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# Experiences of Parents With Chronically Ill Children Regarding the Affordable Care Act

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*Walden University*

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# Walden University

College of Social and Behavioral Sciences

This is to certify that the doctoral dissertation by

Kimberly V. Bracey

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Abstract

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by

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MA, Belhaven University, 2013

BS, Belhaven University, 2011

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Public Policy and Administration

Walden University

May 2019

## Abstract

Ways in which the implementation of the Patient Protection and Affordable Care Act (ACA) affect parents with chronically ill children are not well understood. The purpose of this phenomenographic study was to gain greater insight into the perceived experiences of parents of chronically ill children regarding implementation of the ACA in a southern state. Argyris's intervention theory provided the framework for the study. Face-to-face interviews were conducted with a purposeful sample of 12 female parents who are caregivers of chronically ill children. Data were analyzed and coded to identify categories and themes. Findings indicated that parents view physicians and policymakers as key actors in their communities to create more equitable services for parents of chronically ill children through the expansion of Medicaid services in southern state. Many participants did not perceive that the ACA had made significant changes to services received prior to its implementation. Findings may assist health care providers, insurance companies, legislators, and other policymakers to develop appropriate health care policies and interventions to lessen the financial burden experienced by parents of chronically ill children. Providing more support services that address the physical, emotional, and financial needs of parents may improve the health outcomes of their chronically ill children.

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## Dedication

I dedicate this study to my loving and supportive husband, Santore Bracey, and to our children, Jhaiyde, Brittany, Kyla, Isaiah, Maxwell, and Bricelynn. Thank you to my parents and siblings for supporting me financially, emotionally, and spiritually. Thank you to my bishop and pastor, Adrian and Tonya Ware, for praying for me and reminding me that in everything I do, I should use wisdom and strategy.

One of the most important people I must dedicate this study to is Joyce Willis Baker, my aunt who succumbed to multiple myeloma. It was because of your encouragement and strength that I kept focused and motivated to keep moving onward and upward from milestone to milestone.

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## Chapter 1: Introduction to the Study

Health care is under scrutiny by public officials and has been depleted in equity in the Southern state in comparison with the other U.S. states (Tavernise & Gebeloff, 2013). One southern state has the poorest and largest percentage of uninsured people in the United States (Bertrand, 2014) and was one of the 19 states that did not expand Medicaid (Musumeci, 2017). Guendelman, Angulo, and Oman (2005) explained that “children in working poor families have higher odds of being uninsured than those in nonpoor families” (p. 1).

The effects of failing to expand Medicaid are considerable, given that 4% of children under the age of 18 do not have any health coverage, and another 44% of children under the age of 18 have Medicaid and other public insurance, which is their only source of health coverage (Centers for Disease Control and Prevention, 2017). Because one southern state is one of the poorest U.S. states, disparities persist in insurance coverage between the poor and the working poor, which has placed poor children at a disadvantage for access and use of health insurance of any sort (Guendelman et al., 2005). According to data from a 2009–2010 Kaiser Family Foundation report, more than 11.2 million children in the United States have been diagnosed with chronic illnesses such as Down syndrome, cerebral palsy, and autism (Henry J. Kaiser Family Foundation, 2015; Medicaid.gov, n.d.; Musumeci, 2017), and at least 17,000 deaths have been linked to a lack of health coverage (Pallarito, 2009).

Parents with children receiving state-mandated health care who must pay out-of-pocket expenses may feel overwhelmed by medical debt, possibly leading to bankruptcy

(Austin, 2014). Parents who are in a low- to middle-income bracket with children diagnosed with chronic illnesses endure other areas of obligations concerning a child's health care needs. Although a parent may receive Medicaid as a form of health care or receive health care under the Patient Protection and Affordable Care Act (ACA), one southern state did not adopt Medicaid expansion, causing these parents to pay out of pocket for expenses not covered to purchase prescriptions or other health care needs. These costs can impact poor families because parents must choose between purchasing needed items such as food or transportation and medications or copayments not covered under their health care provider for their chronically ill child.

Insufficient employment opportunities and minimal health care in southern state can cause an emotional strain on the parent of a chronically ill child and produce emotional and financial barriers (Cousino & Hazen, 2013). This study addressed a gap in literature concerning limited research on how the implementation of the ACA affects parents with chronically ill children in the Southern state. Chapter 1 includes the background of the study, the statement of the problem, and the purpose statement. I also present the research question, nature of the study, and conceptual framework. The chapter also includes operational definitions, limitations, delimitations, assumptions, and the significance of the study, followed by a summary of the chapter.

## **Background**

Health insurance came about in the United States in the 1930s beginning with the Great Depression (Morrisey, 2008). The Great Depression led to hospitals and physicians implementing forms of insurance to guarantee payment for services rendered (Morrisey,

2008). The growth in Medicaid was affected with expenditures topping \$200 billion by 2000, and enrollment increased from 4 million to 33 million since the time the program began (Klemm, 2000).

Medicaid, accompanied by Medicare in 1965, provided state-mandated health care for impoverished adults and was later expanded to cover children and pregnant women with households under 133% of the federal poverty level (FPL; Morrissey, 2008). In 1989, 16 million of approximately 23.5 million recipients of Medicaid were adult family heads and dependent children (Tallon, 1990). Of those 16 million, at least 8 million were disabled (Tallon, 1990). The Children's Health Insurance Program (CHIP) was developed under former President Clinton's administration with implications for Medicaid- and Medicare-eligible recipients and was connected to benefits under Aid to Families with Dependent Children (Tallon, 1990). Under the provisions of CHIP, children in low- to moderate-income households that fall below 300% of the FPL can receive coverage monitored by federal and state governments (Tallon, 1990). Legislators designed the ACA (2010) to bring significant changes to health care by allowing dependents up to the age of 26 to receive health coverage, regardless of any preexisting conditions (Tallon, 1990).

The ACA is health care reform designed by former President Obama in 2010 (White House, 2015). The ACA came about following the President's awareness of the population that has little or no insurance. Members of Congress developed health care reform to improve access to and use of health care options for low- to middle-income families in the United States. The ACA aimed to improve the access, quality, and

affordability of health care insurance (Obamacare Facts, 2017). Legislators expected the ACA to provide health insurance for individuals regardless of preexisting conditions, make coverage available to dependents who are 26 years of age and younger, expand Medicaid and CHIP, and expand free preventative services (Obamacare Facts, 2017). The law requires larger employers to ensure their employees, establishes a marketplace for subsidized insurance providing tens of millions of individuals, families, and small businesses with free or low-cost health insurance, and decreases the deficit in health care spending (Obamacare Facts, 2017).

Title XIX of the Social Security Act in 1965 authorized Medicaid, alongside Medicare, as law (Medicaid.gov, 2017). All states, the District of Columbia, and U.S. territories have since designed Medicaid programs to provide health insurance for low-income individuals (Medicaid.gov, 2017). Each state, with parameters, administers its Medicaid program differently, which can result in a variety of programs (Medicaid.gov, 2017). The ACA, beginning in 2014, allowed states to have the authority to expand Medicaid eligibility to residents for those under the age of 65 with an income below 133% of the FPL (Medicaid.gov, 2017). This expansion would allow standardization of the rules for determining eligibility and providing benefits through Medicaid, CHIP, and the health insurance marketplace (Medicaid.gov, 2017).

The ACA has expanded access to health insurance to Americans by transforming “the U.S.’s public and private health care financing systems into vehicles for promoting public health by making evidence-based preventative services available nationwide through individual and group health plans, Medicare, and Medicaid” (Cogan, 2011, p. 1).



However, some gaps persist in coverage and knowledge of the kinds of coverage for specific groups in states that opted not to participate in Medicaid expansion; One southern state is one of those states (Kaiser Family Foundation, 2015). Parents who receive health insurance that they deem unaffordable for their chronically ill child fall into this coverage gap when their salaries are too low to pay for their employers' health insurance and simultaneously exceed the household-income parameters to receive Medicaid benefits (Kaiser Family Foundation, 2015).

As of February 2016, at least 12.7 million people nationwide had received health care coverage under the health care marketplace (U.S. Department of Health and Human Services, 2016a). In the Southern state, 104,538 residents received health insurance coverage under the health care marketplace as of February 22, 2015 (U.S. Department of Health and Human Services, 2015). Although one southern state opted not to participate in the expansion of Medicaid, more than \$15 billion will be saved in this state on prescription drugs for covered recipients and those who fall in the coverage gap (U.S. Department of Health and Human Services, 2015). The coverage gap occurs when ACA premium aids are available to those whose household income is considered at least 100% of FPL and up to 400% of FPL (U.S. Department of Health and Human Services, 2015). The coverage gap, nicknamed the doughnut hole, exists because the premium subsidies in the ACA will not be available for those individuals with a household income below 100% of the FPL (Norris, 2017). Subsidies are unavailable for families below 100% of FPL. Initially, Medicaid expansion was part of the law (Norris, 2017). Legislators assumed those families below 100% of FPL would not need subsidies (Norris, 2017). Thus, in

southern state, able-bodied adults without children and many parents with incomes below 100% of FPL cannot receive assistance for health insurance (Norris, 2017). They do not qualify for Medicaid unless you meet previously enacted guidelines (Norris, 2017). The 4,492 people who signed up for marketplace coverage represented 37% of people across the state who were eligible (Kaiser Family Foundation, 2015). Of these residents, 52% were Black, 45% were White, and 2% were Hispanic (Kaiser Family Foundation, 2015).

Health care is not a privilege but is a right of every human being, according to the United Nations Declaration of Human Rights, Article 25; however, one southern state refused to expand Medicaid to recipients of insurance through the health care marketplace (MS Left Me Out, 2018). Furthermore, most legislators in southern state work on a part-time basis and have limited expertise in many areas of responsibility including health care (Weberg, 2017). These legislators can be assigned to public health-related committees and receive on-the-job training without researching the impact of health insurance on low-income families or poor families, with little support from more experienced policymakers (Nicholson and Gruwell, 2018).

Despite the passage of the ACA in 2010, parents who fall into the doughnut hole do not have access to affordable health care (Norton, 2017). Parents of a child who has been diagnosed with a chronic illness, such as sickle-cell anemia, can be burdened with emotional strain and psychological distress (Bemis et al., 2015), negatively affecting their families. When catastrophic events following the diagnosis of a chronic illness arise, parents or guardians seek appropriate health care for a complete cure for the child (Bluebond-Langner, et al., 2007). Many low-income and poor families lack access to

educational and financial means for medical and domestic support (Vonnellich, Ludecke, & Kofahl, 2016).

