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**Children with Special Healthcare Needs: The Cost of Medical Care**

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of  
Philosophy at Virginia Commonwealth University

By

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### **Abstract**

The purpose of this study was to explore factors that impact children with special healthcare needs' (CSHCN) health insurance coverage and out-of-pocket medical expenses. The Ecological Model for Health Promotion developed by McLeroy et al. (1988) was the guiding theoretical framework for this study. Using data from the 2020 National Survey of Children's Health, I conducted descriptive statistics, logistic regressions, and multilevel modeling analyses to determine if health insurance coverage and out-of-pocket expenses for CSHCN differed by individual, family, and community, organization, and policy factors. Results indicated that race, gender, disorder category, insurance type, and family's federal poverty level were associated with CSHCN's type of health insurance, insurance coverage, problems paying for medical bills, and out-of-pocket medical expenses. Implications for research and policy, along with limitations for this study, are reported.

## **Chapter 1: Introduction**

Almost 20% of American children are classified as children with special healthcare needs (CSHCN). However, health insurance policies and out-of-pocket medical costs differ greatly for these children depending on their state of residence (Ghandour et al., 2022; Glickman & Weiner, 2019). With this study, I investigated the most common types of health insurance for CSHCN and the yearly out-of-pocket medical expenses that their families must pay. I explored how health insurance coverage and out-of-pocket expenses for CSHCN differ by factors such as race, insurance type, disorder category, and state of residence.

### **Statement of the Problem**

People with disabilities are less likely to have access to healthcare than those without a disability due to several factors, such as costs, physical or communication barriers, and medical providers' lack of training on caring for a person with a disability (NIHCM Foundation, 2021). Access to quality healthcare is vital for CSHCN, but many of their families struggle to afford the medical care they need (Akobirshoev et al., 2020; Karpur et al., 2019; Pickard & Ingersoll, 2016). For example, Newacheck and Kim (2005) compared medical expenses for families of CSHCN to families with a child without special health care needs (non-CSHCN), along with differences among demographic groups of families of CSHCN. The researchers discovered that CSHCN had three times higher healthcare costs than non-CSHCN and that families of CSHCN with high out-of-pocket medical costs were more likely to be from households below the federal poverty level (FPL; Newacheck & Kim, 2005). Black, Indigenous and People of Color (BIPOC) families of CSHCN also have more difficulty paying medical bills (Akobirshoev et al., 2020). It appears that America's most vulnerable populations (e.g., CSHCN, families below the FPL,

racially and ethnically diverse families) are often the ones that have increased difficulty paying medical bills, which limits their children's access to needed healthcare.

### ***Financial Burden***

The cost of healthcare for CSHCN matters because their medical bills can financially burden their families. Researchers have differing opinions about what amount is considered a burden on the family, ranging from medical expenses above \$250 per year (Lindley & Mark, 2009) to above 8.35% of the total family income (Wisk et al., 2020). Out-of-pocket costs exceeding 10% of the annual family income were considered an extreme financial burden (Wisk et al., 2020). The percentages that Wisk et al. (2020) give are for the entire family's medical expenses. So, if the CSHCN's out-of-pocket costs take up a large portion of those percentages, any medical expenses for other family members could add to their burden. However, some CSHCN have an increased risk of burden due to their racial or ethnic background.

### ***Disability***

Families of children with an emotional disability or more severe health conditions were more likely to have increased financial burdens (Lindley & Mark, 2010). The majority of children with developmental disabilities had public health insurance and were more likely to have lower family incomes than typically developing children (Prokup et al., 2019). Similarly, families of children with ASD were more likely to have lower incomes and difficulty paying medical bills than CSHCN that did not have ASD and families of non-CSHCN (Karpur et al., 2019).

### ***Race & Ethnicity***

In America, racial and ethnic diversity has increased significantly over the past decade. For example, the percentage of Americans identifying as two or more races increased from 2.9%

in 2010 to 10.2% in 2020 (National Healthcare Quality and Disparities Report, 2022). Due to COVID-19, the overall life expectancy in the United States decreased from 2019 to 2020.

However, the decrease in life expectancy was greater for Hispanic and Black Americans, with a decline of 3.0 and 2.9 years, respectively, than for White Americans, with a decline of 1.2 years (National Healthcare Quality and Disparities Report, 2022). Although there are multiple avenues for families to access health insurance and healthcare for CSHCN, public policies with historically racist and ableist undertones affect healthcare access for CSHCN (McLellan et al., 2022). CSHCN generally need more healthcare services than their peers without special healthcare needs, but state and federal policies do not always protect and provide services for these children. Further, CSHCN are disproportionately impacted by discrimination and poverty (McLellan et al., 2022). According to the 2022 National Healthcare Quality and Disparities Report, Hispanic, Black, and multiracial Americans are less likely to have health insurance than White Americans.

### ***Public Health Insurance and State Differences***

From 2016 to 2019, only 40% of CSHCN had only public health insurance, such as Medicaid or CHIP, while the majority of CSHCN had only private health insurance or a combination of both (Schiff et al., 2022). Families of CSHCN with public health insurance are less likely to struggle to pay medical expenses than those with private health insurance (Musumeci, 2018; Zickafoose et al., 2015). Providing more families of CSHCN with public health insurance would be beneficial, but states have different eligibility requirements for public health insurance. It is easier for CSHCN to qualify for public health insurance via an income pathway than it is to qualify based on disability status (Musumeci, 2018). While there is a national eligibility standard of below 138% of the FPL for Medicaid through the Affordable Care

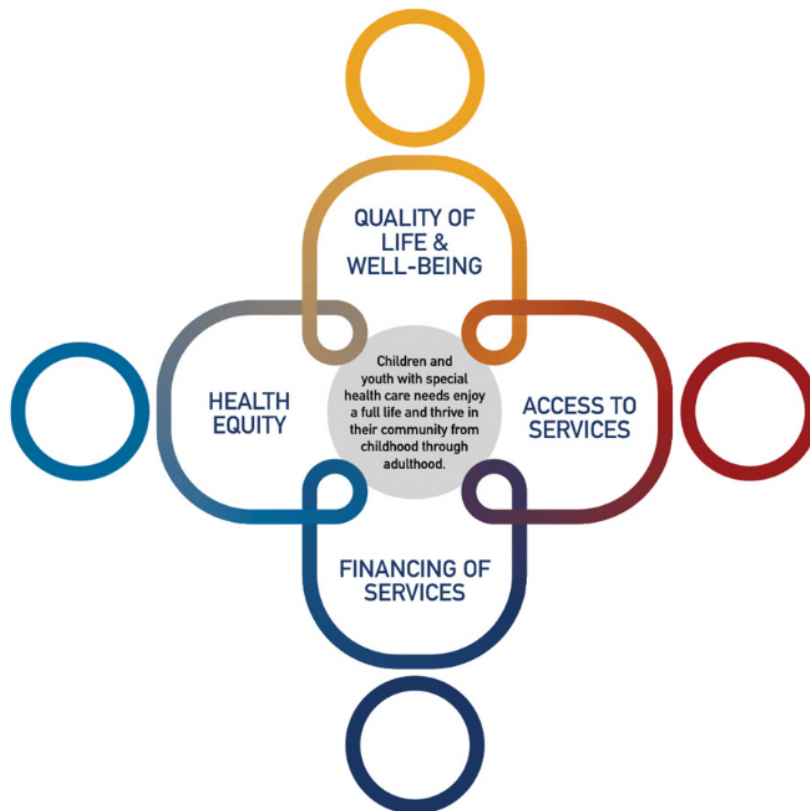
Act, beyond this, it is up to states to determine their eligibility requirements (Brooks et al., 2020; Musumeci, 2018). This means that a CSHCN's state of residence could impact whether or not they qualify for public health insurance. There is a gap in the literature that explains how race, insurance type, and state of residence can collectively impact the out-of-pocket medical expenses for CSHCN.

### **Theoretical Framework**

McLellan et al. (2022) presented The Blueprint for Change, a conceptual framework to address four key components that promote a full life for children (see Figure 1 below). These four components are Quality of Life and Well-Being, Access to Services, Financing of Services, and Health Equity. The Blueprint for Change was a starting point for me when I began to think about planning my dissertation. My study focused primarily on the bottom component, the Financing of Services, however, accessing health insurance and being able to afford out-of-pocket expenses also relates to the other three components (McLellan et al., 2022).

### **Figure 1**

*The Blueprint for Change*



The theoretical framework that guided this study was the Ecological Model for Health Promotion developed by McLeroy et al. (1988), which was based on Bronfenbrenner's Ecological Model (1979). McLeroy and colleagues' (1988) Ecological Model for Health Promotion is composed of five main levels:

1. Intrapersonal factors
2. Interpersonal processes and primary groups
3. Institutional factors
4. Community factors
5. Public policy

This model fit my research topic on health insurance and out-of-pocket expenses for CSHCN because many levels of factors are important to consider, from race at the individual

level to the state of residence eligibility policies for Medicaid and CHIP. Health insurance and medical finances are complex topics that differ greatly across individuals and even states. An individual does not exist in isolation; they are impacted by their family, community, and laws. It is necessary to consider the higher-level factors that can impact a CSHCN's health insurance and out-of-pocket costs beyond simply factors at the individual level. For example, the family's socioeconomic status (SES) can impact the CSHCN's Medicaid and CHIP eligibility based on their state of residence. This involves factors at the primary group level, the community level, and the public policy level. The factors within each level are connected and influenced by each other. The Ecological Model for Health Promotion addresses these multilevel factors, and I discuss this framework further in Chapter 2 (McLeroy et al., 1988).

### **Rationale & Significance for the Study**

The data for this study was collected during the first year of the pandemic; however, the survey did not explicitly address COVID-19 and its impact. However, Gigli and Graaf (2022) reported that from 2019 through 2020, there were no significant changes in family income, medical costs, or insurance coverage for American children. As more research is published, researchers will be able to see the full impact of the pandemic on healthcare access, medical costs, and insurance coverage for CSHCN.

The purpose of this quantitative study was to explore factors that are associated with CSHCN's health insurance type and out-of-pocket medical expenses. This study was a secondary data analysis that updated current literature by using 2020 data, only included CSHCN as the participants, and compared out-of-pocket expenses among different insurance types, races, disorder categories, and state of residence. Much of the available literature on health insurance and out-of-pocket costs for CSHCN uses older data, often prior to the passing of the Affordable

Care Act in 2010, and compares CSHCN to non-CSHCN. This study concentrated solely on CSHCN and the differences within groups of CSHCN.

This study specifically focused on the impact of race, disorder category, insurance type, and state of residence on out-of-pocket expenses for CSHCN so that this study can lead to future research and policy on improving health insurance coverage and lowering out-of-pocket expenses for CSHCN. I examined differences by state because health insurance regulation and medical costs in each state vary greatly (Glickman & Weiner, 2019). This study could benefit CSHCN and their families by revealing gaps in state and national systems that create burdens and barriers for CSHCN.

### **Research Questions**

This study investigated the following research questions:

1. What individual characteristics are associated with having health insurance and with the type of health insurance held?
2. Does the health insurance of children with special healthcare needs cover needed healthcare services?
  - a. Is the child's race, insurance type, and disorder category associated with the likelihood that their healthcare needs are covered by health insurance?
3. Among children with special healthcare needs that reported out-of-pocket expenses, do their families have problems paying for their medical bills?
  - a. Is the child's race, insurance type, and disorder category associated with the likelihood that their family has problems paying for their medical bills?
4. To what extent are families of children with special healthcare needs associated with higher out-of-pocket medical expenses?



- a. To what extent are individual factors such as race, sex, insurance type, and age of the child associated with the likelihood of paying more in out-of-pocket expenses?
- b. To what extent is a state-level factor such as state distribution of total population by Federal Poverty Level associated with the likelihood of paying more in out-of-pocket expenses?

### **Overview of the Methodology**

This study was a secondary data analysis using the 2020 National Survey of Children's Health (NSCH). Data collection took place between June 2020 and January 2021 (Child and Adolescent Health Measurement Initiative [CAHMI], 2022). Parents of children ages 0-17 in the United States completed the survey, but I only included responses of parents of CSHCN for this study. The total number of survey responses in the 2020 data set was 42,777. When I removed non-CSHCN from the data set, the total number of survey responses was 10,044 CSHCN. To answer research questions 1, 2, and 3, I conducted descriptive statistics and logistic regression analyses to compare differences between racial groups, disorder categories, and insurance types.

For my fourth research question, the main analysis was multilevel modeling, which accounted for nesting at the state level. The dependent variable was yearly out-of-pocket medical costs, with Level 1 being the individual and Level 2 grouping individuals within the same state. The dependent variable was an ordinal variable, and the five answer choices were: "No medical or health care expenses or less than \$250", "\$250 - \$499", "\$500 - \$999", "\$1,000 - \$5,000", or "More than \$5,000" (CAHMI, 2022). Level 1 predictors for this study included individual characteristics such as race, age, insurance type, and disorder category of CSHCN. Level 2 focused on the state, and the final model included a Level 2 predictor from data provided by the

Kaiser Family Foundation on the state distribution of total population below 200% FPL (Kaiser Family Foundation, 2022). More specific details about the methodology for this study are provided in Chapter 3.

### **Definition of Key Terms**

#### **Affordable Care Act**

*Affordable Care Act* is defined as legislation that was passed in 2010 that expanded Medicaid and provided less costly insurance options (Brooks et al., 2020).

#### **Children with Special Healthcare Needs (CSHCN)**

The definition for *Children with Special Healthcare Needs (CSHCN)* comes from the National Survey of Children's Health Codebook (Child and Adolescent Health Measurement Initiative [CAHMI], 2022).

To qualify as having special health care needs, the following criteria must be met: a) the child currently experiences a specific consequence; b) the consequence is due to a medical or other health condition; and c) the duration or expected duration of the condition is 12 months or longer. The first part of each screener question asks whether a child experiences one of five different health consequences:

- 1) Use or need of prescription medication.
- 2) Above average use or need of medical, mental health or educational services.
- 3) Functional limitations compared with others of the same age.
- 4) Use or need of specialized therapies (OT, PT, speech, etc.).
- 5) Treatment or counseling for emotional or developmental problems.

The second and third parts of each screener question ask those responding “yes” to the first part of the question whether the consequence is due to any kind of health condition

and if so, whether that condition has lasted or is expected to last for at least 12 months.

All three parts of at least one screener question (or in the case of question 5, the two parts) must be answered “YES” in order for a child to meet CSHCN Screener criteria for having a special health care need (p. 58).

### **Children's Health Insurance Program (CHIP)**

*Children's Health Insurance Program (CHIP)* is defined as a federal insurance program for children that is administered by states. States can choose to combine CHIP with Medicaid or keep it as a separate program (Brooks et al., 2020).

### **Employer-Sponsored Insurance**

*Employer-Sponsored Insurance* is defined as health insurance that is obtained through a family member's job.

### **Federal Poverty Level (FPL)**

*Federal Poverty Level (FPL)* is defined as the measure of a family's total income to determine if they are eligible for government programs and benefits. For example, in 2020, the poverty guideline or 100% FPL was \$12,760 for one adult (Department of Health and Human Services, 2020). The poverty guidelines are set each year by the federal government. If the Medicaid eligibility for a state is below 138% FPL, that would mean an adult would need to make less than 138% of \$12,760, which is less than \$17,608.80, to be eligible for Medicaid in that state.

### **Medicaid**

*Medicaid* is defined as a federal insurance program that is administered by states. There is a national requirement that “states must cover all children in families with incomes up to 138%

of the federal poverty level” (Musumeci, 2018, p. 903). Medicaid coverage differs in each state and CSHCN can have Medicaid coverage by meeting financial or disability requirements.

