86 (0.79, 0.92)	118	21.7	0.95 (0.84, 1.07)	305	56	1.01 (0.95, 1.07)
Metro Atlanta, GA	359	77	Reference	117	25.1	Reference	269	57.7	Reference
Educational attainment									
< HS				19	20.2	0.57 (0.44, 0.73)	25	26.6	0.63 (0.54, 0.74)
HS				72	20.4	0.62 (0.53, 0.72)	147	41.6	0.75 (0.69, 0.81)
Some college				174	32.4	0.87 (0.77, 1.00)	276	51.4	0.90 (0.84, 0.95)
≥ Bachelor's degree				87	19.2	Reference	343	75.6	Reference

Abbreviations: aPR = prevalence ratio; CH STRONG = Congenital Heart Survey To Recognize Outcomes, Needs, and well-being; CHD = congenital heart defects; CI = confidence interval; GA = Georgia; HS = high school; NH = non-Hispanic.

^a Adjusted for CHD severity, age group, sex, self-reported race/ethnicity, and site of birth.

^b Additionally adjusted for education.