The lack of access to health care and health insurance can impact those in the coverage gap mentally and financially (Garfield, et al., 2016). This insurance gap can impact the entire family, causing distress and worry and bringing financial, emotional, and social concerns for a child living with cancer (Mellace, 2010). Of patients' parents who were struggling financially, 66% also suffer from depression or anxiety, 29% of the patients' parents delayed filling their prescriptions, and 22% of the patients' parents skipped the patients' doses to extend their medications (Mellace, 2010). An entire family can be disrupted by the stress of a parent of a child with a chronic illness (Long & Marsland, 2011) due to unexpected medical costs that are not covered by health insurance.

Chronic illnesses can impact the family system at multiple levels, from individual family members' experiences of day-to-day changes, roles, responsibilities, and related distress to disruptions in relationships among family members and functionality in the family system (Long & Marsland, 2011). Treatment may cause financial stress for chronically ill children such as pediatric-oncology patients and their families (Warner, Kirchhoff, Nam, & Fluchel, 2015). Life-saving cancer therapy is costly and may result in financial burden (Warner et al., 2015). Low-income families often have insurance that provides inadequate coverage for treatment or do not have insurance coverage at all (Garfield, Damico, Stephens, & Rouhani, 2014). Many times, these families rely on a variety of sources for income and food that include unstable or low-paid part-time work,

food stamps, Temporary Assistance for Needy Families, Social Security Insurance, and Social Security Disability Insurance benefits.

Low-income families struggle to provide the necessities and are often on the verge of poverty (Garfield et al., 2014). However, “because the Affordable Care Act envisioned low-income people receiving coverage through Medicaid it does not provide financial assistance to people below poverty for other coverage options” (Garfield et al., 2014, p. 1). States that did not expand Medicaid caused adults to enter the coverage gap in which their income is too high to receive Medicaid for their child but too low to receive premium tax credits under the health care marketplace (Garfield et al., 2014). Health insurance in the Southern state has been a controversial topic among recipients and physicians, with stakeholders differing about what should and should not be available in health care or medical treatment (Kaiser Family Foundation, 2016). One southern state’s failure to expand Medicaid coverage leaves some families in the coverage gap due to fluctuating incomes (Kaiser Family Foundation, 2016).

Although one southern state’s policymakers continue to debate health care reform, 32 million citizens received access to quality health care through health insurance and facilities such as community health centers (Adashi, Geiger, & Fine, 2010). Although underserved residents can receive primary care through community health centers, pediatric cancer patients are unable to receive services due to limited resources (Cook et al., 2007). Globally, these limited resources include oncology prescriptions, oncology screenings, and education about the disease for the parent (Hunger, 2013). Nationally and in the Southern state, health care centers are limited in these same resources (Cook, et al.,

2007). Health centers have little access to areas such as oncology education and care for pediatric patients who have been diagnosed or underdiagnosed with some form of chronic illness or condition (Cook, et al., 2007).

In March 2010, a congressional uproar ensued during a discussion of health care and possible health care reform (Adashi, et al., 2010). Political leaders expressed opinions about President Obama's ideas on health care reform and Medicaid expansion (Kapur, 2014). The ACA (2010), also dubbed Obamacare, was enacted to help recipients receive health care at lower costs and receive the same medical treatment as individuals with health insurance coverage from a private agency regardless of preexisting health conditions (Hall & Lord, 2014). Following health care reform, other provisions became part of the law, such as employers' responsibilities and health-benefit exchanges (Wolters Kluwer, 2014).

McMorrow, Kenney, and Coyer (2011) examined data from the Current Population Study and ACA coverage policies and conducted what they called a timely analysis regarding health care policy issues, noting the expansion of the ACA for children and their families. McMorrow et al. also investigated the expansion of Medicaid as well as federal subsidiaries for the purchasing of health insurance exchanges, which would improve coverage for low- to moderate-income families. McMorrow et al. argued that with the increase in health spending, more investigation should go into affordability problems associated with high deductibles and cost-sharing, which could potentially expose larger problems with cost containment measures. Federal legislators designed the ACA to improve accessibility and affordability of coverage for many Americans, but

special attention may be required during implementation to ensure that children aged 0 to 18 years in particularly complex coverage situations benefit from reform (McMorrow et al., 2011, p. 1). For complex coverage situations such as chronic illnesses, “Congress should help fund the development of cancer quality and outcomes measures ... [and] the government should do more to standardize clinical decision-making tools and make them available to the public in an easily-understood format” (Ault, 2014, p. 1).

Mayo, Griffin, Pribonic, and Rollins (2016) explained the lack of coverage following the ACA may exacerbate health problems for people who are uninsured. People who lack insurance tend to live in states that did not expand Medicaid, largely in the South and in Spanish-speaking communities, among those who are no married and who have less than a high school education (Mayo et al., 2016). Researchers have not worked to understand why those who are uninsured choose to forgo health insurance (Mayo et al., 2016).

With so many southern residents remaining uninsured, many families live below the FPL and find the costs of health care unaffordable (Blumberg, 2012). Medicaid came about to lessen the burdens that could afflict low-income and poor families, but the laws governing access to these policies and knowledge needed to acquire all health care options are not easily accessible (Cook, et al., 2007). A gap in the literature existed regarding limited research on how the implementation of the ACA affected parents with chronically ill children. This study was essential because policymakers will be able to understand the need for their intervention in health care for parents with chronically ill children. Findings may enable legislators to develop adequate provisions in the design of

health care policies in southern state. This study could close a gap in research regarding the impact of implementation of the ACA on parents with chronically ill children.

### **Problem Statement**

I discovered limited research on how the implementation of the ACA affects parents with chronically ill children. Cecere (2009) found that annually, at least 45,000 uninsured, working-age adults' deaths prior to the ACA linked to a lack of health coverage. Cousino and Hazen (2013) reported Centers for Disease Control and Prevention statistics showing that at least 15% of U.S. families have chronically ill children with special needs, which can cause great stress for parents of these children.

Interventions can relieve parenting stress (Cousino & Hazen, 2013). Parents of children with chronic illnesses have additional needs for medical care that can include expensive medications and personal support (Brown et al., 2008). The financial burden of medical care for these children may be a prominent factor in why families file for bankruptcy (Austin, 2014).

It was vital to explore the perceptions and experiences of parents with chronically ill children because researchers have cited marked stresses on parents that could lead them to be unable able to work and lack the ability to financially care for their child if they, too, become ill. Health care providers, insurance companies, and legislators may benefit from the findings of this study by developing health care policies and intervention processes in hospitals and government to lessen the burdens on parents.

The ACA included many provisions designed to increase access by lowering the cost of insurance and increasing access to services; however, it was still unclear in the

literature if the implementation of the ACA has had a significant impact on parents in southern state with chronically ill children. The broader public-policy issue includes how changes in health care policy and access to health care insurance impact parents of chronically ill children, especially parents in the Southern state where policymakers did not implement Medicaid expansion. Findings from this study may be used to reduce the number of unexpected hospitalizations and employment disruptions because of financial strain on parents by providing more comprehensive supportive care for pediatric patients (see Warner et al., 2015). Despite safety social nets designed for individuals to receive adequate health care, this qualitative phenomenographic study was needed to explore how the implementation of the ACA affects parents of children with chronic illnesses.

### **Purpose of the Study**

The purpose of this qualitative, phenomenographic study was to gain greater insight and knowledge about how the implementation of the ACA affects parents with chronically ill children in the Southern state. Health care providers, insurance companies, and legislators may benefit from the findings of this study by developing health care policies and intervention processes in hospitals and government to lessen the burdens on parents. A substantial area of concern was for the parents receiving state-mandated health care for their chronically ill child or health care under the ACA in a state that did not expand Medicaid. The purpose of the ACA is to allow individuals to receive coverage without being concerned about costs or receiving services due to preexisting conditions, but the effect of the ACA on parents with chronically ill children had not been adequately studied.



The Center for Mississippi Health Policy (2016) noted that “compared to the nation, one southern state’s children are significantly more likely to have higher rates of public coverage and to have lower rates of private coverage” (para. 5) and “approximately half (48%) of one southern state’s children are covered by a public program, such as Medicaid or the Children’s Health Insurance Program (CHIP)” (para. 14). Children under state-mandated health programs are limited to physicians who are covered in that network (Center for Mississippi Health Policy, 2016). This system could cause a medical mishap due to a child not being treated holistically or being seen for only one issue or complaint. The social safety net designed for a chronically ill child would not provide adequate health care for the child if legislators placed limits on who could treat the child or for what issues the child could be seen.

By examining factors informing the decision-making processes of policymakers and parents, this study provided insight for policymakers in health care and addressed the gap in the literature by exploring parents’ perceptions of health care costs, access, and use of care. This study also extended knowledge about the information legislators in southern state seek when deciding on health care policies and where they pursue information. Findings may encourage additional research and bridge the gap between those who use the knowledge and those who produce the knowledge (see Dodson, Geary, & Brownson, 2015).

### **Research Question**

How do parents with chronically ill children in the Southern state perceive their experiences with the ACA?

## Conceptual Framework

The conceptual framework used to guide this study was Argyris's (1970) intervention theory. Argyris's theory explains that to intervene means to enter into a system of ongoing relationship or to come between persons, groups, or objects to help those in need. Government intervention can prompt policymakers to take action through health-service research in policy design by intervening to see which policies work and which do not (Almeida & Bascolo, 2006). The purpose is to assist policymakers in knowing when they should intervene and when it is inappropriate to intervene. Legislators intervened in 2010, passing the ACA, yet little research has been done to understand how parents with chronically ill children perceive the effects of the Act.

The intervention theory framework helped me craft the research question and methodology for this study. Intervention theory proposes that operative intervention depends on suitable and beneficial comprehension to offer a variety of distinct alternatives (Argyris, 1970). The goal is for as many individuals as possible to choose alternatives and experience accountability for their choice (Ault, 2014). Individuals should affirm that interventions are functioning because of internal rather than external influences on conclusions (Argyris, 1970). "Both formal and personal sources are devoid of everyday practical information of the kind that is needed by poor people" (Chatman & Pendleton, 2010, p.1). The role of a legislator is an influential one, steering decisions for health care policies for a population that may or may not be exposed to them. Tichenor, Donohue, and Olien (1970) noted five reasons to explain the knowledge gap:

1. People of higher socioeconomic status have better communication skills, education, reading, comprehending, and remembering information.
2. People of higher socioeconomic status can store information more easily or remember the topic from background knowledge.
3. People of higher socioeconomic status might have a more relevant social context.
4. People of higher socioeconomic status are better in selective exposure, acceptance, and retention.
5. The nature of the mass media is that it is geared toward persons of higher socioeconomic status.

These five reasons could impact low-income or poor parents or guardians with chronically ill children, due to the lack of knowledge of state policymakers. Racial, minority, rural, and low-income people continue to have insufficient access to quality health care (Purnell et al., 2017). For decades, policymakers have worked to eliminate health care differences without success due to a lack of knowledge (Purnell et al., 2017).