### **Children without Special Healthcare Needs (Non-CSHCN)**

*Children without Special Healthcare Needs (Non-CSHCN)* is defined as a child or children that does not meet the criteria for having special health care needs.

### **Out-of-Pocket Expenses/Costs**

*Out-of-Pocket Expenses/Costs* is defined as medical costs that the family member pays for and are not covered by insurance. This does not include premiums or costs that were or will be reimbursed by insurance.

### **Health Insurance Premiums**

*Health Insurance Premiums* is defined as the amount a person pays for their insurance policy, not including copayments.

## **Organization of the Study**

There are five chapters that comprise this dissertation. Chapter 1 is the introduction to this study and includes an overview of the problem and my purpose for this study. Chapter 2 is a narrative literature review that was guided by my theoretical framework, the Ecological Model for Health Promotion (McLeroy et al., 1988), to explore the recent literature surrounding health insurance and out-of-pocket expenses for CSHCN. In Chapter 3, I describe the methodology for my secondary data analysis. The results of this study are described in Chapter 4, and the discussion and implications are included in Chapter 5.

## Chapter 2: Review of the Literature

This study aimed to investigate American children with special healthcare needs' (CSHCN) health insurance coverage and out-of-pocket medical expenses. Additionally, I analyzed if health insurance coverage and expenses differed by insurance type, disorder category, race, and family FPL.

### Method

#### Search Procedures

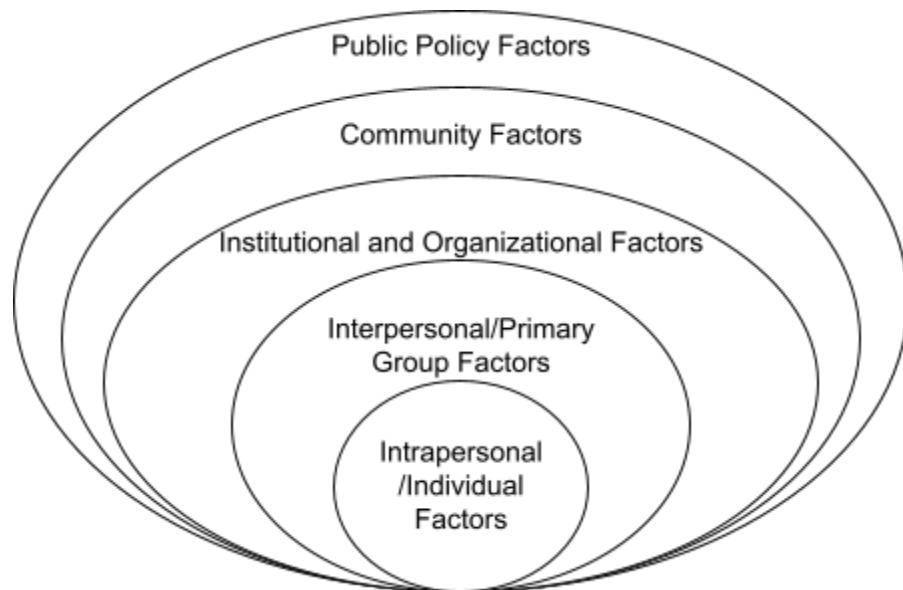
I conducted a narrative literature review and limited my search to include articles published in the last 20 years, with a primary focus on articles published after 2010, the year the Affordable Care Act was passed into law (U.S. Centers for Medicare & Medicaid Services, n.d.). I included more recent literature, particularly studies published within the last decade, to account for healthcare technological advances, policy changes, and the impact of COVID-19. I searched for literature in ProQuest, PubMed, Academic Search Complete, and VCU's online library catalog. I excluded any articles that were about healthcare outside of the United States. I excluded international literature because healthcare in America is very different from healthcare in other countries. My search terms included a combination of the following terms: CSHCN, children with special healthcare needs, children with disabilities, medical expenses, health insurance, Medicaid, out-of-pocket costs, out-of-pocket expenses, insurance, coverage, CHIP, Children's Health Insurance Program, healthcare, and cost of care. I also searched on pediatric Journal sites, such as *Pediatrics*, the *Journal of Pediatric Health Care*, and the *Journal of the American Medical Association Pediatrics*. Next, I examined the reference lists of identified articles for additional articles to include. Lastly, I searched online for policy documents about healthcare laws and health insurance options.

## Theoretical Framework

The guiding framework for my study, represented by the diagram in Figure 2, was the Ecological Model for Health Promotion developed by McLeroy et al. (1988).

### Figure 2

*Ecological Model for Health Promotion*



The framework was based on Bronfenbrenner's Ecological Model (1979), which nests the individual, household, and community levels within the wider social influences level (Cragg & Macdowall, 2013). The Ecological Model for Health Promotion developed by McLeroy et al. (1988) has five main levels, comprising a system of relationships and environments:

1. Intrapersonal/individual factors
2. Interpersonal/primary group factors
3. Institutional and organizational factors
4. Community factors
5. Public policy factors

This model explores how individual behavior affects and is affected by their social environment. The levels are thus strongly interrelated, rather than discrete. The first level is the intrapersonal/individual factors level and includes a person's beliefs, attitudes, and their individual development. The second level, interpersonal/primary group factors, includes family and friends that give support, provide influence, and social identity. The third level is the institutional and organizational factors. This level includes work, school, or other organizational structures that can influence health. The fourth level is community factors, which include interactions and relationships among different organizations and groups around the person. The last level is the public policy factors, which include laws (local, state, and federal) and procedures in place that protect or serve the community and individual's health. At first, the model appears as a straightforward list, moving progressively from individual to broader socio-political dimensions. However, it is better thought of as a set of nested spheres that are in a continual relationship with one another; influence is bidirectional, moving both inward out, and outward in.

For my specific study, I believed the CSHCN's disability, race, age, and sex would constitute individual factors. I theorized that the primary group factor was the family's FPL, and the organizational factor was private insurance. Lastly, I predicted the community factor to be public health insurance and the public policy factor to be the child's state of residence. Situating these constructs within the interrelated spheres of influence helped with interpreting and understanding the quantitative results of this study.

## **Results**

I organized my review findings into four main parts based on my theoretical framework: individual factors (the child's disability and race/ethnicity), primary group factors (the family's

SES), community factors (COVID-19 and state differences), and public policy factors (the Affordable Care Act and public health insurance). I anticipated that private health insurance would compromise the category of organizational factors because it is based on parental employment. However, the literature on private health insurance was entwined with public health insurance and policy, so I included it within the public policy factors.

### **Individual Factors**

**Disability.** Almost 1 in 5 American children were considered CSHCN in 2019 (Ghandour et al., 2022). Within CSHCN are children with many different disabilities, and their type of disability had an impact on their health insurance coverage and cost. Lindley and Mark (2010) found that children with emotional problems, moderately severe health conditions, and severe health conditions had increased family financial burden. Increased severity in children's health condition resulted in higher odds of the family having financial problems (Lindley & Mark, 2010; Ghandour et al., 2014). Prokup et al. (2019) used data from the 2015 Ohio Medicaid Assessment Survey to compare healthcare between children with developmental disabilities and typically developing children. Almost 70% of the children with developmental disabilities had Medicaid and they were more likely to have family income below 200% FPL (Prokup et al., 2019). Lastly, compared to typically developing children, children with developmental disabilities had increased difficulty accessing healthcare services (Prokup et al., 2019).

Using the 2016 NSCH, Karpur et al. (2019) compared children with Autism Spectrum Disorder (ASD), CSHCN that did not have ASD, and non-CSHCN. Children with ASD were more likely to have families below 100% of the FPL and were less likely to be uninsured. However, almost 20% of the families of children with ASD reported that their insurance was low-quality, which was a higher percentage than families of CSHCN that did not have ASD and



families of non-CSHCN (Karpur et al., 2019). Quality of coverage was determined based on insurance coverage and ability to visit necessary providers. Only 13.4% of non-CSHCN families struggled to pay the child's medical bills compared to 23.7% of CSHCN families and 33.8% of families of children with ASD (Karpur et al., 2019).

Zhang and Baranek (2016) also analyzed health insurance and utilization for children with ASD. From the 2011-2012 NSCH, Zhang and Baranek (2016) reported that 44% of children with ASD had public insurance and were more likely to have their insurance cover needed services than children with ASD with private health insurance. Additionally, children with ASD with public insurance had lower odds of having out-of-pocket medical expenses than those with private insurance (Zhang & Baranek, 2016).

**Race and Ethnicity.** Racial and ethnic diversity has increased significantly in America during the past decade. The percentage of total Americans that identified as White alone decreased from 72.4% in 2010 to 61.6% in 2020 (National Healthcare Quality and Disparities Report, 2022). Wexler et al. (2022) analyzed the 2018-2019 NSCH and found that CSHCN were more than twice as likely to have experienced racial discrimination during their lifetime compared to non-CSHCN. While experiencing racial discrimination was not significantly associated with decreased health, it was significantly associated with increased unmet healthcare needs (Wexler et al., 2022). However, these findings differed from the 2022 National Healthcare Quality and Disparities Report, which identified a lower life expectancy for Hispanic and Black Americans than for White Americans. From 2019 to 2020, the life expectancy in the United States decreased from 78.8 to 77.3, which was a decrease of 1.5 years and largely due to COVID-19. When examining the life expectancy decrease by race or ethnic group, the life expectancy for White Americans decreased by 1.2 years while Black Americans had a decrease

of 2.9 years and Hispanic Americans had a decrease of 3.0 years (National Healthcare Quality and Disparities Report, 2022). In another study, Akobirshoev et al. (2020) analyzed the 2011-2012 NSCH and the 2012 Boston Survey of Children's Health. Similar to the 2022 National Healthcare Quality and Disparities Report, Akobirshoev et al. (2020) found that Black and Hispanic CSHCN had a disproportionately higher risk of poor health than White CSHCN. These discrepancies seem to be in direct contrast to the findings of Wexler et al. (2022).

In 2020, Asian Americans and White Americans were the most likely racial group to have health insurance, at 92.4% and 92.2% respectively (National Healthcare Quality and Disparities Report, 2022). The four racial and ethnic groups with the lowest percentage of people with any type of health insurance were American Indians/Alaskan Natives (72.9%), Hispanic (77.6%), Native Hawaiian/Pacific Islander (85.6%), and Black (88.1%). Aligned with the 2022 National Healthcare Quality and Disparities Report that showed BIPOC Americans, except for Asian Americans, are less likely to have health insurance than White Americans, Akobirshoev et al. (2020) found that ethnically and racially diverse families of children with disabilities had higher unmet healthcare needs and increased difficulty paying medical bills compared to White families. Similarly, Lindley and Mark (2010) found that multi-racial children had increased family financial burden. However, Ghandour and colleagues (2014) compared CSHCN data from 2001 through 2010 and reported that older CSHCN and White non-Hispanic CSHCN had higher out-of-pocket medical expenses.

It is important to note that researchers cannot always analyze race, ethnicity, or SES as isolated factors. Still, inequities surface when analyzing co-occurring factors. Houtrow et al. (2022) stated that "minoritized race, poverty, and special health care needs often track together; for example, 43.4% of Black (children and youth with special health care needs [CYSHCN]) live

in poverty compared with 33.6% of Black non-CYSHCN and only 10.9% of White non-CYSHCN" (p. 2). Similarly, race and ethnicity compound the effect of disability on healthcare so that racially and ethnically diverse children with disabilities have a double burden and face additional disparities in accessing healthcare (Akobirshoev et al., 2020).

### **Primary Group Factors**

**SES.** Cost of care is a barrier to children with disabilities' access to healthcare (Akobirshoev et al., 2020; Karpur et al., 2019; Pickard & Ingersoll, 2016). Ghandour et al. (2022) compared CSHCN and non-CSHCN responses from the 2016-2019 NSCH and found that CSHCN are more likely to experience poverty and have public health insurance than their non-CSHCN peers. Specifically, 23.8% of CSHCN live in poverty compared to only 19.4% of non-CSHCN (Houtrow et al., 2022).

However, looking specifically at SES, the results differed among studies. In 2016, almost 8 in 10 CSHCN with only Medicaid or CHIP coverage lived in low-income households, while CSHCN with private insurance were more likely to live in middle- or high-income households (Musumeci, 2018). Ghandour et al. (2014) reported that families of CSHCN with higher incomes were more likely to have higher out-of-pocket medical expenses than families of CSHCN with lower incomes. Earley et al. (2015) analyzed data from the 2012 Ohio Medicaid Assessment Survey; the sample in this study was CSHCN in metropolitan and Appalachian counties. The researchers reported that CSHCN in rural areas had lower SES but did not have higher unmet healthcare needs than CSHCN in metropolitan areas (Earley et al., 2015). Furthermore, Pickard and Ingersoll (2016) surveyed 244 families of children with ASD and found that 32.14% of lower SES families reported finances and insurance as a barrier to health services for their child

compared to 34.62% of higher SES families. Families from lower SES levels also had increased difficulties with transportation and scheduling for accessing services (Pickard & Ingersoll, 2016).

At all income levels, more families of CSHCN reported difficulty paying medical bills and were less likely to leave their jobs to avoid losing health insurance than families of non-CSHCN (Schiff et al., 2022). Families of CSHCN were twice as likely to avoid changing jobs than families of non-CSHCN at all income levels (Schiff et al., 2022). Additionally, about 1 in 3 CSHCN had disrupted or inadequate health insurance in 2019 (Ghandour et al., 2022). Families from lower and higher SES levels reported that cost was a barrier to accessing healthcare services (Pickard & Ingersoll, 2016). However, families with lower SES reported financial burden at lower cost levels than families with higher SES (Lindley & Mark, 2010).

### **Community Factors**

**COVID-19.** In March 2020, life and healthcare dramatically changed in the United States and around the world due to COVID-19. During the pandemic, BIPOC and people with disabilities had increased mortality rates from COVID-19 (McLellan et al., 2022). Even though this literature review was conducted in 2022, a limited number of published articles have addressed the impact of COVID-19 on health insurance and the cost of healthcare for CSHCN. To illustrate, Gigli and Graaf (2022) compared data collected from the NSCH in 2019 with 2020 data. The researchers discovered that the only barrier that became more impactful from 2019 to 2020 was the inability to obtain an appointment (Gigli & Graaf, 2022). There were not any significant changes in out-of-pocket costs, household income, or insurance coverage from 2019 to 2020. These findings are important to note as my data for this study comes from the 2020 NSCH.

Easterly and his team (2022) also analyzed data from the NSCH, but they compared data from 2016 through 2020. They found that CSHCN were more than twice as likely to have a parent with employment disruption than non-CSHCN, but there was no significant difference between employment disruption for parents of CSHCN from 2019 to 2020 (Easterly et al., 2022). Parents of all children faced increased employment disruption in 2020, which could result in loss of health insurance or income. For families of CSHCN with employer-sponsored health insurance, loss of employment could have devastating consequences.

**State Differences.** Healthcare and health insurance costs vary greatly by the state in which families with CSHCN reside (Glickman & Weiner, 2019). Additionally, the total percentage of CSHCN in each state differs. Ghandour et al. (2022) reported that the Western region of the United States had a lower percentage of CSHCN and that overall, states had large differences in percentages of CSHCN, from 13.6% in Hawaii to 24% in West Virginia. The researchers did not find a significant difference in the percentage of CSHCN between rural and urban areas (Ghandour et al., 2022). However, there was a disproportionate percentage of CSHCN in states that were more rural and with worse economies, such as West Virginia, Mississippi, Kentucky, and Louisiana (Houtrow et al., 2022).