Poorly educated parents or guardians with chronically ill children continue to be ignorant of health care (Chatman & Pendleton, 2010). Policymakers need to more efficiently target this population to help members better understand their health care options (Cook, et al., 2007). In this study, I worked to identify factors related to policymakers' knowledge and parents' knowledge of health care accessibility in southern state. Chapter 2 presents a more detailed analysis of the conceptual framework.

### **Nature of the Study**

I conducted this qualitative, phenomenographic study to better understand the experiences of parents with chronically ill children. Phenomenography is a form of qualitative research first used in the early 1980s to answer questions about thinking and learning in distinct ways (Marton, 1986a). Phenomenography allows researchers to describe experiences not as they are but how they appear to people because people perceive and have experiences and perceptions about them (Marton, 1986a). Angelhoff (2017) used a phenomenographic method to evaluate the sleep quality, mood, and other elements of parents experiencing the stresses of their ill child who needed medical care. Roy, Schumm, and Britt (2014) used a phenomenographic approach to address the initial experiences, challenges, and opportunities of parents with children who have special needs.

The phenomenographic method was appropriate for this study because it can help health care providers, insurance companies, and legislators develop health care policies and intervention processes in hospitals and government to lessen the burdens of a parent, after understanding the experiences of a parent with a chronically ill child. In the present study, the target population was parents of chronically ill children in the central southern state area. I conducted interviews to explore how parents with chronically ill children in the Southern state perceive their experiences with the ACA. Findings from this study may benefit legislators in improving health care policy.

### **Definitions**

I used the following operational terms and phrases throughout the study:

*Affordable:* Affordable health care means an individual can pay for health care (Russell, 1996).

*Affordable Care Act (ACA):* The ACA, also known as Obamacare, is a health care reform act passed by Congress and signed into law by President Obama in March 2010. The goal was to make all Americans insurable by requiring insurers to accept all applicants at rates based on population averages, regardless of health status (Hall & Lord, 2014).

*Catastrophic illness:* A catastrophic illness can result from traffic accidents, newborns with severe congenital problems, people afflicted with lingering cancers, and victims of acquired immune deficiency syndrome (Wyszewianski, 1986). The term catastrophic also means one who is poor, stricken with an illness, and has no health coverage, not even Medicaid (Wyszewianski, 1986).

*Children with special health care needs:* The Health Resources and Services Administration (2016) defined children with special health care needs as having or being at increased risk for chronic physical, developmental, behavioral, or emotional conditions and requiring health and related services of a type or amount beyond that required by children generally.

*Children's Health Insurance Program (CHIP):* CHIP is insurance coverage for children under the age of 19 whose parents exceed the income level to receive Medicaid but do not earn enough to pay for private coverage (Medicaid.gov, 2017).

*Chronic illness:* Chronic illnesses include nonfatal or fatal diseases or frailty (Lubkin & Larsen, 2006). Nonfatal diseases include vision or hearing problems; serious

fatal diseases could be cancers and organ conditions; frailty could mean the body has little reserve left and any disturbance can cause multiple health conditions and costs (Lubkin & Larsen, 2006).

*Coverage gap:* The coverage gap (or doughnut hole) refers to the situation in which prescription drug expenses exceed the initial coverage limit but do not reach the catastrophic level of coverage (Medicare Resources, 2017).

*Federal poverty level (FPL):* FPL is the minimum amount of gross income a family may need for food, transportation, clothing, shelter, and other aspects of life deemed essential (Medicaid.gov, 2017).

*Financial burden:* Financial burden means expenses that cause worry due to a responsibility (Financial Burden, 2017).

*Health care reform:* Health care reform is a guideline used in discussing changes in health policy creation that could affect health care in each locality; health-care-policy reform includes prioritizing public expenditures for education and health (Williamson, 2002).

*Health Insurance Portability and Accountability Act:* An act passed during President Clinton's administration in 1996 designed to protect the privacy of all medically related information and documents of a patient to doctors and health care facilities (U.S. Department of Health & Human Services, 2013). This act is also known as the privacy rule (U.S. Department of Health & Human Services, 2013).

*Intervention theory:* Intervention theory addresses the processes used to enter an ongoing relationship, to come between or among people, or the objects to help them (Argyris, 1970).

*Legislator:* A legislator, also known as a policymaker, develops, introduces, or enacts laws and statutes at the local, tribal, state, or federal level (U.S. Department of Labor, Bureau of Labor Statistics, 2016). Legislators work in elected positions (U.S. Department of Labor, Bureau of Labor Statistics, 2016).

*Low income:* Low income in the United States is a category for those who earn less than twice the FPL (Acuff, 2017).

*Medicaid:* Medicaid is state-mandated health insurance that provides health coverage to eligible U.S. low-income adults, children, pregnant women, elderly adults, and people with disabilities (Medicaid.gov, 2017). States administer Medicaid according to federal requirements (Medicaid.gov, 2017). States and the federal government jointly fund the program (Medicaid.gov, 2017).

*Medicaid expansion:* Medicaid expansion is a provision in the ACA that will allow greater coverage for low-income people (ACA, 2010).

*Parent:* A parent, also known as a primary caregiver, is an adult in a parent–child relationship with a legal relationship to the child; the law confers or imposes rights, privileges, duties, or obligations to the child’s natural or adoptive parents (National Conference of State Legislators, 2017).

*Repeal:* To repeal or revoke health care is to replace proposal components including flat tax credits and to maintain cost-savings provisions (Glied & Jackson, 2017).

*Social safety net:* A social safety net is a means to prevent chronic poverty, conceptualized as ways for people to have protecting and promoting effects (Devereux, 2002).

*Socioeconomic status:* One's socioeconomic status is a measure of their combined economic and social status; higher socioeconomic status tends to be positively associated with better health (Baker, 2011).

*Working poor:* Working poor are families who live on the threshold of poverty despite at least one family member working full time (Torraco, 2016).

### **Assumptions**

This study had several assumptions. The first assumption was that those receiving Medicaid or any state-mandated health coverage in southern state while caring for chronically ill children would have different perceptions of health care than those who have primary health care coverage under a private insurance company. The second assumption was that those who may receive health care strictly under the health care marketplaces through the ACA would also have a different perception of health care coverage in this state from those who have primary health care coverage under a private insurance company. Furthermore, I assumed that all participants would be truthful and transparent in their responses about their perceptions and experiences with health care in southern state. Finally, I assumed a lack of consistency exists regarding medical copays,



treatments, and medical care for children with chronic illness receiving health care, thereby causing mental stress and financial burden for parents of children with chronic illness.

### **Scope and Delimitations**

The scope of this study included how the implementation of the ACA impacted parents of chronically ill children. The choice of one southern state's legislators not to expand Medicaid under the umbrella of the ACA specifically affected those who receive any type of health insurance in this state. I studied the perceptions and experiences of those who receive health care in this state to discern whether the ACA had a negative or positive impact on chronically ill children. I used a nonprobability sample design with a purposeful sampling strategy because it placed emphasis on strategically and purposefully selecting information-rich cases that could yield insights and deep understanding to answer the research question (see Patton, 2002). I worked to understand the comparative impact that health insurance under the ACA, or health care marketplaces had on each participant's care for their chronically ill child, including treatments or other elements needed for their child's overall well-being. Because I live in southern state, it was more efficient to collect data in this state. I selected those who do not have an affluent lifestyle or who have not qualified to be below the FPL to resolve any limitations.

### **Limitations**

In consideration of the laws surrounding the Health Insurance Portability and Accountability Act, I included people from all races in this study who were willing to

offer information regarding their knowledge of health care coverage. The setting of the interviews was a closed yet natural environment that was convenient for the interviewee. Simplification of this study was a weakness, as multiple levels of health insurance exist along with multiple levels of government. To gain a more holistic view of the experiences of these parents, I recruited participants in communities outside of one central southern state who had less access to care.

### **Significance**

Findings from this study could benefit health care providers, insurance companies, and legislators in developing health care policies and intervention processes in hospitals and the government to lessen the burdens of parents caring for chronically ill children. A continuous dialogue has ensued about a repeal of the ACA since the new presidential administration came into office in January 2017; however, little discussion has occurred in southern state as to how implementation of the ACA has affected parents with chronically ill children. This study could influence policymakers in revealing when and when not to intervene in health care decision-making processes or in their work to design a social safety net that is feasible for all parents, regardless of income or background.

Individuals who crafted Medicaid and the ACA desired to assist low-income and poor families by implementing policies that target those who despair from insufficient health equity through value-added access and quality of care (Guendelman, et al., 2005). One southern state's policymakers may be able to use the findings from this study to examine the health care options available in southern state, and to discern how families

who fall into a specific group cannot afford insurance on their own and depend on the insurance received from their state government. Researchers have not examined the psychological stress and financial barriers that face families who qualify for state-mandated health care coverage or health care covered under the health care marketplace. Political leaders could use this study to find ways to intervene and assist parents with chronically ill children by decreasing their financial burden, considering universal assessment when determining family household sizes, and determining which households qualify to use the social safety nets designed for adequate health care.

As parents carry out the duties of caring for their child's education, medical care, and other household demands, policymakers should bear in mind and intervene in the provisions of health care reform, Medicaid expansion, and other challenges parents may encounter. For example, parents supply emotional support to children with cancer. (Norberg & Boman, 2008).

The current literature reflected a gap related to research about how the implementation of the ACA affected parents with chronically ill children. This study could influence the decision-making processes of one southern state's policymakers by informing them of the perceptions and experiences of parents with chronically ill children as they design social safety nets surrounding health care to ensure adequate accessibility and use. In comprehending the ACA, health insurance through Medicaid, CHIP, and the marketplaces helped shape this study. Following the outcome of this study for parents in southern state with chronically ill children, components in health care should be a priority statewide and nationally. This study may lead to quality training and education for health-

insurance companies, physicians, and policymakers who could also craft enhanced intervention methods for the public.

### **Summary**

This chapter introduced intervention theory and potential factors involving the gap in literature related to limited research on how the implementation of the ACA affects parents with chronically ill children. To determine whether the intervention processes in health care by policymakers are deficient, I conducted this study using a qualitative, phenomenographic design because of the limited research on the implementation of the ACA for one southern state's parents of chronically ill children. The purpose of this study was to fill the gap in literature concerning how implementation of the ACA affects parents with chronically ill children in southern state. A qualitative, phenomenographic study aided in the evaluation of the experiences of parents and guardians with health care in southern state. Examining the history of health insurance in southern state and the ACA may serve as a reference for health insurance companies, physicians, and policymakers to obtain knowledge and insights in health care. Chapter 2 presents a review of extant literature on the intervention of policymakers, parents with chronically ill children who fall below the FPL, and the ACA.

## Chapter 2: Literature Review

The current literature indicated a gap in that children with special health care needs were at “increased risk for unmet medical needs” (Feldman, Buysse, Hubner, Huffman, & Loe, 2015, p. 1). Research pertaining to the ACA and the experiences of parents with chronically ill children was limited; however, Feldman et al. (2015) studied the experiences of parents with chronically ill children, the ACA, the rationale of policymakers to legislate health care coverage, and legal provisions on universal health care. This literature review addresses human impact, legislation, practice, and a need for continuous examination of the health care products offered to parents in southern state.