Health insurance costs have been consistently rising since before and after the enactment of the Affordable Care Act in 2010 (U.S. Centers for Medicare & Medicaid Services, n.d.). The average household income increased by about 20% from 2010 to 2016; however, the average cost of employer-sponsored family health insurance premiums, which is the amount a person pays for their insurance policy, increased by about 28% during that same time (Glickman & Weiner, 2019). The numbers varied greatly when looking at the average household income and cost of employer-sponsored family health insurance premiums in each state. From 2010 to 2016,

premium costs increased by 58% in Alaska but only 14.7% in Mississippi (Glickman & Weiner, 2019). In other states, like Idaho and Montana, premiums increased by more than 40% (Glickman & Weiner, 2019).

Problematically, in the vast majority of all states, the average household income increase was less than the premium cost increase over the six years that were analyzed (Glickman & Weiner, 2019). Several states, like Delaware, Louisiana, West Virginia, and Maine, had a less than 10% increase in average household income between 2010 and 2016. Researchers calculated the healthcare cost burden by dividing the median income by the average employer-sponsored insurance premium. They found that in only three states (Minnesota, Tennessee, and Texas) and the District of Columbia, the cost burden decreased from 2010 to 2016 (Glickman & Weiner, 2019). These three states and D.C. had a decreased cost burden because the average income increase was greater than the average employer-sponsored insurance premium increase. The average cost burden across all states in 2016 was 30% (Glickman & Weiner, 2019). However, this study did not specifically evaluate insurance costs for CSHCN and only focused on employer-sponsored insurance. Further, CSHCN often have public health insurance, but this does not cover their family members. If the families have a slight increase in medical expenses due to their CSHCN, this could be financially detrimental as families already endure an increasing cost burden for health insurance and care for other members of their family.

### **Public Policy Factors**

**Cost of Care Prior to The Affordable Care Act.** The average out-of-pocket medical expenses for CSHCN has changed many times throughout the decades. Newacheck and Kim (2005) analyzed data from the 2000 Medical Expenditure Panel Survey and reported that the yearly out-of-pocket cost of healthcare for CSHCN was double that of a non-CSHCN, at about

\$350 compared to \$175 per year. Within CSHCN, children who were Black or from lower-income families were significantly less likely to have higher out-of-pocket costs, while children without health insurance were twice as likely to have out-of-pocket costs exceeding \$500 per year compared to children with health insurance (Newacheck & Kim, 2005).

Lindley and Mark (2009) analyzed a later data set using the 2005 and 2006 NSCH. The researchers found that almost 25% of families with a CSHCN had yearly out-of-pocket healthcare costs exceeding \$1,000. Additionally, almost 1 in 4 families experienced financial burden due to their child's health condition (Lindley & Mark, 2009). From their data analysis, Lindley and Mark (2009) determined that yearly out-of-pocket healthcare costs above \$250 were associated with financial burden for the family. The researchers also reported that CSHCN's sex was not significantly associated with family financial burden (Lindley & Mark, 2009). Using the same data set, but from 2007, Bethell et al. (2010) discovered that about 1 in 6 children had a gap in their health insurance coverage during the previous year, with increased odds of experiencing a gap for children with public insurance, Hispanic children, and children from low-income households. Almost one-quarter of parents answered that their child's health insurance was never or sometimes adequate and insurance inadequacy reports varied between states, from about 31% in Minnesota to 16% in Hawaii (Bethell et al., 2010). About 10% of the children in the data set were uninsured (Bethell et al., 2010).

**After the Enactment of The Affordable Care Act.** The Affordable Care Act (also known as Obamacare) was passed and became law in 2010 (U.S. Centers for Medicare & Medicaid Services, n.d.). This law provided Americans and their families with more options for health insurance. Schiff et al. (2022) analyzed data from 2016 to 2019 and found that about half of all CSHCN only had employer-sponsored insurance, 40% only had public health insurance

(primarily Medicaid or Children's Health Insurance Program [CHIP]), 8% had a combination of the two, and 4% of CSHCN were uninsured.

Even with the Affordable Care Act, families of CSHCN still face financial burdens. Stabile and Allin (2012) calculated that having a CSHCN costs a family about \$3,000 annually, which breaks down to about \$1,000 in direct medical expenses and \$2,000 in lost income. This is higher than Lindley and Mark's (2009) finding that 25% of CSHCN families have medical costs exceeding \$1,000, however Stabile and Allin include lost parental income in their estimate. These high costs are important as Wisk et al. (2020) defined extreme financial burden as annual out-of-pocket medical expenses for the entire family, not including insurance premiums, that was 10% or higher of the family's total annual income. Thus having a CSHCN can contribute to an extreme financial burden on the family, especially when other family members need healthcare and have medical expenses in addition to the CSHCN.

***Public Health Insurance.*** Wisk et al. (2020) analyzed 92,165 survey responses from families with at least one child using data from the 2000-2017 Medical Expenditure Panel Survey. By comparing data from 2000 through 2017, Wisk et al. (2020) was able to analyze differences from before and after the Affordable Care Act became law. After the Affordable Care Act was passed, families were less likely to be uninsured, and more families were eligible for Medicaid or CHIP (Wisk et al., 2020). For CSHCN with family income below 138% of the FPL, many were enrolled in Medicaid through the poverty level option because it is quicker and easier to demonstrate eligibility based on income than disability (Musumeci, 2018).

In 2016, 44 states provided Medicaid or CHIP to between 35% to 66% of all CSHCN within their state (Musumeci, 2018). A significant decrease in the percentage of families with extreme financial burden from healthcare costs was found from before the passing of the



Affordable Care Act, at 5.5%, to after its passing, at 3.6% (Wisk et al., 2020). In contrast, Schiff et al. (2022) reported that from 2016 to 2019 there was a decrease in public insurance coverage for CSHCN and families had increased difficulty paying medical expenses. Schiff et al. (2022) found that 41.3% of CSHCN had public insurance in 2016 compared to 39.0% in 2019. During the same time period, the percentage of non-CSHCN with public health insurance also decreased and the percentage of non-CSHCN families that struggled to pay medical bills increased (Schiff et al., 2022).

Public health insurance was reported as being associated with increased healthcare access for children with disabilities (Earley et al., 2015; Prokup et al., 2019; Zickafoose et al., 2015). Zickafoose et al. (2015) analyzed data from a 2012-2013 phone-based survey of 12,197 parents with a child enrolled in CHIP. CSHCN with CHIP had increased access to healthcare services and received more needed referrals than CSHCN without health insurance. Compared to CSHCN with private health insurance, CSHCN with CHIP had similar access to healthcare, and their families reported not feeling stressed about the child's healthcare needs and not struggling to pay medical bills (Zickafoose et al., 2015). Medicaid was also beneficial in reducing or preventing additional healthcare disparities among children with disabilities (Earley et al., 2015; Prokup et al., 2019). In 2016, only slightly more than half of CSHCN with private insurance reported that their insurance always met their needs, compared to 87% of CSHCN with Medicaid or CHIP (Musumeci, 2018). Similarly, Musumeci (2018) shared that only 19% of CSHCN with private insurance reported that out-of-pocket expenses are always reasonable, while that percentage was much higher at 82% for CSHCN with only Medicaid or CHIP. Private health insurance was associated with higher out-of-pocket expenses for CSHCN (Ghandour et al., 2014). Further,

Zhang and Baranek (2016) found that families of children with ASD with private insurance had a greater financial burden than those with public insurance.

In addition, Medicaid was beneficial among rural CSHCN and smaller groups of CSHCN with specific disabilities. Earley et al. (2015) found that rural CSHCN were poorer and more likely to have Medicaid than CSHCN in metropolitan areas, but that rural CSHCN did not have higher unmet healthcare needs. Another example of the benefit of Medicaid can be seen in the Prokup et al. (2019) study, where children with developmental disabilities had significant healthcare disparities compared to children without disabilities. For children with developmental disabilities, having Medicaid significantly lowered their rate of healthcare disparities compared to children with developmental disabilities that had private insurance (Prokup et al., 2019).

***State Policy Differences.*** Even among federal programs, such as Medicaid and CHIP, differences between states are common. Almost all states (i.e., 49 out of 50) provide Medicaid or CHIP coverage for children with family incomes below 200% of the FPL, but only 19 states cover children with family incomes at or above 300% of the FPL (Brooks et al., 2020). States can decide if they want to operate CHIP as a separate program, a Medicaid expansion program, or a combination of the two options (Brooks et al., 2020). Sixteen states operate CHIP as a Medicaid expansion program and give children covered by CHIP full Medicaid benefits, while 35 states operate CHIP as a separate program or a combination of the two options (Brooks et al., 2020). Before the Affordable Care Act, 13 states with separate CHIP programs had waiting periods of six months or longer, but since the Affordable Care Act was passed, the law requires that states cannot have a waiting period longer than 90 days (Brooks et al., 2020). Twenty-nine states do not require children in Medicaid or CHIP to pay copayments, and 31 states provide children with Medicaid or CHIP 12-month continuous eligibility so that they do not have gaps in

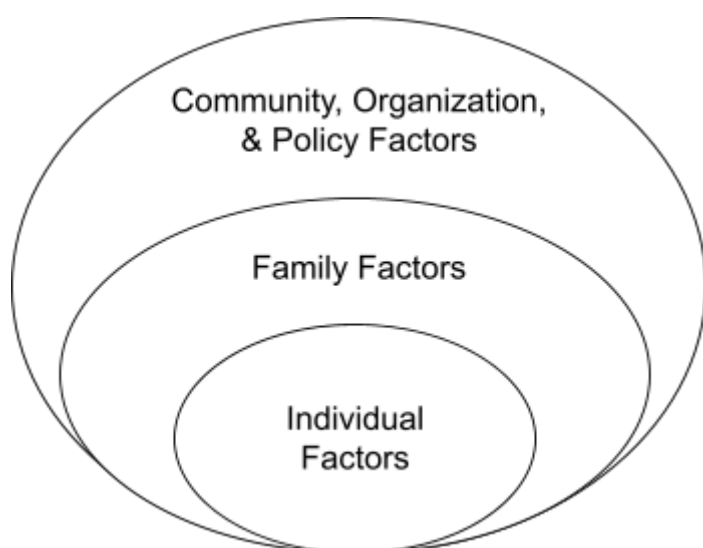
coverage (Brooks et al., 2020). Across all states, families of children with Medicaid or CHIP are not allowed to be charged more than 5% of their family income for out-of-pocket healthcare costs (Brooks et al., 2020).

### **Summary of Findings and Updated Framework**

After I completed my literature review, I adapted the Ecological Model for Health Promotion to combine the last three spheres, institutional and organizational factors, community factors, and public policy factors, into one factor level (McLeroy et al., 1988). From the CSHCN health insurance and medical expenses literature, it was difficult to separate policy from community and organization because policy can differ based on community and organization. For example, CSHCN in Vermont may qualify for Medicaid while CSHCN in North Carolina with the same household income may not qualify for Medicaid because of their state eligibility policies.

### **Figure 3**

*Updated Framework for Study*



The literature review demonstrated the importance of public health insurance, specifically within the community, organization, and policy factors of my framework. CSHCN with public

health insurance were less likely to have high out-of-pocket costs and more likely to report their out-of-pocket costs as reasonable (Schiff et al., 2022; Musumeci, 2018). However, there appears to be a disconnect between the benefits of public health insurance for CSHCN and the acceptance of public health insurance by medical providers. Unfortunately, many medical providers prefer to serve those with private insurance because they are paid more than when they charge people with Medicaid (Houtrow et al., 2022; Prokup et al., 2019). Since many CSHCN have public health insurance, such as Medicaid, they can have increased difficulty finding providers that accept their insurance or are forced to wait long periods of time for appointments (Houtrow et al., 2022). This is an issue within the community and public policy factors. Medical providers not accepting public health insurance would be a barrier to healthcare access within the community factors, but it is based on public policy (e.g., differential billing practices) and could be addressed within the public policy factors sphere.

Additional community and public policy factors were the impact of COVID-19 and state regulations. While COVID-19 did have an increased mortality rate for BIPOC and people with disabilities, it did not have a major impact on CSHCN's insurance coverage and out-of-pocket expenses, at least according to 2020 data (McLellan et al., 2022; Gigli & Graaf, 2022). Researchers may see changes in this impact on insurance and out-of-pocket expenses as research using 2021 and 2022 data are published. In addition, the impact of a CSHCN's state of residence was part of the community and public policy factors. State regulations regarding public health insurance for CSHCN differ greatly, so it may be more beneficial for families of CSHCN to live in a state with better health insurance coverage for their child. Changing communities could have a positive impact on families of CSHCN based on the state's policies. Figure 3 addresses the difficulty in separating organization, community, and public policy factors by combining these

into one level. Examining health insurance and medical expenses for CSHCN through the lens of the modified framework more clearly demonstrates how changes in what might seem like a remote sphere of influence (i.e., policy) have immediate consequences in the lives of CSHCN and their families.

At the individual and family factor levels, disability, race, ethnicity, and SES appear to be factors that influence health insurance type and out-of-pocket expenses (Akobirshoev et al., 2020; Earley et al., 2015; Ghandour et al., 2014; Lindley & Mark, 2010; Musumeci, 2018). While the Affordable Care Act is a national policy, CSHCN from different racial and ethnic backgrounds do not appear to have the same access to health insurance and have differing out-of-pocket costs. This could partially explain why White Americans have a higher life expectancy than Hispanic and Black Americans (National Healthcare Quality and Disparities Report, 2022). Race/ethnicity, SES, and disability are not factors that can be examined in isolation. These factors compound upon each other to create higher levels of burden for families of CSHCN (Akobirshoev et al., 2020).

Another family factor to consider is that medical expenses for the family are not solely based on the CSHCN. Family members of the CSHCN are not covered by the CSHCN's public health insurance if it is given based on disability. Further, if the medical expenses of the CSHCN causes a financial strain on the family, then any additional medical expenses for other members of the family adds to that strain. Many CSHCN have siblings, and if the sibling needs medical care this can add to the family's total out-of-pocket medical expenses.

## **Summary**

The purpose of this narrative literature review was to investigate current research and policy on health insurance and out-of-pocket medical expenses for CSHCN. Structured by the

Ecological Model for Health Promotion (McLeroy et al., 1988), I organized my review around individual factors, primary group factors, community factors, and public policy factors. This review revealed that public health insurance for CSHCN is beneficial for reducing out-of-pocket medical expenses but is problematic in that states have differing qualification policies, and not all medical providers accept public health insurance. Additionally, disability, race, ethnicity, and SES of the CSHCN has an impact on their health insurance type and out-of-pocket costs.

Much of the available literature on health insurance and out-of-pocket costs for CSHCN uses older data, often prior to the passing of the Affordable Care Act, and compares CSHCN to non-CSHCN. My study will fill this gap by using 2020 data to examine the combined impact of race/ethnicity, disability, SES, insurance type, and state of residence on out-of-pocket medical expenses for CSHCN. In the next chapter, I will discuss my methodology and analysis plan for this study. I conducted a secondary data analysis using a large national data set and included analyses for logistic regression and multilevel modeling.

### Chapter 3: Methodology

In this chapter, I will describe the data source, research design, sampling, measures, and analyses. This study was a secondary data analysis using a national data set, the National Survey of Children's Health (CAHMI, 2022). The research questions for this study were:

1. What individual characteristics are associated with having health insurance and with the type of health insurance held?
2. Does the health insurance of children with special healthcare needs cover needed healthcare services?
  - a. Is the child's race, insurance type, and disorder category associated with the likelihood that their healthcare needs are covered by health insurance?
3. Among children with special healthcare needs that reported out-of-pocket expenses, do their families have problems paying for their medical bills?
  - a. Is the child's race, insurance type, and disorder category associated with the likelihood that their family has problems paying for their medical bills?
4. To what extent are families of children with special healthcare needs associated with higher out-of-pocket medical expenses?
  - a. To what extent are individual factors such as race, sex, insurance type, and age of the child associated with the likelihood of paying more in out-of-pocket expenses?
  - b. To what extent is a state-level factor such as state distribution of total population by Federal Poverty Level associated with the likelihood of paying more in out-of-pocket expenses?