Several researchers acknowledged the stress levels, financial burden, and other barriers experienced by parents who care for chronically ill children. This literature review addresses parents’ accessibility to health care as well as their experiences with ACA, policymakers’ intervention efforts, and other factors that may involve social inequity. Chapter 2 is organized as follows: (a) the conceptual framework, including the definition of the ACA; (b) an overview of health insurance in southern state and the position of parents; (c) an overview of Medicaid in southern state; (d) an assessment of health care challenges with access, equity, and intervention processes; and (e) the health care coverage gap. I also discuss deficiencies in the literature to clarify the gap.

### **Literature Search Strategy**

I found literature related to the study using the following key words: ACA, history of health care, history of health care in southern state, health care access, health care equity, intervention theory, chronic illness, parents, coverage gap, health care

marketplace, doughnut hole, and coverage gap. Databases accessed included ProQuest and EBSCOhost. I also searched the *Journal of Medicine*, Centers for Disease Control and Prevention, Mississippi Department of Health, Henry J. Kaiser Foundation, and Google Scholar. I narrowed results to information published between 2010 and 2017 regarding the ACA and health care in southern state.

Since the passage of the ACA and one southern state's legislation opting out of expanding Medicaid in the Southern state, I explored factors that may be barriers or gaps in research for those who are parents and receive health care assistance in the health care marketplace under the umbrella of the ACA or Medicaid. I also assessed the minimal research on how the implementation of the ACA affects parents of children with chronic illnesses. I made some allowances to this approach, finding works related to health care, policymakers, qualitative methodology, and coding. I also included older works addressing the conceptual framework for this study.

### **Conceptual Framework**

To comprehend the role of health care in southern state, its accessibility, and parent experiences, I needed a framework to research the differences in experiences of parents who may receive health care under the ACA, Medicaid, or personal health insurance. Although health care was affected by one southern state opting not to expand Medicaid, I needed a theory to explain when policymakers should and should not intervene in the decision-making processes that would bring about desirable outcomes for chronically ill children. I chose intervention theory, which proposes that to intervene is to enter into an ongoing relationship, to come between or among people, groups, or objects

to help them (Argyris, 1970). I applied this conceptual framework when focusing on the ACA, intervention methods by one southern state's policymakers, health care as a social safety net for the public, health care access, health care equity, and Medicaid expansion. Following the findings of Feldman et al. (2015), I used intervention theory to understand the ongoing relationship between policymakers and the public and intervention processes with parents and their children who have special medical needs. I focused on intervention processes of policymakers, health care access and equity, and the impact of the implementation of the ACA.

## **Literature Review**

### **Health Care Access and Equity**

I identified a gap in literature concerning how implementation of the ACA affects parents with chronically ill children. Regarding access and equity in southern state's health care, Ku, Berkowitz, and Ullman (1998) mentioned that low-income and poor people, particularly in rural areas, have limited access to health care and a shortage of medical providers. Even less long-term access is available to those diagnosed with developmental disabilities, intellectual disability, or a mental illness (Ku et al., 1998). The underinsured population of children with special health care needs represents a hidden and largely underserved population (Kogan, Newacheck, Honberg, & Strickland, 2005). Kogan et al. (2005) analyzed the prevalence of underinsured children with special health care needs, the relationship to health care accessibility, and family financial problems. The researchers concluded that health care for children with special health care needs or those with a chronic illness was inadequate to satisfy the requirements.

Being underinsured can impact a parent with a child needing special health care. Inadequate intervention processes among policymakers and their communication with parents with chronically ill children can impact access to all health care options and the equity of those options. All benefits anticipated under the ACA could destabilize well-functioning elements of the current system-delivery program for children, which could undermine the ACA's promise for improving child health (Cheng, Wise, & Halfon, 2015). Chang et al. (2015), using a "voltage drop framework," assessed the impact of the ACA on health care delivery and suggested framing "policy correctives to improve child health system performance" (p. 1). Although children's health care may be a minimal part of U.S. budget spending, a child's health provides the foundation for adult health and should be protected in ACA implementation (Cheng et al., 2015).

### **Intervention of Policymakers and Barriers in Communication**

The 50 state legislators in southern state make thousands of health-policy decisions every year (Ballotpedia, 2017; National Conference of State Legislators, 2015). Decisions include the appropriation of the budget, doctors obtaining licensure, services covered by insurance, and the management of personal health information (Ballotpedia, 2017). Policies in southern state regarding health care also affect the access and quality of care and not only what citizens pay. The access and equity of health care can affect the overall health of an individual; furthermore, health care can place a strain on what income is readily available for accessible and equitable health care for recipients as well as on state budgets (Ballotpedia, 2017).



The intervention of policymakers to establish a social safety net such as the ACA is vital because its lack could have a crippling impact on parents receiving health care under the ACA (Corlette, et al., 2015). Although legislators designed the ACA to focus on adults, a focus on the efforts for children in clinical care, research, and education for the incorporation of child-health programs is essential to prevent inadvertent injury to those methods designed to care for any child (Keller & Chamberlain, 2014). Parents of children with special health care needs have higher medical expenditures that include out-of-pocket expenses, so policymakers should intervene with these families (Newacheck & Kim, 2005); legislators should include in their policymaking processes to protect these families because they are at risk of burdensome expenses (Newacheck & Kim, 2005). Although Newacheck and Kim (2005) identified children with or without health care needs and the inconvenience of unaffordable health care expenses, they presented no specific discussion of parents who may be covered under health care through government-assistance health care programs such as Medicaid.

### **Patient Protection and Affordable Care Act of 2010**

The ACA provided people in the United States with options to register for health care that was thought to be affordable. This act did not consider preexisting medical conditions; however, family household size is considered in the enrollment process. The purpose of the enactment was to reduce the number of the uninsured people nationwide. Officials found that nursery-care workers, hair stylists, barbers, and those working in like industries were not receiving health care, and that a workforce lacking health care is an

unhealthy workforce (Wright, 2013). Furthermore, this act does not discriminate based on one's race or cultural background (ACA, 2010).

Most of those who are uninsured know little or nothing about the insurance marketplaces available online (Kaiser Health News, 2017). Health disparities continue following current decisions made by policymakers and financial support for health-equity studies. A gap persisted in the literature to identify the contribution of researchers and intervention processes by policymakers in southern state for parents of chronically ill children.

The ACA provides an infrastructure for health care in southern state (Varner, 2014). Inequalities in health care, however, persist. Although the ACA provides a valuable first step in reducing disparities, progress depends on whether opportunities in the ACA help or hinder populations at risk for impaired health and limited access to medical care (Adepoju, Preston, & Gonzales, 2015). Legislators declared this enactment would provide health care for those who have preexisting conditions and dependents up to the age of 26 (ACA, 2010). However, accessibility to knowledge about the impact of opting out of Medicaid expansion in southern state by health care recipients in this state, and adequate intervention by policymakers for parents of chronically ill children, could affect parents' understanding and experiences about the implementation of health care reform.

### **Southern state and the Affordable Care Act**

In the Southern state, the government persists in unremitting discussion about the ACA and Medicaid expansion (Whitaker, 2013). Following the health care reform, one

southern state's residents had the option to enroll in health care coverage they could afford. Under this new health care law, children under the age of 26 could be covered until they reach 26 years of age (U.S. Department of Health and Human Services, 2015). Although numbers diminished for those who were uninsured, one southern state, although not adopting the expansion for Medicaid, has a population that falls into the coverage gap. Although employed, these people still do not qualify for Medicaid and are not in a financial position to pay for insurance through their employer.

### **Southern state, the Uninsured, and Out-of-Pocket Costs**

According to the U.S. Department of Labor, Bureau of Labor Statistics (2015), One southern state has had wavering numbers in employment and unemployment. In 2015, the employment rate ranged from 80.3% to 87.3% (U.S. Department of Labor, Bureau of Labor Statistics, 2015). Opportunities for employment are available but not plentiful. The National Center for Children in Poverty (2014) reported that, as of 2013, "on average, families need an income of about twice the federal poverty threshold to meet their most basic needs" (para. 5). In a state that has one of the highest impoverishment rates in the United States, the uninsured population included at least 454,000 in one southern state, as of 2012 (Kaiser Family Foundation, 2014b).

Though the ACA alleged it will fill the gaps for children and their parents (Kaiser Family Foundation, 2014a), the out-of-pocket expenses for a parent receiving benefits from this act can increase substantially, due to prescription drugs and other medical debts (Blumberg, 2012). Out-of-pocket payments among low-income adults accounted for 10% of income, and even more when including proxies for health-insurance premiums

(Blumberg, 2012). Financial burdens double for those with employer-sponsored insurance (Blumberg, 2012).

### **Patient and the Parent**

Without insurance plans such as those supportive services that fall under the ACA, the Southern state will suffer economically, creating insufficient numbers of jobs following the formation of this act. Lack of insurance plans will cause families who cannot receive coverage to be unable to receive proper care from physicians. Those who receive Medicaid will suffer from not receiving the medications or treatment they need, once state officials deny Medicaid expansion.

Parental support is central to the healing process of children with chronic illnesses (Park et al., 2015). A major goal of this act is to “improve access to affordable health coverage for everyone and protect consumers from abusive insurance company practices” (White House, 2015, para 2). Although these health care reforms are significant, they may be insufficient to address the needs of parents of children with chronic illnesses. This population of parents has additional needs for medical care that can consist of multiple chemotherapy treatments, medications, and personal support and respite (Brown et al., 2008). Additionally, the high cost of many tests recommended for risk-based surveillance may not be covered or only partially covered by insurance policies (Brown et al., 2008). Researchers identified significant benefits from health care reform and other policies to assist parents with children diagnosed with chronic illnesses (Brown et al., 2008). However, parents tend to experience psychological and financial stress from being

a parent with little or no income while caring for a chronically ill child (Warner et al., 2015).

### **Chronic Illnesses Needing Specialized Medical Treatment**

When developing guidelines for the ACA, congressional members understood that some modifications would ensue as the act progressed and as people assessed how the policy affects the public. Following President Obama's signature on March 23, 2010, Manchikanti, Caraway, Parr, Fellows, and Hirsch (2011) argued the new law would fundamentally change most aspects of health care, including not only insurance, but also the delivery of care. However, debates during and following enactment led to general confusion among the populace about its impact.