## Data Source

I analyzed data from the 2020 NSCH. I submitted a request to use the most recent version of the NSCH data set, which was approved on September 7th, 2022 by the Child and Adolescent Health Measurement Initiative (CAHMI), Data Resource Center (DRC). The most up-to-date and available for publication data set with a codebook is uploaded yearly in spring, so the 2020 NSCH data set was the most current.

The data was from a cross-sectional survey of parents with children ages 0-17 in the United States. The survey is administered yearly by mail and online through a random selection of addresses and is available in English and Spanish (CAHMI, 2022). In 2020, 90.4% of the survey participants completed the survey online, while 9.6% completed the paper version of the survey (United States [US] Census Bureau, 2021). For households with more than one child, one focal child was randomly selected. Based on the age of the child, the parent was given one of three versions of the survey: 0 to 5 years old, 6 to 11 years old, or 12 to 17 years old.

For the 2020 NSCH, data was collected between July 2020 and January 2021 and the overall survey response rate was 42.4% (US Census Bureau, 2021). The survey was made up of 11 sections of questions: This Child's Health, This Child as an Infant, Health Care Services, Experience with This Child's Health Care Providers, This Child's Health Insurance Coverage, Providing for This Child's Health, This Child's Learning/Schooling and Activities, About You and This Child, About Your Family and Household, About You and Other Parent or Caregiver in the Household, and Household Information (US Census Bureau, 2021).

Additionally, to answer research question 4, I included state distribution of total population by FPL provided by the Kaiser Family Foundation (2022) using the American Community Survey Data. I chose to include this data set to analyze if the state distribution of



total population below 200% FPL accounted for additional state level variance in my multilevel modeling analysis. I was not able to include the 2020 state level data because there were issues with data collection due to COVID-19 (Kaiser Family Foundation, 2022). Instead, I included the 2021 state distribution of total population below 200% FPL data.

## **Participants**

Results included responses for parents of CSHCN with children of all ages, from 0 to 17. The only exclusion criteria was if the participant did not complete the survey on a child with special healthcare needs. The definition for Children with Special Healthcare Needs came from the NSCH Codebook (CAHMI, 2022).

To qualify as having special health care needs, the following criteria must be met: a) the child currently experiences a specific consequence; b) the consequence is due to a medical or other health condition; and c) the duration or expected duration of the condition is 12 months or longer. The first part of each screener question asks whether a child experiences one of five different health consequences:

- 1) Use or need of prescription medication.
- 2) Above average use or need of medical, mental health or educational services.
- 3) Functional limitations compared with others of same age.
- 4) Use or need of specialized therapies (OT, PT, speech, etc.).
- 5) Treatment or counseling for emotional or developmental problems.

The second and third parts of each screener question ask those responding ‘yes’ to the first part of the question whether the consequence is due to any kind of health condition and if so, whether that condition has lasted or is expected to last for at least 12 months.

All three parts of at least one screener question (or in the case of question 5, the two

parts) must be answered 'YES' in order for a child to meet CSHCN Screener criteria for having a special health care need. (p. 58)

From the 2020 NSCH data set, there were 10,044 CSHCN out of a total of 42,777 responses, which means I incorporated about 23% of the total available responses (CAHMI, 2022).

### **Dependent Variables**

For research questions 1, 2, and 3, I analyzed five different models using logistic regression. The first question was: "Is this child currently covered by any kind of health insurance or health coverage plan?" It was a binary variable with answer choices "Yes" or "No." The second question was: "What type of health insurance coverage, if any, did the child have at the time of the survey?" This was a nominal variable with the answer choices: "Public health insurance only," "Private health insurance only," "Public and private insurance," and "Uninsured." The third and fourth questions were categorical variables with the answer options "Always," "Usually," "Sometimes," and "Never." The third question was "How often does this child's health insurance offer benefits or cover services that meet this child's needs?" and the fourth question was "How often does this child's health insurance allow them to see the health care providers they need?" The final question was, "During the past 12 months, did your family have problems paying for any of this child's medical or health care bills?" It was a binary variable with the answer choices "Had problems paying medical bills" or "Did not have problems paying medical bills" (CAHMI, 2022).

For research question 4, I conducted a multilevel modeling analysis to measure the annual out-of-pocket medical expenses from the question, "Including co-pays and amounts reimbursed from Health Savings Accounts (HSA) and Flexible Spending Accounts (FSA), how much money did you pay for this child's medical, health, dental, and vision care during the past

12 months? Do not include health insurance premiums or costs that were or will be reimbursed by insurance or another source” (CAHMI, 2022). This question had ordinal responses.

Participants chose one of the following answers to the question: “No medical or health care expenses or less than \$250”, “\$250 - \$499”, “\$500 - \$999”, “\$1,000 - \$5,000”, or “More than \$5,000.”

### **Independent Variables**

The independent variables for this study were sex (“male”, “female”), insurance type (“Public Health Insurance Only”, “Private Health Insurance Only”, “Public and Private Health Insurance”, “Uninsured”), child’s race/ethnicity (“White, Non-Hispanic”, “Black, Non-Hispanic”, “Hispanic”, “Other/Multiracial, Non-Hispanic”), child’s age (0-17), and child’s state of residence (includes all 50 states and the District of Columbia). I also added independent variables to address the CSHCN’s disability/disorder. I created a variable for the CSHCN’s disorder category. I categorized the CSHCN into five disorder categories: only neurodevelopmental disorders, only emotional and behavior disorders, only genetic disorders, 2+ disorders, and CSHCN without a Neurodevelopmental, Emotional/ Behavioral, or Genetic Disorder. Only neurodevelopmental disorders were comprised of CSHCN with any of the following: learning disability, intellectual disability, ADHD, speech or other language disorder, cerebral palsy, vision impairment, hearing impairment, autism, epilepsy/seizures, or Tourette syndrome (United States Environmental Protection Agency, 2015). Only emotional and behavior disorders were comprised of CSHCN with any of the following: has anxiety problems, has depression, or has behavioral or conduct problems. Lastly, only genetic disorders were comprised of CSHCN with any of the following: blood disorder, cystic fibrosis, down syndrome, genetic or inherited condition, or heart condition. If the CSHCN had two or more disorder categories, such as a genetic disorder and a

neurodevelopmental disorder, then they were placed into the 2+ disorder category. If CSHCN in the sample did not have any of the above disorder categories, they were categorized as CSHCN without a Neurodevelopmental, Emotional/ Behavioral, or Genetic Disorder.

Additionally, I included the variable child's household income level based on the federal poverty level (FPL). The options for FPL were "0-99% FPL," "100-199% FPL," "200-399% FPL," and "400% FPL or greater." The Data Resource Center for Child and Adolescent Health stated that many participants choose not to answer questions related to income and that in 2020, 19.7% of responses were missing FPL information (CAHMI, 2022). To adjust for the high number of missing responses, the Census Bureau completed a single imputation value of 1= "0-99% FPL" (CAHMI, 2022). Lastly, for research question 4, I included the state distribution of total population below 200% FPL in the final model of my analysis (Kaiser Family Foundation, 2022).

### **Data Cleaning**

I began by removing all non-CSHCN responses from the data set. Next, I removed responses that were incomplete or missing data for the variables I analyzed. After I removed missing or incomplete responses, the sample size was reduced from 10,044 to 9,762. The responses removed were 2.8% of the total sample size. All of the variables were categorical or ordinal variables, so I made them into factors in R before conducting my analyses.

### **Data Analyses**

I analyzed the 2020 NSCH data set and included analyses for descriptive statistics, logistic regression, and multilevel modeling. I also included tests for model fit. All analyses were conducted using Posit, formerly known as RStudio, a statistical computing software (Posit, 2023).

**Table 1***Research Questions and Planned Analyses*

Research Question	Analysis
<ol style="list-style-type: none"> <li>1. What individual characteristics are associated with having health insurance and with the type of health insurance held?</li> <li>2. Does the health insurance of children with special healthcare needs cover needed healthcare services?               <ol style="list-style-type: none"> <li>a. Is the child's race, insurance type, and disorder category associated with the likelihood that their healthcare needs are covered by health insurance?</li> </ol> </li> <li>3. Among children with special healthcare needs that reported out-of-pocket expenses, do their families have problems paying for their medical bills?               <ol style="list-style-type: none"> <li>a. Is the child's race, insurance type, and disorder category associated with the likelihood</li> </ol> </li> </ol>	<p>Descriptive Statistics, Logistic Regression Analyses</p>

<p>that their family has problems paying for their medical bills?</p>	
<p>4. To what extent are families of children with special healthcare needs associated with higher out-of-pocket medical expenses?</p>	<p>Descriptive Statistics, Multilevel Modeling Null Model</p>
<p>4a. To what extent are individual factors such as race, sex, insurance type, and age of the child associated with the likelihood of paying more in out-of-pocket expenses?</p>	<p>Multilevel Modeling Model 1: Individual Level Factors</p>
<p>4b. To what extent is a state-level factor such as state distribution of total population by Federal Poverty Level associated with the likelihood of paying more in out-of-pocket expenses?</p>	<p>Multilevel Modeling Model 2: State Level Factor FPL</p>

### **Descriptive Statistics**

I calculated descriptive statistics to understand the sample characteristics, including major demographics for the CSHCN such as age, sex, and race.

## **Logistic Regression Analyses**

For research questions 1, 2, and 3, I conducted five logistic regression models to compare differences between racial groups, disorder groups, and insurance types, controlling for other characteristics. The first model, does the child currently have health insurance, was a binary logistic regression because the dependent variable was binary. The second model, is the child currently covered by any of the health insurance or health coverage plans, was a multinomial logistic regression because the dependent variable had nominal outcomes. The dependent variables for Models 3 and 4 were ordinal, which was appropriate for ordinal logistic regression analyses (Harrell, 2015). I set the significance level to  $p < 0.05$  for each variable. Next, I checked if the confidence intervals overlapped between the groups, which would indicate that the difference was not statistically significant (Sofroniou & Hutcheson, 2002). I also checked the proportional odds assumption for each model to ensure it was not violated (Christensen, n.d.; Christensen, 2022). I tested the proportional odds assumption to ensure that there was just one set of coefficients that describe the relationship between every pair of outcome groups (UCLA: Statistical Consulting Group, 2021). Lastly, Model 5 was a binary logistic regression. The dependent variable was binary, whether or not the family had problems paying for the CSHCN's medical bills. I also checked for multicollinearity to check the assumptions for the models (Harrell, 2015).

I decided to convert the logit coefficients to odds ratios to interpret the results for each model (Harrell, 2015; Alwan et al., 2020). This would help a broader audience to understand my results. Table 2 shows the survey questions I used for these models.

### **Table 2**

*Survey Questions and Logistic Regression Analyses*

Model Number	Survey Question & Response Options	Logistic Regression Analysis
1	<p>Is this child currently covered by any kind of health insurance or health coverage plan?</p> <ul style="list-style-type: none"> <li>● Yes</li> <li>● No</li> </ul>	<ul style="list-style-type: none"> <li>- Binary Logistic Regression</li> <li>- Compare differences between racial groups</li> <li>- Compare differences between disorder groups</li> </ul>
2	<p>What type of health insurance coverage, if any, did the child have at the time of the survey?</p> <ul style="list-style-type: none"> <li>● Public health insurance only</li> <li>● Private health insurance only</li> <li>● Public and private insurance</li> <li>● Uninsured</li> </ul>	<ul style="list-style-type: none"> <li>- Multinomial Logistic Regression</li> <li>- Compare differences between racial groups</li> <li>- Compare differences between disorder groups</li> </ul>
3	<p>How often does this child's health insurance offer benefits or cover services that meet this child's needs?</p> <ul style="list-style-type: none"> <li>● Always</li> <li>● Usually</li> <li>● Sometimes</li> <li>● Never</li> </ul>	<ul style="list-style-type: none"> <li>- Ordinal Logistic Regression</li> <li>- Compare differences between racial groups</li> <li>- Compare differences between insurance types</li> <li>- Compare differences between disorder groups</li> </ul>
4	<p>How often does this child's health insurance allow them to see the health care providers they need?</p>	<ul style="list-style-type: none"> <li>- Ordinal Logistic Regression</li> <li>- Compare differences between racial groups</li> <li>- Compare differences between insurance</li> </ul>



	<ul style="list-style-type: none"> <li>● Always</li> <li>● Usually</li> <li>● Sometimes</li> <li>● Never</li> </ul>	<ul style="list-style-type: none"> <li>- types</li> <li>- Compare differences between disorder groups</li> </ul>
6	<p>During the past 12 months, did your family have problems paying for any of this child's medical or health care bills?</p> <ul style="list-style-type: none"> <li>● Had problems paying medical bills</li> <li>● Did not have problems paying medical bills</li> </ul>	<ul style="list-style-type: none"> <li>- Binary Logistic Regression</li> <li>- Compare differences between racial groups</li> <li>- Compare differences between insurance types</li> <li>- Compare differences between disorder groups</li> </ul>

### Multilevel Modeling

For research question 4, I conducted a multilevel modeling analysis to account for nesting at the state level (Garson, 2019). The specific type of multilevel modeling that was conducted in this study was the cumulative link models for ordinal data. The question from the survey that was used for the outcome was (CAHMI, 2022):

Including co-pays and amounts reimbursed from Health Savings Accounts (HSA) and Flexible Spending Accounts (FSA), how much money did you pay for this child's medical, health, dental, and vision care during the past 12 months? Do not include health insurance premiums or costs that were or will be reimbursed by insurance or another source.

The dependent variable was yearly out-of-pocket medical costs, with Level 1 being the individual and Level 2 grouping individuals within the same state. The dependent variable was

an ordinal variable, and the five answer choices were: “No medical or health care expenses or less than \$250”, “\$250 - \$499”, “\$500 - \$999”, “\$1,000 - \$5,000”, or “More than \$5,000.” Level 1 predictors for this study were race/ethnicity, age, sex, insurance type, household FPL, and disorder category. Level 2 focused on the state of residence.

For my final model that included a Level 2 predictor, I included data from the Kaiser Family Foundation on the state distribution of total population below 200% FPL (Kaiser Family Foundation, 2022). I added this data to help explain additional state variance in my model. Once I determined the best model fit, I converted the results into odds ratios to provide a more in-depth interpretation (Harrell, 2015; Alwan et al., 2020).

### **Null Model**

My null model had the yearly out-of-pocket cost as the dependent variable and the state as the level-2 clustering variable. I calculated the Akaike information criterion (AIC), the Bayesian information criterion (BIC), and Log-Likelihood values for my null model and compared them to my other models to determine if my model improved when more factors were included. If the AIC and BIC values decreased from my null model to models with additional factors, that meant the model improved and showed a better fit. The Log-Likelihood values also measure goodness of fit, and a higher value for the Log-Likelihood demonstrates a better model fit.

### **Model 1**

The first model built onto the null model. I added Level 1 predictors for the CSHCN. The Level 1 predictors were: age of the CSHCN, sex of the CSHCN, race of the CSHCN, the needs of the CSHCN, the family’s FPL, and the insurance type for the CSHCN. Previous research demonstrated that race and insurance type can affect out-of-pocket medical expenses, so I

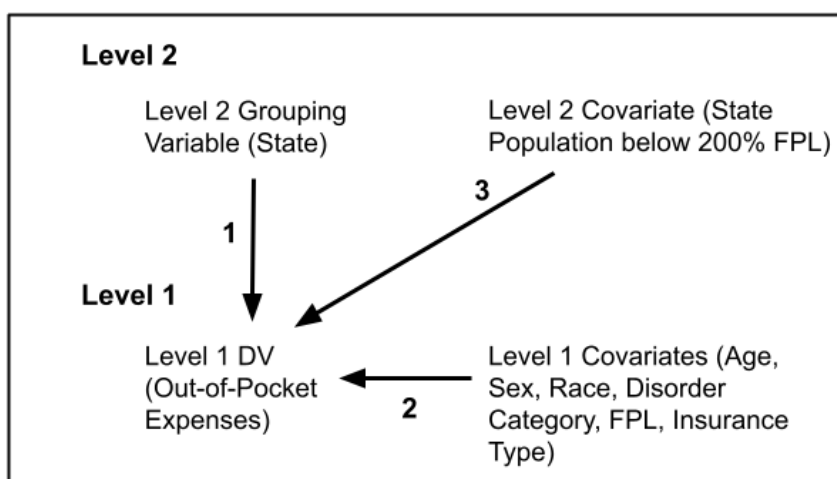
included these along with other individual factors that could account for some of the variance in my model (Akobirshoev et al., 2020; Musumeci, 2018).

## Model 2

The final model included a Level 2 predictor, state distribution of total population below 200% FPL. I included this additional variable to help account for state level variance. To determine model improvement, I examined each model's AIC, BIC, and Log-Likelihood values. If Model 2 was the best model, it would have the lowest AIC and BIC and higher Log-Likelihood values. I determined if the variables were statistically significant by examining the p-value for each variable. I set the significance level to  $p < 0.05$  for each variable.

## Figure 4

### *Model Levels*



## Assumptions

In addition to AIC, BIC, and Log-Likelihood values, I checked the proportional odds assumption for my final model to ensure it was not violated (Christensen, n.d.; Christensen, 2022).

## Chapter 4: Results

This Chapter reports the results of this study. The purpose of this secondary data analysis was to explore factors that impact CSHCN's health insurance coverage and out-of-pocket medical expenses. In this Chapter, I will describe the descriptive statistics for my sample and explain the results of each analysis based on each research question.

The research questions for this study were:

1. What individual characteristics are associated with having health insurance and with the type of health insurance held?
2. Does the health insurance of children with special healthcare needs cover needed healthcare services?
  - a. Is the child's race, insurance type, and disorder category associated with the likelihood that their healthcare needs are covered by health insurance?
3. Among children with special healthcare needs that reported out-of-pocket expenses, do their families have problems paying for their medical bills?
  - a. Is the child's race, insurance type, and disorder category associated with the likelihood that their family has problems paying for their medical bills?
4. To what extent are families of children with special healthcare needs associated with higher out-of-pocket medical expenses?
  - a. To what extent are individual factors such as race, sex, insurance type, and age of the child associated with the likelihood of paying more in out-of-pocket expenses?

- b. To what extent is a state-level factor such as state distribution of total population by Federal Poverty Level associated with the likelihood of paying more in out-of-pocket expenses?

### Descriptive Statistics

I analyzed the descriptive statistics to better understand the sample characteristics; see Table 3 below. After removing missing data, the total sample size was 9,762. The removed missing data was 2.8% of the total sample size, which is below the accepted threshold for missingness (Garson, 2019). Slightly more than half of the CSHCN were male, 56.6%, and almost all were currently insured, 96.6%. The majority (61.7%) of the CSHCN had private health insurance, and 27% of the sample had annual out-of-pocket medical expenses for the CSHCN that were \$1,000 or higher.

**Table 3**

*Descriptive Statistics of Total Sample (N = 9,762)*

CSHCN's Sex					
	Male	Female			
	5,528 (56.6%)	4,234 (43.4%)			
CSHCN's Race/Ethnicity					
	Hispanic	White, Non-Hispanic	Black, Non-Hispanic	Other/Multi-Racial, Non-Hispanic	
	1219 (12.5%)	6661 (68.2%)	735 (7.5%)	1147 (11.7%)	
CSHCN's Disorder Category					
	CSHCN without Neurodevelopmental, Emotional/Behavioral, or Genetic Disorder	Only Neurodevelopmental Disorders	Only Emotional and Behavioral Disorders	Only Genetic Disorders	2+ Disorders
	2876 (29.5%)	1402 (14.4%)	1406 (14.4%)	530 (5.4%)	3548 (36.3%)

Family's Federal Poverty Level	0-99% FPL	100-199% FPL	200-399% FPL	400%+ FPL	
	1347 (13.8%)	1736 (17.8%)	3012 (30.9%)	3667 (37.6%)	
CSHCN Currently Insured	Yes	No			
	9430 (96.6%)	332 (3.4%)			
CSHCN's Type of Health Insurance	Uninsured	Private Insurance Only	Public Insurance Only	Private and Public	
	332 (3.4%)	6028 (61.7%)	2677 (27.4%)	725 (7.4%)	
Current insurance meets CSHCN's needs	Always	Usually	Sometimes or Never	Uninsured	
	5255 (53.8%)	3302 (33.8%)	873 (8.9%)	332 (3.4%)	
Current insurance out-of-pocket expenses are reasonable	Always	Usually	Sometimes or Never	No Out-of-Pocket Expenses	Uninsured
	1228 (12.6%)	2803 (28.7%)	3093 (31.7%)	2306 (23.6%)	332 (3.4%)
Current insurance coverage allows CSHCN to see needed providers	Always	Usually	Sometimes or Never	Uninsured	
	6449 (66.1%)	2422 (24.8%)	559 (5.7%)	332 (3.4%)	
Family had problems paying for CSHCN's medical or health care bills					

	Yes	No	No medical expenses		
	1526 (15.6%)	5806 (59.5%)	2430 (24.9%)		
Family's Annual Out-of-Pocket Medical Expenses					
	No care expenses or less than \$250	\$250 - \$499	\$500 - \$999	\$1000 - \$5000	More than \$5000
	4133 (42.3%)	1511 (15.5%)	1479 (15.2%)	2108 (21.6%)	531 (5.4%)

### Findings Associated With Research Questions

#### Research Question 1

*What individual characteristics are associated with having health insurance and with the type of health insurance held?* To answer research question 1, I conducted a binary logistic regression to analyze if the CSHCN currently had health insurance (see Table 4), and a multinomial logistic regression to analyze what type of health insurance the CSHCN had (see Table 5). I checked for multicollinearity in Model 1, the binary logistic regression. Model 1 had low variance inflation factor (VIF) values, all of which were below 5, which demonstrated that multicollinearity was not a problem (Harrell, 2015). To determine model fit, I removed all the variables except one and created a null model, which I compared to Model 1. While the BIC slightly increased, 2,928.6 to 2,934.2, the AIC decreased, 2,899.9 to 2,840.8, and the Log-Likelihood scores increased, -1,445.95 to -1,407.41, which showed that the model improved when additional variables were added.

Model 1 shows the results for the logistic regression model testing whether individual characteristics of CSHCN were associated with having health insurance. The CSHCN's age, sex, and their family's FPL were significantly associated with having health insurance, holding all other variables constant. For each additional year in age, the odds of a CSHCN having health

insurance decreased by 5.0% (OR = 0.95,  $p < 0.001$ ). The odds of a female CSHCN having health insurance were 26.0% lower than for a male CSHCN (OR = 0.74,  $p < 0.05$ ). The odds of a CSHCN with a family between 0-99% FPL having health insurance were 51.0% lower than for a CSHCN with a family between 200-399% FPL (OR = 0.49,  $p < 0.001$ ). The odds of a CSHCN with a family between 100-199% FPL having health insurance were 45.0% lower than for a CSHCN with a family between 200-399% FPL (OR = 0.55,  $p < 0.001$ ). The odds of a CSHCN with a family 400% or higher FPL having health insurance were 39.0% higher than for a CSHCN with a family between 200-399% FPL (OR = 1.39,  $p < 0.05$ ). The CSHCN's race/ethnicity and disorder category were not statistically significant.

**Table 4**

*Model 1 Results: CSHCN with Health Insurance*

Variable	Model 1 Has Insurance	
	OR	p-value
CSHCN's Age	0.95	<0.001 ***
CSHCN's Sex (Ref. is Male)		
Female	0.74	0.01*
CSHCN's Race/Ethnicity (Ref. is White, Non-Hispanic)		
Hispanic	0.97	0.8
Black, Non- Hispanic	0.85	0.4
Other/ Multi- Racial, Non- Hispanic	0.92	0.6
CSHCN's Disorder Category (Ref. is CSHCN without Neuro, EBD, or Genetic Disorder)		
Only Neuro Disorders	0.86	0.4
Only EBD	1.32	0.15



Only Genetic Disorders	1.82	0.08
2+ Disorders	1.14	0.3
Family's FPL (Ref. is 200%- 399% FPL)		
0-99% FPL	0.49	<0.001 ***
100-199% FPL	0.55	<0.001 ***
400% FPL or greater	1.39	0.04 *

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\*\*\* = p < .001      \*\* = p < .01      \* = p < .05

I also checked assumptions for the multinomial logistic regression (Model 2). It is less straightforward to check assumptions for multinomial logistic regressions than other logistic regressions (UCLA: Statistical Consulting Group, 2021). The VIF values were all below 5, which ruled out multicollinearity. I removed all the variables except one and created a null model, which I compared to Model 2 to determine model fit. The AIC decreased, 18,378.69 to 15,080.8, the BIC decreased, 18,464.9 to 15,361.1, and the Log-Likelihood scores increased, -9,177.34 to -7,501.41, all of which showed improved model fit when additional variables were added.

Model 2 shows the results for the logistic regression model for CSHCN's type of health insurance. The reference was set to private health insurance only, so the first comparison was uninsured to private health insurance only. The CSHCN's sex, the race/ethnicity category of Black non-Hispanic, and their family's FPL were significantly associated with being uninsured compared to having private insurance only, holding all other variables constant. The odds for female CSHCN relative to male CSHCN is 37% higher for being uninsured compared to private insurance only, holding all other variables constant (OR = 1.37, p < 0.01). The odds for Black non-Hispanic CSHCN relative to White non-Hispanic CSHCN is 87% higher for being

uninsured compared to private insurance only, holding all other variables constant (OR = 1.87,  $p < 0.01$ ). The odds of CSHCN with a family between 0-99% FPL relative to CSHCN with a family between 200-399% FPL is 593% higher for being uninsured compared to private insurance only, holding all other variables constant (OR = 6.93,  $p < 0.001$ ). The odds of CSHCN with a family between 100-199% FPL relative to CSHCN with a family between 200-399% FPL is 273% higher for being uninsured compared to private insurance only, holding all other variables constant (OR = 3.73,  $p < 0.001$ ). The odds of CSHCN with a family at 400% or higher FPL relative to CSHCN with a family between 200-399% FPL is 42% lower for being uninsured compared to private insurance only, holding all other variables constant (OR = 0.58,  $p < 0.001$ ). The CSHCN's age, the race/ethnicity categories of Hispanic and Other/Multi-racial non-Hispanic, and the disorder category were not statistically significant.

The next comparison for Model 2 was public and private insurance to private health insurance only. The CSHCN's age, race/ethnicity category of Black non-Hispanic, disorder category, and their family's FPL were significantly associated with having public and private insurance compared to having private insurance only, holding all other variables constant. For each additional year in age, the odds for CSHCN are 6% lower for having public and private insurance compared to private insurance only, holding all other variables constant (OR = 0.94,  $p < 0.001$ ). The odds for Hispanic CSHCN relative to White non-Hispanic CSHCN is 36% higher for having public and private insurance compared to private insurance only, holding all other variables constant (OR = 1.36,  $p < 0.05$ ). The odds for Black non-Hispanic CSHCN relative to White non-Hispanic CSHCN is 103% higher for having public and private insurance compared to private insurance only, holding all other variables constant (OR = 2.03,  $p < 0.001$ ). The odds for other/multiracial non-Hispanic CSHCN relative to White non-Hispanic CSHCN is 29%

higher for having public and private insurance compared to private insurance only, holding all other variables constant (OR = 1.29,  $p < 0.05$ ). The odds for CSHCN with only a neurodevelopmental disorder relative to CSHCN without neurodevelopmental, emotional/behavioral, or genetic disorders is 65% higher for having public and private insurance compared to private insurance only, holding all other variables constant (OR = 1.65,  $p < 0.001$ ). The odds for CSHCN with only a emotional or behavior disorder relative to CSHCN without neurodevelopmental, emotional/behavioral, or genetic disorders is 84% higher for having public and private insurance compared to private insurance only, holding all other variables constant (OR = 1.84,  $p < 0.001$ ). The odds for CSHCN with only a genetic disorder relative to CSHCN without neurodevelopmental, emotional/behavioral, or genetic disorders is 65% higher for having public and private insurance compared to private insurance only, holding all other variables constant (OR = 1.65,  $p < 0.05$ ). The odds for CSHCN with 2+ disorders relative to CSHCN without neurodevelopmental, emotional/behavioral, or genetic disorders is 277% higher for having public and private insurance compared to private insurance only, holding all other variables constant (OR = 3.77,  $p < 0.001$ ). The odds of CSHCN with a family between 0-99% FPL relative to CSHCN with a family between 200-399% FPL is 210% higher for having public and private insurance compared to private insurance only, holding all other variables constant (OR = 3.10,  $p < 0.001$ ). The odds of CSHCN with a family between 100-199% FPL relative to CSHCN with a family between 200-399% FPL is 147% higher for having public and private insurance compared to private insurance only, holding all other variables constant (OR = 2.47,  $p < 0.001$ ). The odds of CSHCN with a family at 400% or higher FPL relative to CSHCN with a family between 200-399% FPL is 52% lower for having public and private insurance compared

to private insurance only, holding all other variables constant (OR = 0.48,  $p < 0.001$ ). The CSHCN's sex was not statistically significant.

The last comparison for Model 2 was public health insurance only to private health insurance only. The CSHCN's age, race/ethnicity, disorder category, and their family's FPL were significantly associated with having public and private insurance compared to having private insurance only, holding all other variables constant. For each additional year in age, the odds for CSHCN are 4% lower for having public health insurance only compared to private insurance only, holding all other variables constant (OR = 0.96,  $p < 0.001$ ). The odds for Hispanic CSHCN relative to White non-Hispanic CSHCN is 76% higher for having public health insurance only compared to private insurance only, holding all other variables constant (OR = 1.76,  $p < 0.001$ ). The odds for Black non-Hispanic CSHCN relative to White non-Hispanic CSHCN is 136% higher for having public health insurance only compared to private insurance only, holding all other variables constant (OR = 2.36,  $p < 0.001$ ). The odds for other/multiracial non-Hispanic CSHCN relative to White non-Hispanic CSHCN is 48% higher for having public health insurance only compared to private insurance only, holding all other variables constant (OR = 1.48,  $p < 0.001$ ). The odds for CSHCN with only a neurodevelopmental disorder relative to CSHCN without neurodevelopmental, emotional/behavioral, or genetic disorders is 50% higher for having public health insurance only compared to private insurance only, holding all other variables constant (OR = 1.50,  $p < 0.001$ ). The odds for CSHCN with only a emotional or behavior disorder relative to CSHCN without neurodevelopmental, emotional/behavioral, or genetic disorders is 48% higher for having public health insurance only compared to private insurance only, holding all other variables constant (OR = 1.48,  $p < 0.001$ ). The odds for CSHCN with 2+ disorders relative to CSHCN without neurodevelopmental, emotional/behavioral, or

genetic disorders is 119% higher for having public health insurance only compared to private insurance only, holding all other variables constant (OR = 2.19,  $p < 0.001$ ). The odds of CSHCN with a family between 0-99% FPL relative to CSHCN with a family between 200-399% FPL is 1003% higher for having public health insurance only compared to private insurance only, holding all other variables constant (OR = 11.03,  $p < 0.001$ ). The odds of CSHCN with a family between 100-199% FPL relative to CSHCN with a family between 200-399% FPL is 436% higher for having public health insurance only compared to private insurance only, holding all other variables constant (OR = 5.36,  $p < 0.001$ ). The odds of CSHCN with a family at 400% or higher FPL relative to CSHCN with a family between 200-399% FPL is 80% lower for having public health insurance only compared to private insurance only, holding all other variables constant (OR = 0.20,  $p < 0.001$ ). The CSHCN's sex and disorder category for only genetic disorders were not statistically significant.