Although some specialized health physicians—pediatric oncologists for example—were widely supportive (Kantarjian, Steensma, & Light, 2013), some outside the medical professionals believed this act was catastrophic and economically damaging to ACA recipients and business owners (Williams, 2013). Strengths of this act included that many patients have health care insurance for the first time, can access care, and can transfer from one coverage plan to another without major penalties. The ACA has many flaws, but is an improvement over previous law. As it is implemented, its unintended ill-effects can be remedied with further litigation, as was done with Social Security and Medicare. Kantarjian et al. (2013) advocated oncologists work to retain and improve the ACA.

The disadvantages of the ACA are that some plans do not cover expensive prescriptions for drugs, such as those for oncology patients (or require a large

copayment), and the United States lacks sufficient numbers of physicians to see all the newly insured patients. Williams (2013) found three problems with the ACA: benefits were not entirely disclosed, the act controlled prices in the medical industry, and the act negatively impacts jobs and the economy. These perceptions of the act resonate with some residents who have a growing concern about the wellness of their child and the affordability of treatment to make their child well again. These parents wonder if the ACA will provide better assistance with health care for their child (Norberg & Boman, 2008).

Components of the ACA include that patients have health care insurance for the first time and therefore can access care and transfer from one coverage plan to another without major penalties. The Henry J. Kaiser Family Foundation (2015) noted that the amount of employer-sponsored coverage decreased between the years 2000 and 2010, leading to the growth in the number of uninsured when an individual suffered a job loss. Following the ACA, the number of uninsured people decreased between the years 2010 and 2013 (Henry J. Kaiser Family Foundation, 2015).

Shi and Singh (2015) averred the ACA will provide greater access to affordable, high-quality health care, whereas others believed the act was likely to fail to provide greater access. Evaluation of the ACA began by expanding on the conditions of the act, the conceptual framework, and the methods used to support this quantitative inquiry. In the next section, I explore the current literature on parent involvement with financial burden, anxiety, and socioeconomic status, as well as the ability to access insurance under the health care marketplace according to secondary research. The following section

delves into the current literature on the ACA and whether parents of children with childhood cancer have had access to insurance outside of that offered by an employer. Additionally, this review investigates the numerous obstacles parents face while trying to care for an ill child and maintain their households when possibly facing poverty.

### **Expectations from the ACA**

The ACA's expansion of insurance coverage was expected to increase demand for primary-care services (Huang & Finegold, 2013). Continuous insurance coverage, though, is a significant component of valuable health care (Smits-Seemann et al., 2015). Assessment of insurance gaps in pediatric cancer is an understudied area (Smits-Seemann et al., 2015). Due to the rising costs in treatment, oncologists face barriers in treating pediatric patients who are underinsured or lack insurance (Drasga & Einhorn, 2014). Oncologists are challenged to draft a wellness plan for cancer patients who have little or no insurance.

The stress that accompanies a family when a child is diagnosed with a catastrophic illness such as cancer can be a burden on the parent and their families. Trying to define what is affordable for a family who may have expenses outside of medical treatments can cause a dilemma in providing a treatment schema (Drasga & Einhorn, 2014). If a patient requires treatment from a physician that may fall outside of the network of their insurance carrier, their treatment could be limited; if they receive any treatment at all, patients and their parents may experience financial strain. Should the patient not receive the care they may need to get well or to stabilize, this could cause the

parent to become anxious, stressed, or even fall into a state of depression (Cousino & Hazen, 2013).

One southern state was one of the states that did not expand Medicaid, and Antos (2013) argued that the Medicaid expansion was not a good idea for states or for the poor. States cannot be certain that the federal support promised in the ACA will remain available, and a better deal might be possible after the election of a new president. More money in the Medicaid program may exacerbate existing problems of access to providers and a more humane policy may be to give those who are poor a choice in health plans (Antos, 2013). However, a need persists to promote policies that encourage more primary-care providers and community health centers to practice in areas with the greatest expected need for services (Warner, Park, Stroup, Kinney, & Kirchhoff, 2013).

Finding relevant literature specifically on the ACA was not a challenge. Currently, the nation's health care system has been under criticism because of the costs and lack of benefits. The ACA has been accused of failing to provide for certain citizens (Smits-Seeman, et al., 2015). The conflict between the wealthy, the impoverished, and the working insured adult versus the working uninsured adult has caused those in political office to displace their focus on uninsured adults rather than the impact of their decisions on health insurance for the whole family (Grogan, 2012).

Political officials who drafted the guidelines of the ACA presented it to the public as a means for all U.S. citizens to have some form of health coverage. Despite tax credits and even some U.S. residents still without health care, the health care provided under this act was presumed to effectively integrate the uninsured and insured, regardless of race,



gender, and background or income status (Kogan, 2005). Dorn, Minton, and Huber (2015) provided examples of programs being coordinated in outreach and enrollment to increase the number of children receiving health care, following the Medicaid expansion in Louisiana. One southern state, however, is a neighboring state that did not adopt the idea of Medicaid expansion. Following Medicaid expansion, “95.4% (of those) with the eligibility continued for these children at renewal while less than one percent can lose coverage for procedural reasons” (Dorn et al., 2015, p. 2).

The ACA has brought much discussion of new opportunities for program incorporation and management. Penalties for failing to enroll for health care in the marketplace can result in fines for individuals of at least 1% of their income over the tax-filing limit, whichever is greater (Blumenthal & Collins, 2014). Those families whose income ranges between “100% and 400% of the FPL are eligible for support to assist in gaining health insurance but they must purchase plans that are under the marketplaces to get these funds” (Blumenthal & Collins, 2014, p. 1). Although Blumenthal and Collins (2014) explained the ease with which one may attain health coverage, Nussbaum (2012) asked if it is likely Congress will make a person purchase health insurance.

A gap in research persisted regarding policies instigated by the ACA including outside expenses that are unfunded by health insurance for a family to maintain and survive daily. The literature did not discuss other means for a family with an ill child, such as food and transportation, for wellness and survival. Under the health care marketplace, a child may receive free preventative services, but if that child has a chronic illness, calling for medicines outside of those covered under the marketplace, the family

may or may not be able to afford the medication, bringing another stressful situation to the family.

### **Children With Special Health Care Needs**

Children with special health care needs have increased risk for chronic emotional and behavioral conditions (Fry-Bowers, 2014). The United States has approximately 11.2 million children with special needs and many fall into the children with special health care needs category (Fry-Bowers, 2014). The testing of the ACA under health care law has impacted many children who fit in the children with special health care needs category and the scope and access to care for these children is essential (Fry-Bowers, 2014).

To opt into the Medicaid-expansion incentive would have improved access to health care for children who are classified as children with special health care needs in the Southern state. With a minimum of at least 4 million children nationally receiving health care under the marketplaces (Kenney, Buettgens, Guyer, & Herblein, 2011, as cited in Fry-Bowers, 2014), health care for these families would have allowed flexibility for insurance coverage in state marketplaces. Because the ACA has the potential to service all groups, including children with special health care needs, policymakers' communication to address any gap, implementations of the ACA, and management of the elements in the ACA could determine the communication regarding access to proper health care coverage (Fry-Bowers, 2014).

### **Medicaid Expansion in southern state**

The concept of adopting Medicaid expansion in southern state made a marked impression on those who have children with special medical needs. Legislators aimed for Medicaid expansion to insure more people; however, it left out designation for many minorities and single-parent homes (Tavernise & Gebeloff, 2013). One idea of the ACA was to assist more minorities and single-parent families, but it appeared to Tavernise and Gebeloff (2013) to do the opposite: The 26 states that forbid Medicaid expansion are “home to about half of the country’s population, but about 68 percent of poor, uninsured blacks and single mothers” (p. 1).

It is unimaginable how the two-parent home or those individuals from an ethnic-majority background have been affected without the expansion of Medicaid in this state. One southern state’s neighboring state, Louisiana, has adopted Medicaid expansion for those who are receiving health insurance under the marketplace in Louisiana. Those affected in Louisiana under the Medicaid expansion are part of the roughly 16 million individuals on Medicaid, as of 2016, nationwide, making a huge impact on public health (Cohn, 2016). Why would one southern state disallow Medicaid to be expanded when the Southern state has been deemed one of the poorest states in the United States? (Bertrand, 2014). Although the U.S. Supreme Court allowed Medicaid expansion to be an option for states, if one southern state opted to adopt Medicaid expansion, the state’s population would have experienced at least a 40% decrease in the uninsured population (Henry J. Kaiser Family Foundation, 2015). Of one southern state’s residents, 29% fall into the

Medicaid-coverage gap, whereas 15% are eligible for Medicaid (Henry J. Kaiser Family Foundation, 2015).

Those who fall in the coverage gap or those who cannot afford their employer's insurance and make too great an income to receive Medicaid, have little recourse in the health care policies promoted by one southern state's public officials. Chronic health conditions for pediatric patients are on the rise and parenting stress can bring forth depressive symptoms, causing additional needs for health care coverage to care for themselves and their sick child (Cousino & Hazen, 2013). Authors opining about one southern state's decision to not adopt Medicaid expansion do not include such calculations. Although these political individuals may cite a lack of funding, one southern state is not excused from assisting those who are in the workforce and caring for a chronically ill child, have an increased possibility of becoming ill themselves while providing pediatric care.

Feldman et al. (2015) stated that, with the ACA's complex legislation, the challenges of this health bill continue, with a pending Supreme Court case challenging the provisions of health care subsidies to those who purchase from the federal rather than state insurance exchanges (p. 207). Feldman et al. identified the ACA as an important health care law that provided health insurance for many individuals who were uninsured. Through their evaluations, Feldman et al. found that children with special health care needs should receive measurable improvement in health care, and the families of these children should have input with public officials about decision-making processes when health care is discussed.

Access to health care under the marketplace has become clearer in recent years. The equity of health care under the marketplace, however, still has problems, as officials adjust this policy to cover all Americans, despite their income or previous medical conditions. Most authors debate the equity of this health care policy for adults, because children under the age of 12 can receive health care under Medicaid. Medicaid, however, allows coverage for only a group of medications, medical treatments, and forms of disease prevention such as immunizations that may or may not help the child. Those medical means covered under Medicaid only provide enough health care assistance for a child to be treated but not cured. Better efforts in health care for pediatric patients could improve their health and lower the costs of health care (Grant, Goldsmith, Gracy, & Johnson, 2016).

Nearly 40% of children with special health care needs, such as those with chronic illnesses, have public insurance coverage such as Medicaid or CHIP (Fry-Bowers, 2014); however, children who are predominantly covered by private health insurance rely on public and private health insurance. It is imperative that physicians inform policymakers regarding the real-world impact of their decisions regarding coverage standards and provider networks. The “gaps” in health care can be recognized and sealed if legislators communicate with families who care for children with special health care needs such as the chronically ill (Fry-Bowers, 2014).