**Table 5**

*Model 2 Results: Differences Between Insurance Types*

<i>Reference is Private Insurance Only</i>	Uninsured		Private and Public Insurance		Public Insurance Only	
	OR	p-value	OR	p-value	OR	p-value
CSHCN's Age	1.03	0.07	0.94	<0.001 ***	0.96	<0.001 ***
CSHCN's Sex (Ref. is Male)						
Female	1.37	0.008 **	1.08	0.37	1.03	0.60
CSHCN's Race/ Ethnicity (Ref. is						
Hispanic	1.34	0.08	1.36	0.012 *	1.76	<0.001 ***

White, Non-Hispanic)	Black, Non-Hispanic	1.87	0.002 **	2.03	<0.001 ***	2.36	<0.001 ***
	Other/ Multi-Racial, Non-Hispanic	1.28	0.18	1.29	0.04 *	1.48	<0.001 ***
CSHCN's Disorder Category (Ref. is CSHCN without Neuro, EBD, or Genetic Disorder)	Only Neuro Disorders	1.38	0.06	1.65	<0.001 ***	1.50	<0.001 ***
	Only EBD	0.91	0.64	1.84	<0.001 ***	1.48	<0.001 ***
	Only Genetic Disorders	0.62	0.17	1.65	0.011 *	1.29	0.053
	2+ Disorders	1.31	0.06	3.77	<0.001 ***	2.19	<0.001 ***
Family's FPL (Ref. is 200%-399% FPL)	0-99% FPL	6.93	<0.001 ***	3.10	<0.001 ***	11.03	<0.001 ***
	100-199% FPL	3.73	<0.001 ***	2.47	<0.001 ***	5.36	<0.001 ***
	400%+ FPL	0.58	<0.001 ***	0.48	<0.001 ***	0.20	<0.001 ***

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\*\*\* = p < .001      \*\* = p < .01      \* = p < .05

## Research Question 2

*Does the health insurance of children with special healthcare needs cover needed healthcare services? Is the child's race, insurance type, and disorder category associated with the likelihood that their healthcare needs are covered by health insurance?* As seen in the descriptive statistics table above, 53.8% of parents reported that the CSHCN's health insurance always met their needs, and 8.9% reported that it only sometimes or never met the CSHCN's needs. Additionally, 66.1% of the parents stated that the CSHCN's insurance always allowed

them to see needed medical providers, and 5.7% reported that the CSHCN's insurance sometimes or never allowed them to see needed providers. Out of the total sample, 3.4% of CSHCN were uninsured.

Models 3 and 4 analyzed if the health insurance of CSHCN covered needed healthcare services (see Table 6). For Model 3, the question was if the CSHCN's health insurance met their needs, and the question for Model 4 was if the CSHCN's health insurance coverage allowed them to see needed medical providers. The answer choices for both questions were: sometimes or never, usually, and always. I checked the assumptions of both Models by testing the proportional odds assumption, to ensure that just one set of coefficients describes the relationship between every pair of outcome groups (UCLA: Statistical Consulting Group, 2021). The proportional odds assumption was not violated for either model. Next, I removed all the variables except for one and created a null model, then I compared the null model to Model 3, and then Model 4, to determine model fit. For Model 3, the AIC decreased, 20,106.6 to 16,980.7, the BIC decreased, 20,149.7 to 17,110.1, and the Log-Likelihood scores increased, -10,047.29 to -8,472.37, all of which showed improved model fit when additional variables were added. For Model 4, the AIC decreased, 17,532.4 to 14,478.9, the BIC decreased, 17,575.5 to 14,608.2, and the Log-Likelihood scores increased, -8,760.22 to -7,221.44, all of which showed improved model fit when additional variables were added.

The results of Model 3 are for the ordinal logistic regression model to examine if the CSHCN's health insurance met their needs. The CSHCN's age, sex, the race/ethnicity category of Black non-Hispanic, the disorder category of only emotional/behavioral disorder and 2+ disorders, family FPL at 400% or higher, and health insurance category were significantly associated with CSHCN's health insurance meeting their needs, holding all other variables

constant. For each additional year in age, the odds of a CSHCN having health insurance meet more of their needs (moving up one level) increased by 1% (OR = 1.01,  $p < 0.01$ ). The odds of Black non-Hispanic CSHCN having health insurance meet more of their needs were 41% higher than for White non-Hispanic CSHCN (OR = 1.41,  $p < 0.001$ ). The odds of CSHCN with only an emotional or behavioral disorder having health insurance meet more of their needs were 33% lower than for CSHCN without neurodevelopmental, emotional/behavioral, or genetic disorders (OR = 0.67,  $p < 0.001$ ). The odds of CSHCN with 2+ disorders having health insurance meet more of their needs were 39% lower than for CSHCN without neurodevelopmental, emotional/behavioral, or genetic disorders (OR = 0.61,  $p < 0.001$ ). The odds of a CSHCN with a family 400% or higher FPL having health insurance meet more of their needs were 12% higher than for a CSHCN with a family between 200-399% FPL (OR = 1.12,  $p < 0.05$ ). The odds of CSHCN with public health insurance only having health insurance meet more of their needs were 92% higher than for CSHCN with private health insurance only (OR = 1.92,  $p < 0.001$ ). The odds of CSHCN with public and private insurance having health insurance meet more of their needs were 39% higher than for CSHCN with private health insurance only (OR = 1.39,  $p < 0.001$ ). The CSHCN's sex, the race/ethnicity categories of Hispanic and Other/Multi-racial non-Hispanic, disorder category of only neurodevelopmental disorders and only genetic disorders, and family's FPL category of 0-99% FPL and 100-199% FPL were not statistically significant.

Model 4 shows the results for the ordinal logistic regression model for the CSHCN's health insurance coverage allowing them to see needed medical providers. The CSHCN's race/ethnicity category of Black non-Hispanic, the disorder category of only neurodevelopmental disorder, only emotional/behavioral disorder, and 2+ disorders, family FPL at 400% or higher,



and health insurance category were significantly associated with CSHCN's health insurance coverage allowing them to see needed medical providers, holding all other variables constant. The odds of Black non-Hispanic CSHCN having health insurance coverage allowing them to see needed medical providers (moving up one level) were 44% higher than for White non-Hispanic CSHCN (OR = 1.44,  $p < 0.001$ ). The odds of CSHCN with only a neurodevelopmental disorder having health insurance coverage allowing them to see needed medical providers were 17% lower than for CSHCN without neurodevelopmental, emotional/behavioral, or genetic disorders (OR = 0.83,  $p < 0.05$ ). The odds of CSHCN with only an emotional or behavioral disorder having health insurance coverage allowing them to see needed medical providers were 43% lower than for CSHCN without neurodevelopmental, emotional/behavioral, or genetic disorders (OR = 0.57,  $p < 0.001$ ). The odds of CSHCN with 2+ disorders having health insurance coverage allowing them to see needed medical providers were 45% lower than for CSHCN without neurodevelopmental, emotional/behavioral, or genetic disorders (OR = 0.55,  $p < 0.001$ ). The odds of a CSHCN with a family 400% or higher FPL having health insurance coverage allowing them to see needed medical providers were 15% higher than for a CSHCN with a family between 200-399% FPL (OR = 1.15,  $p < 0.01$ ). The odds of CSHCN with public health insurance only having health insurance coverage allowing them to see needed medical providers were 37% higher than for CSHCN with private health insurance only (OR = 1.37,  $p < 0.001$ ). The odds of CSHCN with public and private insurance having health insurance coverage allowing them to see needed medical providers were 26% higher than for CSHCN with private health insurance only (OR = 1.26,  $p < 0.01$ ). The CSHCN's age, sex, the race/ethnicity categories of Hispanic and Other/Multi-racial non-Hispanic, disorder category of only genetic disorders, and family's FPL category of 0-99% FPL and 100-199% FPL were not statistically significant.

**Table 6***Models 3-5 Results*

Variable	Model 3 Insurance Meets Needs		Model 4 Insurance Allows Needed Provider		Model 5 Problems Paying Medical Bills	
	OR	p-value	OR	p-value	OR	p-value
CSHCN's Age	1.01	0.002 **	1.00	0.47	0.99	0.12
CSHCN's Sex (Ref. is Male)						
Female	0.98	0.60	0.99	0.87	1.16	0.02 *
CSHCN's Race/Ethnicity (Ref. is White, Non-Hispanic)						
Hispanic	0.96	0.51	0.89	0.08	1.11	0.26
Black, Non- Hispanic	1.41	<0.001 ***	1.44	<0.001 ***	1.16	0.25
Other/ Multi- Racial, Non- Hispanic	1.10	0.15	0.96	0.59	0.92	0.43
CSHCN's Disorder Category (Ref. is CSHCN without Neuro, EBD, or Genetic Disorder)						
Only Neuro Disorders	0.91	0.14	0.83	0.02 *	1.00	0.98
Only EBD	0.67	<0.001 ***	0.57	<0.001 ***	1.68	<0.001 ***
Only Genetic Disorders	0.85	0.08	0.93	0.53	1.51	0.002 **
2+ Disorders	0.61	<0.001 ***	0.55	<0.001 ***	1.79	<0.001 ***
Family's FPL (Ref. is 200%- 399% FPL)						
0-99% FPL	1.03	0.72	1.10	0.25	1.03	0.81
100-199% FPL	0.98	0.72	0.90	0.11	1.26	0.006 **

	400% FPL or greater	1.12	0.03 *	1.15	0.009 **	0.33	<0.001 ***
CSHCN's Insurance Type (Ref. is Private Insurance Only)	Public Health Insurance Only	1.92	<0.001 ***	1.37	<0.001 ***	0.90	0.26
	Public and Private Insurance	1.39	<0.001 ***	1.26	0.007 **	1.01	0.95
	Uninsured	-	-	-	-	2.00	<0.001 ***

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\*\*\* = p < .001

\*\* = p < .01

\* = p < .05

### Research Question 3

*Among children with special healthcare needs that reported out-of-pocket expenses, do their families have problems paying for their medical bills? Is the child's race, insurance type, and disorder category associated with the likelihood that their family has problems paying for their medical bills?* Table 3, above, shows the descriptive statistics that partially answers research question 3. Altogether, 15.6% of the parents reported that their family had problems paying for the CSHCN's medical or health care bills.

For Model 5 (see Table 6), I conducted a binary logistic regression and the question was if the family had problems paying for the CSHCN's medical bills during the past 12 months. The answer choices were, did not have problems paying medical bills or had problems paying medical bills. Participants that responded that they did not have any medical bills were excluded from this model. I checked for multicollinearity in Model 5. The VIF values were all low, below 5, and demonstrated that multicollinearity was not a problem (Harrell, 2015). To determine model fit, I removed all the variables except one and created a null model, which I compared to

Model 5. The AIC decreased, 7,495.0 to 7,033.6, the BIC decreased, 7,522.6 to 7,144.0, and the Log-Likelihood scores increased, -3,743.48 to -3,500.82, all of which showed improved model fit when additional variables were added.

For Model 5, which examined if the family had problems paying for the CSHCN's medical bills during the past 12 months, the CSHCN's sex, the disorder category of only emotional/behavioral disorders, only genetic disorders, and 2+ disorders, family FPL category of 100-199% FPL and 400% FPL or greater, and the health insurance category of uninsured were significantly associated with problems paying for the CSHCN's medical bills during the past 12 months, holding all other variables constant. The odds of female CSHCN having problems paying for the CSHCN's medical bills were 16% higher than for male CSHCN (OR = 1.16,  $p < 0.05$ ). The odds of CSHCN with only an emotional or behavioral disorder having problems paying for the CSHCN's medical bills were 68% higher than for CSHCN without neurodevelopmental, emotional/behavioral, or genetic disorders (OR = 1.68,  $p < 0.001$ ). The odds of CSHCN with only a genetic disorder having problems paying for the CSHCN's medical bills were 51% higher than for CSHCN without neurodevelopmental, emotional/behavioral, or genetic disorders (OR = 1.51,  $p < 0.01$ ). The odds of CSHCN with 2+ disorders having problems paying for the CSHCN's medical bills were 79% higher than for CSHCN without neurodevelopmental, emotional/behavioral, or genetic disorders (OR = 1.79,  $p < 0.001$ ). The odds of CSHCN with a family between 100-199% FPL having problems paying for the CSHCN's medical bills were 26% higher than for CSHCN with a family between 200-399% FPL (OR = 1.26,  $p < 0.01$ ). The odds of CSHCN with a family 400% or higher FPL having problems paying for the CSHCN's medical bills were 67% lower than for CSHCN with a family between 200-399% FPL (OR = 0.33,  $p < 0.001$ ). The odds of uninsured CSHCN having problems paying

for the CSHCN's medical bills were 100% higher than for CSHCN with private health insurance only (OR = 2.00,  $p < 0.001$ ). The CSHCN's age, race/ethnicity, the disorder category of only neurodevelopmental disorders, the family FPL category of 0-99% FPL, and the insurance categories of public only insurance and public and private insurance were not statistically significant.

#### **Research Question 4**

*To what extent are families of children with special healthcare needs associated with higher out-of-pocket medical expenses? To what extent are individual factors such as race, sex, insurance type, and age of the child associated with the likelihood of paying more in out-of-pocket expenses? To what extent is a state-level factor such as state distribution of total population by Federal Poverty Level associated with the likelihood of paying more in out-of-pocket expenses?* Family's annual out-of-pocket medical expenses for their CSHCN (see Table 3) was analyzed as part of the descriptive statistics. For parents of CSHCN, 42.3% reported no medical expenses or expenses less than \$250, however 21.6% reported expenses between \$1,000-5,000 and 5.4% reported annual expenses more than \$5,000.

To answer research question 4, I first created a Null Model with only the dependent variable, amount the family spent annually on out-of-pocket medical expenses for the CSHCN, and the state level. The intraclass correlation coefficient (ICC) was 0.054, which meant that 5.4% of the total variability in out-of-pocket expenses was accounted for by differences between states, and this demonstrated the need for a multilevel modeling approach (Garson, 2020). Next, I created Model 1 and added level 1 covariates for age of the CSHCN, sex of the CSHCN, race of the CSHCN, CSHCN's disorder category, the family's FPL, and the insurance type for the CSHCN. Lastly, I created Model 2 by adding a state level predictor, state distribution of total

population below 200% FPL. Table 7, below, shows the three models and their results. After conducting the analysis for the three models, I compared the models to determine if the model improved when more factors were added. The AIC and BIC decreased from the Null Model to Models 1 and 2, however they increased slightly from Model 1 to Model 2. The Log-Likelihood increased from the Null Model to Models 1 and 2, but it only barely increased from Model 1 to Model 2. Overall, the model improved significantly from the Null Model, and I decided to use Model 2 since the model fit was similar to Model 1 and it included a state level factor.

For Model 2, all variables were statistically significant except for the disorder category of only neurodevelopmental disorders and the state level predictor, state distribution of total population below 200% FPL. The odds ratios can be seen in Table 8 below. For each additional year in age, the odds for CSHCN are 2% higher for having higher out-of-pocket annual expenses (moving up one level), holding all other variables constant (OR = 1.02,  $p < 0.001$ ). The odds of female CSHCN having higher out-of-pocket annual expenses were 11% higher than for male CSHCN (OR = 1.11,  $p < 0.05$ ). The odds of Hispanic CSHCN having higher out-of-pocket annual expenses were 21% lower than for White non-Hispanic CSHCN (OR = 0.79,  $p < 0.001$ ). The odds of Black non-Hispanic CSHCN having higher out-of-pocket annual expenses were 46% lower than for White non-Hispanic CSHCN (OR = 0.54,  $p < 0.001$ ). The odds of Other/Multiracial non-Hispanic CSHCN having higher out-of-pocket annual expenses were 23% lower than for White non-Hispanic CSHCN (OR = 0.77,  $p < 0.001$ ). The odds of CSHCN with only an emotional or behavioral disorder having higher out-of-pocket annual expenses were 18% higher than for CSHCN without neurodevelopmental, emotional/behavioral, or genetic disorders (OR = 1.18,  $p < 0.05$ ). The odds of CSHCN with only a genetic disorder having higher out-of-pocket annual expenses were 83% higher than for CSHCN without neurodevelopmental,

emotional/behavioral, or genetic disorders (OR = 1.83,  $p < 0.001$ ). The odds of CSHCN with 2+ disorders having higher out-of-pocket annual expenses were 42% higher than for CSHCN without neurodevelopmental, emotional/behavioral, or genetic disorders (OR = 1.42,  $p < 0.001$ ). The odds of CSHCN with a family between 0-99% FPL having higher out-of-pocket annual expenses were 44% lower than for CSHCN with a family between 200-399% FPL (OR = 0.56,  $p < 0.001$ ). The odds of CSHCN with a family between 100-199% FPL having higher out-of-pocket annual expenses were 25% lower than for CSHCN with a family between 200-399% FPL (OR = 0.75,  $p < 0.001$ ). The odds of CSHCN with a family 400% or higher FPL having higher out-of-pocket annual expenses were 38% higher than for CSHCN with a family between 200-399% FPL (OR = 1.38,  $p < 0.001$ ). The odds of CSHCN with public health insurance only having higher out-of-pocket annual expenses were 94% lower than for CSHCN with private health insurance only (OR = 0.06,  $p < 0.001$ ). The odds of CSHCN with public and private insurance having higher out-of-pocket annual expenses were 63% lower than for CSHCN with private health insurance only (OR = 0.37,  $p < 0.001$ ). The odds of uninsured CSHCN having higher out-of-pocket annual expenses were 59% lower than for CSHCN with private health insurance only (OR = 0.41,  $p < 0.001$ ).

**Table 7**

*MLM Models: Out-of-Pocket Medical Expenses*

	<b>Null Model</b>	<b>Model 1</b>	<b>Model 2</b>
AIC	27799.6	23905.3	23906.0
BIC	27835.5	24049.0	24056.9
Log.Lik.	-13894.81	-11932.64	-11932.00
<b>Individual</b>		<b>Estimate</b>	<b>Estimate</b>
Age of CSHCN		0.017 ***	0.017 ***
Female (Reference Male)		0.10 *	0.10 *
CSHCN's Race/Ethnicity (Ref. is White, Non-Hispanic): Hispanic		-0.235 ***	-0.237 ***

CSHCN's Race/Ethnicity: Black, Non-Hispanic	-0.615 ***	-0.619 ***
CSHCN's Race/Ethnicity: Other/Multiracial, Non-Hispanic	-0.263 ***	-0.262 ***
Disorder Category (Ref. is CSHCN without Neuro, EBD, or Genetic Disorder): Only Neuro Disorders	-0.020	-0.022
Disorder Category: Only EBD	0.166 *	0.168 *
Disorder Category: Only Genetic Disorders	0.604 ***	0.604 ***
Disorder Category: 2+ Disorders	0.352 ***	0.352 ***
Family's FPL (Ref. is 200%- 399% FPL): 0-99% FPL	-0.585 ***	-0.587 ***
Family's FPL: 100-199% FPL	-0.282 ***	-0.283 ***
Family's FPL: 400% FPL or greater	0.321 ***	0.324 ***
CSHCN's Insurance Type (Ref. is Private Insurance Only): Public Only Insurance	-2.797 ***	-2.80 ***
CSHCN's Insurance Type: Public & Private Insurance	-0.996 ***	-0.997 ***
CSHCN's Insurance Type: Uninsured	-0.890 ***	-0.893 ***
<b>State</b>		
State Variance	0.057	0.036
State Population Percent Below 200% FPL		0.752

\*\*\*p<0.001 \*\*p<0.01 \*p<0.05

**Table 8**

*Odds Ratio: Out-of-Pocket Medical Expenses*

Model 2	OR	p-value
Age of CSHCN	1.02	<0.001 ***
Female (Ref. Male)	1.11	0.016 *
CSHCN's Race/Ethnicity (Ref. is White, Non-Hispanic): Hispanic	0.79	<0.001 ***
CSHCN's Race/Ethnicity: Black, Non-Hispanic	0.54	<0.001 ***
CSHCN's Race/Ethnicity: Other/Multiracial, Non-Hispanic	0.77	<0.001 ***
Disorder Category (Ref. is CSHCN without Neuro, EBD, or Genetic Disorder): Only Neuro Disorders	0.98	0.741
Disorder Category: Only EBD	1.18	0.011 *



Disorder Category: Only Genetic Disorders	1.83	<0.001 ***
Disorder Category: 2+ Disorders	1.42	<0.001 ***
Family's FPL (Ref. is 200%- 399% FPL): 0-99% FPL	0.56	<0.001 ***
Family's FPL: 100-199% FPL	0.75	<0.001 ***
Family's FPL: 400% FPL or greater	1.38	<0.001 ***
CSHCN's Insurance Type (Ref. is Private Insurance Only): Public Only Insurance	0.06	<0.001 ***
CSHCN's Insurance Type: Public & Private Insurance	0.37	<0.001 ***
CSHCN's Insurance Type: Uninsured	0.41	<0.001 ***
State Population Percent Below 200% FPL	2.12	0.257

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\*\*\*p<0.001   \*\*p<0.01   \*p<0.05

## Conclusion

In this Chapter I described the results of the descriptive statistics, logistic regression models, and multilevel modeling analyses for this study. Results from these analyses revealed that factors such as age, race, sex, disorder category, family FPL, and insurance type had a significant impact on CSHCN's health insurance coverage and medical costs. Research question two results suggest that increased age, being Black non-Hispanic, insurance type, and having a family with 400% or higher FPL were associated with increased likelihood that their healthcare needs were covered by health insurance. However, for CSHCN having one or more of the three disorder categories there was a decreased likelihood that their healthcare needs were covered by health insurance. Results of research question three suggested that CSHCN with a family with 400% or higher FPL were associated with the decreased likelihood that their families had problems paying their medical costs. Female CSHCN, CSHCN with one or more of the three disorder categories, CSHCN with a family between 100-199% FPL, and uninsured CSHCN were associated with increased likelihood that their families had problems paying their medical costs. Lastly, for research question 4, increased age, being female, CSHCN having one or more of the

three disorder categories, and having a family with 400% or higher FPL were associated with the increased likelihood that the CSHCN had higher out-of-pocket medical expenses. In contrast, public insurance only, private and public insurance, being uninsured, being Hispanic, Black non-Hispanic, or other/multiracial non-Hispanic, and having a family with 200% or lower FPL were associated with the decreased likelihood that the CSHCN had higher out-of-pocket medical expenses. In Chapter 5, I will discuss these findings, provide implications for future research and policy, and discuss limitations of the current study.

## Chapter 5: Discussion

The present study examined the impact of race, insurance type, disorder category, family FPL, and state of residence on insurance coverage and out-of-pocket expenses for CSHCN. In this chapter, I will discuss the findings reported in Chapter 4 and connect them with previous literature. I organized my findings based on my updated framework for the Ecological Model for Health Promotion discussed in Chapter 2 (see Figure 3). Finally, I will discuss the implications of the findings, recommendations for future research, and the limitations of this study.

### Overview of the Study

The purpose of this secondary data analysis was to explore factors that impact CSHCN's health insurance coverage and out-of-pocket medical expenses. By using 2020 data and focusing on CSHCN, I updated the literature base and provided an in-depth analysis of health insurance coverage and out-of-pocket costs specific to this population. I conducted descriptive statistics, logistic regressions, and multilevel modeling to answer the following research questions:

1. What individual characteristics are associated with having health insurance and with the type of health insurance held?
2. Does the health insurance of children with special healthcare needs cover needed healthcare services?
  - a. Is the child's race, insurance type, and disorder category associated with the likelihood that their healthcare needs are covered by health insurance?
3. Among children with special healthcare needs that reported out-of-pocket expenses, do their families have problems paying for their medical bills?
  - a. Is the child's race, insurance type, and disorder category associated with the likelihood that their family has problems paying for their medical bills?

4. To what extent are families of children with special healthcare needs associated with higher out-of-pocket medical expenses?
  - a. To what extent are individual factors such as race, sex, insurance type, and age of the child associated with the likelihood of paying more in out-of-pocket expenses?
  - b. To what extent is a state-level factor such as state distribution of total population by Federal Poverty Level associated with the likelihood of paying more in out-of-pocket expenses?

### **Discussion of Findings and Connection with Relevant Literature**

#### **Research Question 1**

*What individual characteristics are associated with having health insurance and with the type of health insurance held?* For the sample in this study, 96.6% of the CSHCN had health insurance while 3.4% were uninsured. The type of health insurance differed between CSHCN, with about 62% with private only insurance, 27% with public only insurance, and 7% with private and public insurance. These percentages differed from Schiff et al.'s (2022) finding that about 50% of CSHCN had private only insurance and 40% had public only insurance. In this study, there were less CSHCN with public only insurance and more with private only insurance.

For the individual factors level, based on my updated framework, age and sex were associated with the odds of CSHCN having health insurance. Age of the CSHCN was significantly associated with having health insurance, but it only had a slight practical significance because for each additional year in age, the odds of a CSHCN having health insurance decreased by only 5%. Female CSHCN were less likely to have health insurance than male CSHCN. This is a new finding as previous literature on CSHCN did not discuss the odds of

sex impacting health insurance. At the family factors level, family FPL was associated with having health insurance. CSHCN with a family below 199% FPL had decreased odds of having health insurance, while CSHCN with a family 400% or higher FPL had increased odds of having health insurance. The most likely explanation for this finding is that families with higher incomes would be better able to afford the cost of health insurance.

At the individual factors level, age, sex, race, and disorder category were associated with the CSHCN's type of health insurance. Age of the CSHCN was significantly associated with having health insurance, but it only had a slight practical significance because for each additional year in age, the odds of CSHCN having private and public insurance decreased by 6% and for public only insurance they decreased by only 4%. In alignment with the previous finding that female CSHCN were less likely to have health insurance than male CSHCN, the odds for female CSHCN relative to male CSHCN were higher for being uninsured compared to private insurance only. Hispanic, Black non-Hispanic, and other or multiracial non-Hispanic CSHCN had higher odds for having private and public insurance and public only insurance compared to White non-Hispanic CSHCN. Additionally, Black non-Hispanic CSHCN had higher odds for being uninsured compared to White non-Hispanic CSHCN. This aligns with the National Healthcare Quality and Disparities Report (2022) that shared that BIPOC Americans were less likely to have health insurance than White Americans. Previous research also supports the finding that Black non-Hispanic CSHCN are more likely to have public and private insurance or public only insurance than White non-Hispanic CSHCN. A higher percentage of Black non-Hispanic CSHCN live in poverty than White non-Hispanic CSHCN, so they are more likely to have public health insurance due to falling below the FPL requirement for their state (Houtrow et al., 2022).

CSHCN with only neurodevelopmental, emotional or behavior, genetic, or 2+ disorders had higher odds for having private and public insurance compared to CSHCN without neurodevelopmental, emotional/behavioral, or genetic disorders. Likewise, CSHCN with only neurodevelopmental, emotional or behavior, or 2+ disorders had higher odds for having public only insurance compared to CSHCN without neurodevelopmental, emotional/behavioral, or genetic disorders. This finding supports Karpur et al.'s (2019) conclusion that children with ASD, which is a neurodevelopmental disorder, were less likely to be uninsured than other CSHCN and Prokup et al.'s (2019) finding that the majority of children with developmental disabilities had Medicaid.

At the family factors level, family FPL was associated with the CSHCN's type of health insurance. CSHCN with a family below 199% FPL, relative to CSHCN with family FPL between 200-300%, had increased odds of being uninsured, having public and private insurance, and having public only insurance, compared to private insurance only. In comparison, CSHCN with a family 400% or higher FPL had decreased odds of being uninsured, having public and private insurance, and having public only insurance, compared to private insurance only. Again this supports previous findings that tied lower income CSHCN to public health insurance and higher income CSHCN to private health insurance (Musumeci, 2018).

## **Research Question 2**

*Does the health insurance of children with special healthcare needs cover needed healthcare services?* Results indicated that CSHCN's health insurance does cover needed healthcare services, with 87.6% of families of CSHCN reporting that their insurance meets the CSHCN's needs and 90.9% reporting that their insurance always or usually allows the CSHCN

to see needed providers. However, through logistic regression, I was able to determine that different factors impact whether CSHCN's insurance covered needed services.

*Is the child's race, insurance type, and disorder category associated with the likelihood that their healthcare needs are covered by health insurance?* For the individual factors level, race, and disorder category were associated with the odds of having CSHCN healthcare needs covered by their health insurance. While the age of the CSHCN was significantly associated with health insurance coverage, it did not have much practical significance because for each additional year in age, the odds of a CSHCN having health insurance that met more of their needs increased by only 1%. In contrast to previous findings, Black non-Hispanic CSHCN were more likely to have healthcare needs covered by their health insurance than White non-Hispanic CSHCN (Akobirshoev et al., 2020; Wexler et al., 2022). It is possible that Black non-Hispanic CSHCN were more likely to have public only health insurance, which impacts healthcare coverage and will be discussed below. Disorder category was also associated with the likelihood of CSHCN's healthcare needs being covered by health insurance. CSHCN with only emotional or behavior disorders and those with 2+ disorders were less likely to have healthcare needs covered by their health insurance than CSHCN without neurodevelopmental, emotional/behavioral, or genetic disorders. CSHCN with only neurodevelopmental disorders were less likely to have insurance that allowed them to see needed providers than CSHCN without neurodevelopmental, emotional/behavioral, or genetic disorders. Over 65% of CSHCN in this study had a neurodevelopmental, emotional/behavioral, or 2+ disorders, so it is an important finding that having one or more of these disorders is negatively associated with the CSHCN's likelihood of having healthcare needs covered by their health insurance. Similarly, Prokup et al. (2019) reported that children with developmental disabilities had more difficulty

accessing healthcare services than typically developing children, and more families with ASD reported their health insurance as low-quality compared to CSHCN without ASD (Karpur et al., 2019).

At the family factors level, CSHCN families at 400% or higher FPL were more likely to have healthcare needs covered by their health insurance than CSHCN with a family between 200-399% FPL. This is in contrast to Pickard and Ingersoll's (2016) finding that a slightly higher percentage of families with higher SES reported their insurance to be a barrier to health services compared to families with lower SES. However, Pickard and Ingersoll's study focused on families of children with ASD, whereas this study focused on all CSHCN. Lastly, at the community, organization, and policy factors level, CSHCN with public only insurance or public and private insurance were more likely to have healthcare needs covered by their health insurance than CSHCN with private only insurance. This finding aligned with previous literature that reported that public health insurance increased healthcare access for CSHCN compared to CSHCN with private health insurance (Earley et al., 2015; Musumeci, 2018; Prokup et al., 2019; Zickafoose et al., 2015). Additionally, this finding supports Zhang and Baranek's (2016) research that children with ASD with public insurance were more likely to have insurance cover healthcare needs than children with ASD with private health insurance.

### **Research Question 3**

*Among children with special healthcare needs that reported out-of-pocket expenses, do their families have problems paying for their medical bills? Is the child's race, insurance type, and disorder category associated with the likelihood that their family has problems paying for their medical bills?* About 16% of families reported that they had problems paying for CSHCN's medical or health care bills. Karpur et al. (2019) reported a higher percentage, 23.7%, of CSHCN



families that struggled to pay for the child's medical expenses, but they analyzed data that was four years older than the data used in this study so it is possible that this number decreased over time.