### **Parents of Children With Chronic Illnesses**

Parents may experience a negative sequence of events if they have a child who is ill and the parent becomes ill due to high stress levels while caring for the ailing child. If

that parent falls into the coverage gap, receiving little to no health insurance for a chronically ill child, the parent may be unable to undertake treatment for depression, anxiety, or other stress-related illnesses. Parents may address bouts of depression or other mental illnesses following a chronic or catastrophic illness for their child (van Oers et al., 2014). Failing to provide health insurance to assure they can access the quality health care treatment they need to survive an illness may exacerbate their mental stress. The family's response to a child with a chronic illness could lead to several types of disorders, anxiety, and even grief (Davidson, Jones, & Bienvenu, 2012). Communicating the effects of health care modifications by policymakers to parents with chronically ill children could have a significant impact on decisions they make regarding health care policies. Because of the holistic impact on these families, policymakers could then become aware of the experiences of these families, prior to voting to put a health policy into place. Their intervention processes while reviewing the literature reflects inadequate intervention and communication by policymakers for families who care for children with chronic illnesses (Lubkin & Larson, 2006).

An employed parent with a child could qualify for Medicaid; however, Medicaid does not allow access to every prescription, medical doctor, or element that could assist in bettering or curing that child; those entities may not fall under the network for health care coverage through Medicaid. Kapur (2014) provided a thought-provoking interpretation: regardless of what individuals with different viewpoints may deem necessary to care for a child with a chronic illness, not expanding Medicaid in southern state according to the ACA guidelines serves as the best idea for this state's residents.

Medicaid expansion would not only assist the working adult but would allow pediatric patients to access superior medical care. One southern state policymakers could intervene by focusing on a redesign of the health care system to provide a social safety net that provides a high-quality system of services (Strickland et al., 2015). According to current literature, one southern state ranks highest in poverty compared to the other U.S. states (West & Odum, 2016) and lowest in quality health care (Khazan, 2014). This state has once again failed to provide the kind of health care that would soon bring about a healthy adult workforce with an equitable health care system.

Quality health care begins with infants. As the infant matures, they should receive health care that provides wellness for the whole human being. The focus should not be merely to treat an ailment, but to cure an illness. With only a small number of children with chronic illnesses receiving the health care they need, the challenge remains to assure chronically ill children receive the services designed to maximize their well-being throughout adulthood (Strickland et al., 2015). One southern state appeared to have ignored the evidence that has abundantly surrounded the state's policymakers in their decision-making and intervention processes; their decisions can negatively impact the children and families who most need access to health care (West & Odum, 2016). By failing to provide access to health care or health care with equity, parents could pay more for individual insurance, if the ACA is repealed or removed, and could cause families to go into medical indebtedness.

One southern state's officials encourage major corporations to operate in the state, which economically enhances the state, but have missed the mark in providing a healthy

workforce for these corporations to employ. State officials in southern state lack attention to those growing up in poverty, having to set health care insurance policies for just enough health insurance to get by and not get well. Children with special health care needs represent an exceptionally vulnerable subpopulation of children (Jeffrey & Newacheck, 2006). Children with chronic illnesses such as asthma have unmet needs for care and lack consistency in primary care (Halterman, Montes, Shone, & Szilagyi, 2008). Efforts are needed to provide uninterrupted coverage for these children (Halterman et al., 2008). Although current literature demonstrated positive impacts of access and use of health care, literature continues to demonstrate a gap that showed a lack in research exemplifying satisfaction in the quality of health care in southern state following the ACA.

### **One Southern State's Health Care Policies**

Nationally, health care policies, because of the ACA, has extended insurance to more of the formerly uninsured, and according to Sommers (2015), “coverage gains appear to be improving access to primary care and medications, affordability of care, and self-reported health” (p. 2395). Sommers identified that more than 30 million U.S. residents without health insurance in the group of 20 states not expanding Medicaid are low-income adults.

Many times, when an individual hears about the lack of quality health care in southern state, its justification accompanies a fervent connection with the high rate of poverty among residents. The state's low ranking in economic and social development, lack of disability resources, diseases caused by poor diets mainly for those living in food



deserts, and the lack of a quality education paints a derogatory picture of low-income individuals and families in this state (Farmbry, 2014). The positive aspects of abundant agriculture and a low cost of living should not deceive those who must understand and intervene in designing health care policies in this state (Birchley, 2014).

Regarding one southern state's health care, the coverage gap means an individual's income is too high for Medicaid and too low for subsidies (Henry J. Kaiser Family Foundation, 2015). For families whose incomes are at or below 138% of the FPL (\$27,821 for a family of three in 2016), Medicaid expansion was to be a vehicle to cover those with moderate incomes. Those who have an income too low to pay for health insurance from their employer are in the private individual-market risk pool in non-expansion states such as Mississippi (Henry J. Kaiser Family Foundation, 2015).

The Henry J. Kaiser Family Foundation (2015a) discovered some significant facts in providing an overview of children's health coverage:

1. Between 1997 and 2012, involvement in Medicaid and CHIP programs established that the combined effects of eligibility expansions, enrollment simplifications, and outreach efforts led to surges in coverage and a decrease in the number of uninsured. Over the 1997 to 2012 timeframe, the rate of uninsured children was cut in half from 14% to 7%.
2. Rates of uninsured children are higher in the southern region of the United States. More than 7 million children remain uninsured, despite the successes of Medicaid and CHIP, with an estimated 5.2 million remaining eligible for Medicaid or CHIP but not enrolled.

3. The ACA was designed to provide opportunities to improve children's health coverage. In short, ACA recommended transitioning children's coverage up to 133% of the FPL to Medicaid. The ACA restructured health-insurance enrollment processes, which increases effort for adult individuals and could increase enrollment for children and demands for more financing for CHIP through fiscal year 2015. New coverage options also offer access to uninsured children through the new marketplaces.
4. Notably, with the implementation of the ACA, ongoing outreach and enrollment efforts will be significant in additional health-coverage improvements for children.

Although the synopsis of the ACA and the current state of health care in southern state may be complex, various researchers and agencies reported similar information (U.S. Department of Health and Human Services, 2016a). The guidelines of the ACA do not specifically describe aims for the health care needs of children. A small amount of literature specifically clarified that parents of children diagnosed with chronic or catastrophic illnesses would be affected by health insurance implemented under the ACA. With the ACA's significant restructurings through a multifaceted health care system in the United States, the ACA is likely to directly and indirectly affect children's health care (Fry-Bowers, Nicholas, & Halfon, 2014).

### **What Is at Stake Politically and Socially**

Children's health coverage, whether with a chronic or catastrophic diagnosis, may be compromised in unanticipated ways (Fry-Bowers et al., 2014). Children hold an

inexplicably small percentage of overall health care spending, which is not on the priority list of policymakers who mainly consider adult health care recipients with insurance coverage and controlling costs (Fry-Bowers et al., 2014). Compared with those with continuous coverage, children with gaps in coverage are less likely to receive “well-child care,” so the dialogue among policymakers should include eliminating gaps in coverage (Cassedy, Fairbrother, & Newacheck, 2008).

The University of Mississippi Medical Center is the largest hospital in the state and houses the only children’s hospital that treats children with chronic or catastrophic illnesses, including a separate cancer center (University of Mississippi Medical Center, 2016). Many children living in rural areas are transported to the medical center by their parents or by airplane or ambulance. Although the insurance carrier may carry some or all the transportation costs of the airplane or ambulance, the parent must provide transportation to this hospital for medical appointments and screenings, to assess their child’s wellness. Parents may have other children; may live hours away from the hospital; require gas funds for travel, babysitting arrangements, and other needs for their children; need to plan with their employer; and other factors related to travel. Health insurance does not assist with these costs and social service organizations in this state have little assistance available for parents in these circumstances.

One southern state, ranked the poorest state in the United States, has a significant number of parents who care for chronically ill children with little or no income. Obtaining transportation is critical for appropriate access to health care services (Grant et al., 2016). The lack of access to transportation aligns with appointments not being kept,

an inability to fill prescriptions, and poor management of chronic conditions.

Economically vulnerable children experience health disparities, including higher occurrences of acute and chronic conditions, higher mortality rates, and difficulty accessing services (Grant et al., 2016). Literature lacked research on intervention processes of policymakers in southern state who design policies for health care to assist with travel and other forms of reimbursement through state-assisted health care programs or under the umbrella of the ACA.

Reimbursements from Medicaid often cause a Medicaid shortfall or fall below health care needs (Colvin et al., 2016). It may be through a sense of empathy that hospitals can endure financial loss in caring for patients who are uninsured or insured by Medicaid. Although laws protect a patient by requiring service at a hospital despite a lack of insurance, in the Southern state, residents who require prescribed medications that are unaffordable cannot continue treatment for an illness (Kaiser Family Foundation, 2014a). The ACA may not sufficiently regulate for low-income patients or patients with severe health conditions, thereby unfavorably affecting hospitals (Colvin et al., 2016).

Despite the presence of adult transportation services for those who require kidney care, no assistance exists for health care of parents of pediatric patients. A child with chronic health conditions has marked health care needs and requires more transportation and medication than the average child: more appointments, longer hospital stays, and more frequent admissions to hospitals. Policymakers have not intervened in southern state to provide coverage under Medicaid or other marketplaces operated under the ACA

to assist in sufficiently meeting all needs of a chronically ill child regarding health care and health management.

A caregiver's or primary parent's emotions, behaviors, and health also impact a child's pain-management experiences, causing increased distress (Palermo, Valrie, & Karlson, 2014). To provide health insurance is no longer sufficient to care for the complete household. The missing pieces in health care in southern state can cause an ongoing negative effect in that the child who is ill can bring distress to the parent, causing them to become ill after being mentally and physically anguished. Policymakers, according to current literature, have only intervened by providing health care for those who qualify (Glied & Jackson, 2017). Although that health care will assist in the treatment of physical or mental anguish, little documentation shows how policymakers intervene to prevent mental anguish by providing accessible quality care for underinsured and uninsured chronically ill children under the ACA. With a lack of intervention, parents could be unable to be in the workforce. The government may have to pay for another child's health care needs (through Medicaid or CHIP), whereas the parent, who may be a taxpaying citizen, is unable to cover health care costs.

### **Political Analysis and Health Insurance**

Expanding Medicaid significantly assists in protecting and financially aiding low-income enrollees (Dorn et al., 2015). In southern state, Republican legislators, in June 2013, blocked plans to expand Medicaid to an additional 300,000 state residents under the ACA (Advisory Board, 2015). Above all, in rejecting the Medicaid expansion, one southern state's governor turned down an estimated \$426 million in federal funds for the

following year (Steenhuysen, 2013). Nationally, Republicans slated the ACA to imply the public would lose individual control over their medical care to the federal government under the Obama administration (Eng, 2016). The American Public Health Association (2012) reported that the United States spends far more on medical care than any other developing nation, ranking 24th among the 30 Organisation for Economic Co-operation and Development countries in health care expectancy. As of 2012, seven in 10 deaths in the United States relate to preventable diseases such as obesity, diabetes, high blood pressure, heart disease, and cancer; three quarters of U.S. health care dollars are spent treating diseases such as these; however, only 3 cents of each health care dollar are spent on prevention (American Public Health Association, 2012).

Although the ACA provided conditions intended to improve health and health care access among adolescents, McDonough (2016) argued that the ACA not only raised taxes on the wealthiest across the nation, the ACA also increased taxes on unearned income. A developing perception is that adolescents, impoverished citizens, or the well-being of children is not a prominent component in legislation, but the effect on taxes is of greater interest. Although most diseases can be prevented, physicians were taught to treat symptoms and provide medications but lack education on how to prevent illness. The government will continue to spend excessive amounts of money on health care as they appear to not know when to intervene. If public officials do not factor in costs to educate individuals on preventable disease measures, they will not sufficiently design a health care law that allows parents with chronically ill children to receive preventative services with no out-of-pocket costs such as copays or deductibles.

## **Health Insurance Marketplace**

An increasing uneasiness arises about another relevant component of the ACA initiative: the health insurance marketplace. This marketplace was designed to provide a new, simplified mechanism to obtain coverage in the individual market, beginning in 2014 (Dorn et al., 2015). Families with household incomes between 100 and 400% of the FPL who are not eligible for Medicaid or CHIP may qualify for new tax credits to make premiums more affordable (Dorn et al., 2015). Adults with children under the age of 21 can obtain these plans. Those adults who do not fall under these guidelines because their income exceeds the FPL will not be candidates for Medicaid or CHIP. If they receive income they believe is insufficient to pay for their employer-provided health insurance, they fall into the coverage gap, which some have dubbed the doughnut hole.

The coverage gap or doughnut hole affects most adults, as they could still face a large out-of-pocket burden because of uncapped cost sharing in the catastrophic-coverage phase (Trish, Xu, & Joyce, 2016, p. 1564). Children under the age of 12 with catastrophic illnesses could still receive coverage for medications and treatment, but the quality of the medicine and medical management is in question. All drugs are not covered under the ACA initiative or Medicaid. Although the ACA may decrease the amount of out-of-pocket expenses, an impoverished parent may still find those costs excessive. Not all medical doctors in southern state and the nation accept Medicaid or insurance that falls under the health care marketplace, frequently referring those patients to the emergency room of a local hospital for outpatient specialty care (Rhodes et al., 2012, p. 394). Some

are unable to afford the out-of-pocket expenses or costs associated with marketplace insurance (Obamacare Facts, 2016).

Despite countless dialogue about national legislation on immigration, health care policy impacts Latino and immigrant children and families. This population of children comprises more than 40% of uninsured children; however, although more than 90% of Latino children are legal U.S. citizens and are eligible for public insurance, many are not enrolled (Cheng, Wise, & Halfon, 2014b, p. 1733). Additionally, the ACA disallows undocumented citizens from receiving health care under this act. Latino parents of undocumented children may still fall into a coverage gap, likely to experience the same mental anguish and distress as a documented parent would with a child with a chronic illness.

Nevertheless, legislators do not believe the ACA could replace CHIP (Cheng et al., 2014b, p. 1733). If a funding lapse exists for CHIP or Medicaid, the number of uninsured children could more than double and be higher than if the ACA had not been enacted (Cheng et al., 2014b, p. 1733). A widespread population of children experience health disparities. Although the ACA may improve access to health care and health care quality, this enactment was not designed with the needs of children in mind and will need to be adapted to address these needs (Keller & Chamberlain, 2014).

The government's calculation of funding and implementation should also include clinical preventative services that do not require copays or deductible payments (Fox & Shaw, 2015). Doing so could include approval for countless essential services that could improve health and save lives. However, providers and health professionals should



understand that it is imperative for them to comprehend the distinctions of coverage rules to help redouble the potential to improve population health (Fox & Shaw, 2015). Furthermore, policymakers would have to intervene in health care policies in southern state to ensure that chronically ill children fare well under health care reform (Newacheck et al., 2009).

The ACA Medicaid expansion was designed to address the high uninsured rates among adults living below poverty (Garfield et al., 2014); however, those states that decided not to expand Medicaid disproportionately affected people of color. The literature did not include any research on families with children who have chronic illnesses, but Garfield et al. (2014) specified that the result of not expanding Medicaid may cause individuals who become ill to postpone medical care because of costs.

### **Health Care Challenges With Access, Equity, and Intervention Methods**

Although health care under the ACA was crafted to provide health insurance to reduce the number of uninsured individuals with preexisting health conditions as a criterion for coverage, debates continue as to whether this enactment is going to fill the gaps in the intervention processes of policymakers in southern state. Communication of health care policy modifications are also lacking in current literature for those who may comprehend the jargon of health insurance such as *subsidies* and *tax credits*. The average person may only be concerned with the quality of this health care, how easy it is to access, and costs. Medical education must be readily available about the ACA (and physicians must be clear on the impact, development, intervention processes, and ability

to translate their knowledge to their patients (Herrmann, Peters, Williamson, & Rhodes, 2015).

One major factor in implementing education on access to health care in the health care marketplace is that government agencies outside of those groups that provide Medicaid, such as human-services departments, should intervene, but should, first, receive training and education to pass along to prospective recipients who seek health care. A parent who receives news of their child being recently diagnosed with a chronic illness and who is uninsured should not have to endure the stress of knowing what will be paid for, by whom, and how much treatment will be unaffordable. Minorities, such as African Americans, face “financial toxicity,” or financial harmfulness, where costs could negatively affect the ability to access treatment (Hamel et al., 2016, p. 1). These costs could initiate financial stress for parents if they are not receiving the social support they need (Hamel et al., 2016).

Discussions among pediatric-oncologist parents and oncologists should include time taken from work, opportunity costs, and the kinds of societal support families could receive (Hamel et al., 2016). The ACA aimed to generate population health, with accessibility as a public benefit such that citizens could reap the advantages of disease prevention and even tax credits. Research and policy priorities “should continue on major provisions of this enactment” (McMorrow & Polsky, 2016). These provisions include federal subsidies to purchase private insurance under the health care marketplace and Medicaid expansion. The question is not whether the enactment was a good choice for constituents, but if “temporary increases in the Medicaid reimbursement rate to primary

care providers, prioritizing those in medically underserved areas, would provide a haven for those without coverage” (McMorrow & Polsky, 2016, p. 1).

### **Community Medical Homes**

Community health centers are usually located in rural or disadvantaged communities to provide health care for those in underserved areas. With or without insurance, these health clinics can serve as patient-centered medical homes for medical treatment and some disease prevention. Those who these clinics are unable to serve are usually referred to the nearest emergency room for further medical treatment and options. Although these community health centers provide services for children who may need treatment for illnesses such as strep throat or influenza, these clinics do not have the funding, equipment, or other resources to treat a child who may have been diagnosed with a catastrophic illness (Hamel, et al., 2016). Particularly in one rural southern state, social determinants play a role in attracting superior physicians to reside in these areas because of little economic development, poor housing, and poor education facilities for their school-aged children (Antos, 2013).

Policymakers, though elected by the citizenry, may have conflicting interests when it comes to health care. These policymakers, who are the decision makers, should intervene by considering the interests of the taxpayer and not only a selected group. Modification in power and disgruntled feelings may emerge with health care reform among citizens as they may continue to feel powerless and do not completely understand the elements of this enactment. Those with low income in single-parent homes may be unable to afford the care they and their children need, whereas

government officials may only consider citizens' best interests when they need votes to return to office (Birchley, 2014).

### **Health Care Spending**

Because one southern state did not expand Medicaid, some medicines are not covered. Catastrophically ill children may need expensive drugs that may require more money to purchase than typical medications. Parents who may be financially burdened and lack needed support for expensive medications may be unable to obtain prescriptions that could help reverse their child's disease (Whelan, 2010). According to research by the Kaiser Family Foundation (2012), the United States spent \$8,402 per person on health care in 2010, totaling \$2.6 trillion in health care across the country in 2010. These totals for health care expenditures are more than those of any other country in the world (Cunningham, 2015). The Southern state—although not spending \$150 million in uncompensated care, thereby increasing the costs for all citizens—was likely to receive \$1 billion in federal funds to assist low-income adults with needed health care (Small Business Majority, 2013). By failing to adopt Medicaid expansion, despite saved funds, millions of one southern state's residents did not receive the medical treatment they needed to attain cures or return to the workforce; these residents would have provided tax dollars to maintain economic strength and development for the state (Kaiser Family Foundation, 2014b).

Due to preexisting financial circumstances, individuals who were eligible for private insurance under the marketplace were still displeased by their inability to afford some costs, particularly attached to prescriptions and transportation (Gracey & Johnson,

2016). In 2011, more than 10% of a U.S. family's household income was used for out-of-pocket health care expenses (Cunningham, 2015). Excessive medical costs are a significant inconvenience for families who need prescription drugs, especially for those expected to benefit from the ACA's coverage expansions (Cunningham, 2015). Families who may have purchased "nongroup" coverage prior to the implementation of the health-insurance marketplaces in 2014 spent a high amount of their income on health care (Cunningham, 2015). Additionally, more than half of these individuals qualified for premium subsidies, which would have reduced medical-related burden for those who did not have insurance supplied by their employer (Cunningham, 2015).

Healthcare in southern state can affect a family's personal financial conditions and livelihood. For the sake of a child's health, if diagnosed with an illness, a parent could succumb to giving up their home, vehicles, and other assets. A parent of a chronically ill child desires to seek the finest care for their child and provide first-class prescriptions for them without believing they are giving them just enough to get by. Parents of children with chronic illnesses may understand that chronic illnesses such as autism and sickle cell anemia are considered incurable conditions; however, they trust they can find the right medical provider to support them in providing treatment and therapy for the child.

Interest sparked in health care following President Obama's dialogue about a health care plan that could provide health insurance for all Americans, although politicians had been discussing health for 2 decades (Grogan, 2012). Grogan (2012) spoke of the benefits that young adults could receive and those who fall under the age of

18 in the health care marketplace. Despite decades of discussion, it was still difficult to pass a simple law that appeared to aid all Americans rather than any class of Americans (Grogan, 2012). Missing from Grogan's discussion was information about children with chronic illnesses and how policymakers would intervene about these modifications with those who may not have efficient access to this health care reform.

The pieces of health care laws implemented over the years have still caused a large proportion of U.S. children to lack health insurance. Flint (2014) provided a case study about the ACA that discussed the expansion in children's health care following the decrease in human-service programs. Flint pointed to the public's sympathy for children who were unenrolled and eligible children. This can be problematic in southern state because, as Scal (2016) cited, too many adolescents and young adults already have chronic illnesses and are not receiving the medical care they need.