At the individual factors level, sex and disorder category were associated with the likelihood of families with CSHCN having problems paying their medical bills. Sex was one factor that was associated with the likelihood of paying more in out-of-pocket expenses. Female CSHCN had 16% higher odds for their family having problems paying for the CSHCN's medical bills than for male CSHCN. This contrasted with Lindley and Mark's (2009) finding that sex was not significantly associated with family financial burden. One possible explanation for this difference is that Lindley and Mark analyzed data that was collected prior to the passing of the Affordable Care Act in 2010 (U.S. Centers for Medicare & Medicaid Services, n.d.). Another explanation could be that female CSHCN were more likely to be uninsured than male CSHCN (see Table 5).

Disorder category was also associated with the likelihood that families of CSHCN had problems paying their medical bills. CSHCN with only emotional or behavior disorders, genetic disorders, and those with 2+ disorders were more likely to have problems paying for medical costs than CSHCN without neurodevelopmental, emotional/behavioral, or genetic disorders. The 2+ disorder category included neurodevelopmental disorders, and this aligned with Karpur et al.'s (2019) finding that more families of children with ASD struggled to pay their child's medical bills than families of CSHCN without ASD. This is also supported by the research of Lindley and Mark (2010) who reported increased family financial burden for children with emotional problems and more severe health conditions.

Families' FPL category was significant at the family factor level. CSHCN families between 100-199% FPL were more likely to have problems paying medical bills than CSHCN with a family between 200-399% FPL. CSHCN families at 400% or higher FPL were less likely to have problems paying medical bills than CSHCN with a family between 200-399% FPL. This makes sense as families with lower FPL have lower incomes and would be more likely to struggle to pay for the CSHCN's medical bills. Within the community, organization, and policy factors level, CSHCN who were uninsured were more likely to have problems paying medical bills than CSHCN with private only insurance. Without insurance, families of CSHCN would have to pay for the entirety of the medical bills themselves, rather than insurance covering at least part of the bill.

#### **Research Question 4**

*To what extent are families of children with special healthcare needs associated with higher out-of-pocket medical expenses?* While 58% of families of CSHCN had annual out-of-pocket medical expenses below \$500, 27% of families of CSHCN had expenses above \$1,000. This closely aligned with Lindley and Mark's (2009) finding that almost 25% of families of CSHCN had yearly out-of-pocket costs exceeding \$1,000. This finding is important because Lindley and Mark (2009) determined that annual out-of-pocket medical expenses above \$250 were associated with financial burden. Wisk et al. (2020) defined extreme financial burden as annual out-of-pocket expenses for the entire family that was 10% or higher of the family's total annual income. From the data collected, I was not able to determine the family's total annual income or the entire family's out-of-pocket medical expenses, so I was unable to determine if the families of the CSHCN met the threshold for extreme financial burden.

*To what extent are individual factors such as race, sex, insurance type, and age of the child associated with the likelihood of paying more in out-of-pocket expenses?* Individual factors were associated with the likelihood of paying more in out-of-pocket expenses, but the impact of each factor varied greatly. Once again, age of the CSHCN was statistically significant but did not have much practical significance because for each additional year in age, the odds for CSHCN only increased by 2% for having higher out-of-pocket annual expenses. Sex was a factor that was associated with the likelihood of paying more in out-of-pocket expenses. Female CSHCN were more likely to have higher out-of-pocket expenses than male CSHCN. This finding adds to the current literature as previous literature did not discuss the impact of sex on CSHCN's out-of-pocket medical expenses. This also supports my previous finding that families of female CSHCN were more likely to have problems paying for the CSHCN's medical bills than for male CSHCN.

Similar to the findings of Newacheck and Kim (2005) and Ghandour et al. (2014), race was associated with the likelihood of paying more in out-of-pocket expenses. CSHCN who were Hispanic, Black non-Hispanic, or other/multiracial non-Hispanic were less likely to have higher out-of-pocket medical expenses than White non-Hispanic CSHCN. Disorder category was also associated with the likelihood of paying more in out-of-pocket expenses such that CSHCN with only emotional or behavior disorders, only genetic disorders, or 2+ disorders were more likely to have higher expenses than a CSHCN without neurodevelopmental, emotional/behavioral, or genetic disorders. Prior research studies have not compared these disorder categories in regards to out-of-pocket medical expenses, so this finding is a new addition to the research field.

Additionally, the CSHCN's family FPL was associated with the likelihood of paying more in out-of-pocket expenses. Families below 200% FPL were less likely to have higher

out-of-pocket expenses, while families at 400% or higher FPL were more likely to have higher out-of-pocket expenses. This finding supports previous research indicating that CSHCN from lower income families are more likely to have public health insurance, and public health insurance is associated with lower out-of-pocket expenses (Schiff et al., 2022; Musumeci, 2018). Similarly, Ghandour et al. (2014) found that higher income families of CSHCN were more likely to have higher out-of-pocket medical expenses than families of CSHCN with lower incomes. However, lower out-of-pocket medical expenses does not necessarily mean lower financial burden. Lindley and Mark (2010) reported that lower SES families had financial burdens at lower cost levels than higher SES families.

CSHCN's health insurance type was also associated with the likelihood of paying more in out-of-pocket expenses. CSHCN with public only insurance, public and private insurance, and those who were uninsured were less likely to have higher out-of-pocket expenses compared to CSHCN with private only insurance. This supports the Ghandour et al.'s (2014) finding that CSHCN with private health insurance were more likely to have higher out-of-pocket expenses. Another explanation for CSHCN with public health insurance having lower out-of-pocket expenses is that children with public insurance are not allowed to be charged more than 5% of their family's total income for out-of-pocket healthcare expenses (Brooks et al., 2020).

*To what extent is a state-level factor such as state distribution of total population by Federal Poverty Level associated with the likelihood of paying more in out-of-pocket expenses?*

While there was variance between states, which demonstrated the need for multilevel modeling, state distribution of total population below 200% FPL was not statistically significant. So, it appears that the state distribution of total population below 200% FPL is not associated with the likelihood of paying more in out-of-pocket expenses.

## **Policy Implications**

Across all of the research questions for this study, the importance of public health insurance was evident. CSHCN with public health insurance only were more likely to have insurance that met their needs and allowed them to see needed providers, and they were less likely to have high out-of-pocket medical expenses. While public health insurance was clearly important for lowering out-of-pocket medical expenses for CSHCN, only 27.4% of families with a CSHCN in this study had public health insurance. State and federal legislators should consider expanding public health insurance regulations for CSHCN in order to reduce the financial burden that their families face. One possibility, which would reduce variance between states, would be to set a national standard, rather than a minimum, so that all states would have the same eligibility requirements for Medicaid and CHIP. Nineteen states provide Medicaid or CHIP for CSHCN with family incomes at or above 300% of the FPL, so a national eligibility standard of 300% of the FPL would most likely increase the percentage of CSHCN with public health insurance (Brooks et al., 2020). This would create more equitable opportunities for health insurance rather than CSHCN in some states qualifying for public health insurance based on income while CSHCN with the same income in different states do not. As of April 2023, however, millions of Americans are at risk for losing their Medicaid coverage as states begin reverifying individual's qualifications, which had previously been paused by Congress during the pandemic (Tolbert & Ammala, 2023). Of those individuals at risk of losing their Medicaid coverage are over 6.7 million children (Alker & Brooks, 2022). This change could negatively impact CSHCN, and their families, if they lose their Medicaid coverage.

While the CSHCN's family FPL and type of health insurance may change over time, sex, race/ethnicity, and disorder category are individual factors that are out of the CSHCN and their

families' control. Yet, these factors were associated with the likelihood that CSHCN had insurance that covered needed services and the amount of their out-of-pocket medical expenses. Families of female CSHCN were more likely to have higher out-of-pocket costs and have problems paying the CSHCN's medical bills. CSHCN with neurodevelopmental, emotional or behavioral, genetic, or 2+ disorders had worse outcomes for insurance covering needed services, affordability of medical costs, and the amount of their out-of-pocket medical expenses than CSHCN without neurodevelopmental, emotional/behavioral, or genetic disorders. Setting a national standard for public health insurance that at least covers up to 300% of the FPL could address some of these inconsistencies.

Another option that could increase equity for CSHCN families would be to expand the current federal legislation requirement that families of children with Medicaid or CHIP cannot be charged more than 5% of their total family income for out-of-pocket medical expenses (Brooks et al., 2020). This policy could be expanded to all children, regardless of their health insurance type, or at least to all CSHCN because their families are more likely to struggle to pay medical bills for the CSHCN (Karpur et al., 2019). CSHCN with differing race/ethnicity, sex, and disorder categories would have more affordable out-of-pocket expenses with a percentage cap based on family income, and the CSHCN's type of health insurance would be less important. It would be more equitable if legislation was changed so that families of CSHCN with any insurance type would not be charged more than 5% of their total family income for out-of-pocket medical expenses. Setting a maximum for CSHCN's out-of-pocket expenses at 5% of the total family income seems appropriate as Wisk et al. (2020) reported that out-of-pocket expenses above 8.35% of the total family income creates a financial burden on the family. If more evidence is needed prior to federal legislation reform, individual states could elect to set a 5%

out-of-pocket expenses cap for all CSHCN, regardless of insurance type. While health insurance is a national issue, states are given authority of Medicaid and CHIP so long as they meet the national eligibility requirements (Brooks et al., 2020). One or more states could test the results of creating a state law that CSHCN cannot be charged above 5% of their family's total income. Most likely, this legislation would relieve some of the financial burden that families of CSHCN face. To reduce the financial impact on the state, the state could start with the 5% cap only applying to CSHCN with only neurodevelopmental disorders, only emotional and behavior disorders, only genetic disorders, and those with two or more of these disorders. This study demonstrated that these children are more likely to have higher out-of-pocket expenses and that their families were more likely to struggle to pay for their medical bills than families of CSHCN without a neurodevelopmental, emotional or behavioral, or genetic disorder. About 30% of the CSHCN in this study did not have a neurodevelopmental, emotional or behavioral, or genetic disorder, so it would save the state money to initially exclude these children from the 5% out-of-pocket cap and the state would help the CSHCN who need the most financial relief.

### **Implications for Families**

I would recommend that families of CSHCN try to get their child public health insurance because this study, and previous research studies, demonstrated that public health insurance for CSHCN is more likely to cover needed healthcare services at a lower out-of-pocket cost to families (Ghandour et al., 2014; Musumeci, 2018). If possible, I would suggest that families of CSHCN avoid getting private only insurance for their child because it is more likely to be costly for the family, especially if the CSHCN visits medical providers more frequently. The findings of this study did not reflect any benefit for the CSHCN in having private only insurance.

When families of CSHCN begin to consider health insurance options for their CSHCN, they should start by looking at their total annual income and their state's Medicaid eligibility requirements. If they fall below their state's eligibility requirement, I recommend that that family apply for Medicaid based on their income level because it is quicker and easier to demonstrate income eligibility rather than a child's disability eligibility (Musumeci, 2018). If the family of the CSHCN does not meet the income eligibility for Medicaid and has private insurance for their family, I would then recommend that they investigate if the CSHCN can qualify for Medicaid or CHIP based on their disability. CSHCN can have public and private insurance, with Medicaid/CHIP being either the primary or secondary insurance. Having public and private insurance would be more beneficial for the CSHCN as this study has shown that public and private insurance covers needed healthcare services at a lower out-of-pocket cost than having private only insurance.

### **Implications for Research**

This study was unique in that the sample consisted of only CSHCN and that the analyses focused on differences between CSHCN and their impact on health insurance coverage and out-of-pocket costs. The results indicated that race, disorder category, family FPL, and insurance type were strongly associated with CSHCN's health insurance coverage and out-of-pocket costs. The results of this study were based on 2020 data, which did not include questions specific to COVID-19. Researchers should consider replicating this study with more recent data to analyze the impact of COVID-19 on health insurance and out-of-pocket expenses. For CSHCN with private insurance based on parental employment, COVID-19 might have had disastrous effects on their healthcare if their parent lost employment during COVID-19 and subsequently lost their health insurance. According to Alker and Brooks (2022), child enrollment in Medicaid and CHIP



increased by 11% from February 2020 to June 2021. This significant increase may have impacted CSHCN's healthcare coverage and out-of-pocket expenses in 2021 and 2022. There are many different COVID-19 factors that could be significant and should be investigated to analyze CSHCN health insurance and out-of-pocket expenses during and post-pandemic. As many Americans will be unenrolled from Medicaid beginning in April 2023, a future longitudinal study could compare CSHCN's health insurance coverage pre-COVID-19, during COVID-19, and after 2023 (Tolbert & Ammula, 2023).

Another important area for future research is to expand upon the disability analysis. I categorized CSHCN into five disorder categories to further analyze the impact of disability on health insurance coverage and out-of-pocket expenses. Future research studies could analyze and compare individual disability categories (i.e., ASD, Down Syndrome, deaf/hearing impairment) to provide a more in-depth disability analysis.

Lastly, this study determined that there is variance between states for out-of-pocket medical expenses. It is important to research differences by state because health insurance regulation and medical costs in each state vary greatly. The next step would be to determine which states have lower and which states have higher average out-of-pocket expenses for CSHCN. If there is a state with much lower average costs, researchers could explore what the state is doing and how other states could replicate its model. Additionally, I investigated if state distribution of the total population below 200% FPL was associated with out-of-pocket expenses for CSHCN. While this variable was not statistically significant, other state level factors, such as the percentage of CSHCN in the state or state FPL requirements for Medicaid/CHIP, could help explain additional state variance and should be investigated.

## Limitations

One limitation of a secondary data analysis is that I was not able to add questions to the survey that would better address my research questions; I was limited to the available survey questions and responses (Johnston, 2017). The NSCH data was collected in 2020 and does not specifically address the impact of COVID-19. If I were part of the original research team, I would have added survey questions about COVID-19 to investigate if it was associated with families' SES and children's medical expenses. More recent data could provide a better understanding of the effects of COVID-19 on CSHCN's insurance availability and medical expenses.

For the NSCH, household poverty questions often have a high percentage of missing responses (CAHMI, 2022). Participants may refuse to answer questions about income because it can feel intrusive or because it is too complicated to calculate (Davern et al., 2005). In 2020, 19.7% of responses were missing FPL information and the Census Bureau completed a single imputation value of 1= "0-99% FPL" for missing responses (CAHMI, 2022). This was a limitation because all missing responses were given the same value, which may not be correct for all of the participants.

For the multilevel modeling analysis, I added a second data set to determine if state average FPL could explain some of the state variance. I planned to use 2020 state level data to go along with the 2020 data from the NSCH, however 2020 state level data was not published because of data collection disruptions from COVID-19 (Kaiser Family Foundation, 2022). Instead, I used 2021 state level data, which could be different from FPL state averages in 2020 (Kaiser Family Foundation, 2022).

## **Conclusion**

This study updated medical and disability literature through the analysis of more recent data and with a sole focus on CSHCN. The results of this study demonstrated that race, gender, disorder category, insurance type, and family FPL were associated with CSHCN's health insurance coverage and out-of-pocket costs. Additional federal legislation is needed to address these differences between groups of CSHCN so that all CSHCN have access to affordable healthcare that meets their individual needs. Two possible solutions are to create a national Medicaid eligibility standard of 300% of the FPL and to expand the requirement that families of children with Medicaid or CHIP cannot be charged more than 5% of their total family income to all CSHCN regardless of their health insurance type. Future research could expand this study to analyze CSHCN's health insurance coverage and out-of-pocket expenses before COVID-19, during COVID-19, and after 2023.

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