### **Idiosyncratic Coverage-Gap Experience**

The length of time the primary parent is in this gap can be uncertain; however, among children with chronic health conditions, that timeframe can be extensive and become a matter of life and death. With the increasing rate of African Americans and Hispanics in the Southern state, the ACA has allowed a narrowing of coverage between Caucasian and non-Caucasian residents Cunningham, 2015. Nevertheless, African Americans are more likely to benefit less than others because they predominantly reside in one of those states that did not adopt Medicaid expansion (Clemens-Cope, Kenney, Buettgens, Carroll, & Blavin, 2012).

Even after implementation of the ACA, intergovernmental partnerships that govern the system are likely to need greater federal oversight and control (Sparer, France, & Clinton, 2011). Those families concerned about all elements of their child's well-being now face the subjective idea of possibly having to detach themselves from their homestead and livelihood to make fundamental sacrifices to afford health insurance the government deemed affordable. Though parents gained benefits from coverage following the ACA and because their children were now able to be covered, the law includes only those whose income falls below 138% of the FPL. Expenses such as food, gas for transportation, phone usage, and other necessities for a basic and unembellished lifestyle are not in this calculation, particularly for those who have dual-parent households and more than three children (Sparer et al., 2011).

One example is a family of seven—two parents and five children—in which both parents make over \$50,000 a year, but their employer provides expensive health insurance that the parents have agreed is unaffordable. These parents can apply for insurance under the marketplace, but the only factor is the number of children in the home and the income. To maintain an average lifestyle in the United States, with children receiving education in a good school system, in the Southern state, a family of this size would have to pay a minimum of \$1,000 to \$2,000 a month to live in a decent area. If rent or mortgage, utilities, gas for vehicles, and food are deducted after taxes from their payroll, their children will have limited opportunities to participate in school activities or monies set aside for their college savings. One would only have to imagine if this same family had a child with an illness: the impact of the ACA or other health care options

could burden the family in maintaining expenses not covered under the health care marketplace (Garfield & Damico, 2016).

### **Impact of What Is Perceived as Affordable**

Health insurance can save lives, beginning in the foundational steps of a child's life as they mature into adults. Although medical costs are increasing, policymakers should be obliged to consider the impact of the lack of affordability of insurance even under the marketplace. Lack of affordability can damage an individual's perception of government. Lack of education about health care reform that was anticipated to be a social safety net, and the impact on prevention and management of one's health, may exacerbate that damage.

This analysis involves gaining not only insight and the experiences of parents, but also findings from other research studies on the ACA and children with chronic illnesses requiring special medical needs. Available research on the ACA as it affects children with chronic illnesses was minimal and primarily addressed health care that covered the well child. Some literature, nonetheless, discussed the impact of the ACA and cancer, explaining the nonexistence of lifetime limits or caps, adult children being covered up to the age of 26, and the inability of insurance companies to charge higher rates if a patient has a preexisting health condition (Cancer.Net, 2015, p. 1).

The ACA has been a great help to families with or without children with major health ailments. For example, Mullins et al. (2011) cited differences between single parents and parents who have children with chronic health issues (p. 249). Single parents, or those with children with chronic diseases with a low income, are still markedly



impacted in their general health and behaviors. Both categories of parents still experience high levels of stress (Mullins et al., 2011, p. 249).

Researchers noted the cost concerns of patients and how health care providers are identifying barriers in medical care. Stump et al. (2013) identified barriers to those who are insured and not only in an impoverished population. Concerns for costs were greater for those with insurance who were diagnosed with catastrophic illnesses such as cancer among adults (Stump et al., 2013). Lower distress, the ability to identify potential resources and the capability for patients to make optimal treatment decisions could transpire, should policymakers and health care providers frequently participate in the rectification and intervention of decreasing health care costs for all populations.

Fedele, Grant, Wolfe-Christensen, Mullins, and Ryan (2010) used parenting capacity variables to identify parenting characteristics and their effect on the child and family structure. Fedele et al. measured specific influences and mechanisms on child health-adjustment outcomes. Parents provided primary care for chronically ill children. Researchers identified increased vulnerability in those parents who parented children with illnesses such as asthma or diabetes (Fedele et al., 2010). With escalation of chronic illnesses in children, “parenting stress should be targeted for future intervention and specific measures should be used for future studies” (Cousino & Hazen, 2013, p. 809). Neither Fedele et al. nor Cousino and Hazen (2013) cited factors regarding the need for external support for these parents, but did identify the impact chronic illnesses can have on the entire family system.

## Summary and Conclusions

Chapter 2 highlighted the gap in literature concerning how the implementation of the ACA affects parents with chronically ill children. Despite much debate as to whether the ACA should be repealed, considerable positive results accrued since its enactment. Investing in a child's health could improve their lives in the school-age years, yielding adults with good health (Campbell et al., 2014). Investing in the health care of children can go beyond the benefits of good jobs and economic development. Generally, these children with a healthier life could grow to be state officials who understand the importance of equity in health care, accessibility to it, and the effect of intervening in decision-making processes and communication with parents with chronically ill children.

Legislators have a duty to fill the gaps in knowledge, access, and intervention methods concerning health care policy by understanding the requirements of raising a family in southern state and managing health care costs in this state, particularly those health care policies that provide care for chronically ill children (Grogan, 2012). Children with special health needs tend to miss appointments and other preventive medical visits because of falling in the coverage gap or other financial barriers (Norris, 2014). These factors should be reviewed in drafting health care policies. Chapter 3 details the research methodology that explains how data will be collected.

### Chapter 3: Research Method

I explored the perceptions and lived experiences of parents of children with chronic illnesses following the implementation of the ACA. This chapter includes a thorough description of this study's methodology. Beginning with a discussion of the research design and rationale, I clarify my role in providing findings to the reader without bias. I discuss the methodology in detail to provide the reader with information on the study population, setting, sample selection strategy, instrumentation, and data analysis plan. Matters of trustworthiness include transferability and confirmability. This chapter concludes with a description of ethical procedures and a summary.

#### **Research Design and Rationale**

For this study, I used a qualitative, phenomenographic design (see Marton, 1986a). The intent was to examine the gap in literature that acknowledges policymakers' lack of knowledge regarding how their decisions about health-care-coverage standards and providers' networks impact parents with chronically ill children. The following research question guided the study: How do parents with chronically ill children in the Southern state perceive their experiences with the ACA? Qualitative methods of research allow a researcher to approach a study in a field with the limitations of fixed classifications of inquiry. According to Creswell (2007), a qualitative approach would be more appropriate than a quantitative approach when a researcher attempts to make sense of unbiased and interpretive meanings by understanding participants' worldviews. Furthermore, with qualitative methodology, researchers focus on learning participants' problems or issues and not the problems or issues the researcher may observe through the

choice of their topic or those issues that may have been found in literature (Creswell, 2007).

I chose phenomenography because it allowed me to explore the individual experiences of parents and conceptualize phenomena from similarities and dissimilarities in their views. The assessment of different types of health care could vary from parent to parent. Researchers use phenomenographic methods to answer questions about thinking and learning (Marton, 1986a), and researchers may find individuals may answer similar questions in dissimilar ways. Researchers use phenomenography to describe, analyze, and understand experiences, directed toward experimental description (Marton, 1986a).

Researchers commonly use phenomenology to understand the similarities in individual experiences; phenomenography places greater emphasis on the mutual meaning of phenomena (Barnard, McCosker, & Gerber, 1999). The focus on the collective comprehension and experiences was appropriate for my study. The difference in demographics relating to household size, income, and marital status required a methodology that addressed a collective perspective; therefore, I deemed phenomenography was appropriate.

Phenomenography derived from research focused on education and is a tradition for studying health care topics. Barnard et al. (1999) explained three positions of review into which phenomenographic approaches can be organized:

1. overall characteristics of learning;
2. knowledge in domains such as economics, mathematics, or health care; and
3. the ways people recognize different aspects of the world.

Barnard et al. (1999) also explained that phenomenology offers a chance to broadly apply results to health care theory and practice. Phenomenography appeared to be the best method to apply to this study to analyze the perceptions and experiences of parents of chronically ill children following the implementation of the ACA. This method provided the appropriate lens to view dissimilar aspects of parents as well as the common viewpoints of this same population.

### **Role of the Researcher**

The threat of bias exist, and reliability can be diminished when a researcher is basing findings on experiences and not on numerical data (Greenland, et al., 2016). To perform an unbiased study, I worked to prevent external factors from influencing the data with a goal of attaining credibility and reliability in this study. As the observer, I had no personal or professional relationships with the supervising appointee or the participants. This ethical stance continued throughout the study.

I explored the experiences and perceptions of parents receiving health care in southern state for a child with a chronic illness and investigated whether a limited amount of treatment is available for any a recipient of state-mandated or non-state-mandated insurance since the implementation of the ACA. In the process of exploring the perceptions, thoughts, feelings, and experiences of those parents, I used a technique known as bracketing, defined as “mitigating ... the potential deleterious effects of unacknowledged preconceptions related to the research” (Tufford & Newman, 2010, p. 81). While journaling, I described my personal values to manage personal bias. Prior to

agreeing to accept a participant, I ensured the participant had no prior affiliation with me, professionally or personally, to avoid biases or other ethical issues.

## **Methodology**

### **Participant-Selection Logic**

The sample population for this study consisted of 12 individuals who are parents of a child with a chronic illness. I visited a local nonprofit organization in a southern state to identify and select potential participants for this study. The criteria for selected individuals included that participants must receive state-mandated health care under the health care marketplace and have a child with a chronic illness under the age of 18. I selected a sample size of 12 participants because Frankfort-Nachmias and Nachmias (2008) recommended a small sample to allow the researcher and participants time to build a relationship, which could allow participants to feel more comfortable when sharing their experiences.

Participants came from a southern state and were adult female and male legal parents. The three requirements for the participants were that they must be a resident of particular southern state, have a child with a chronic illness under the age of 18, and receive health care under a health care marketplace or Medicaid in the southern state. To answer the interview questions, participants had to have received health care before the implementation of the ACA. Individuals could not participate in this study if they were not covered by health insurance. To protect participants, I conducted interviews in a meeting room of a local public library, or I used a telecommunication device from my HP

laptop for an audio-recorded interview. I used Skype when a parent was unable to meet face-to-face for an interview.

In this qualitative study, the sampling tool used was a nonprobability sample design with a purposeful sampling strategy because it placed emphasis on strategic and purposeful selection information-rich cases, yielding insights and in-depth understandings based on participants' views (as recommended by Patton, 2002). This approach allowed me to analyze a comprehensive review of the experiences of participating individuals on health care and the ACA. All participants electronically signed an informed-consent form assuring them that they could withdraw from the study at any time.

### **Instrumentation**

In this study, I was the primary tool in data collection and used audio-recording devices for interview sessions. Additionally, I made it clear that all conducted interviews were at the discretion of participants with catalogued audio recordings. I chose face-to-face interviews so I could observe the environment and the mood of the participant while having more personal contact with the individual. This format allowed the parent to voice their issues and possible solutions regarding standards in southern state's health care.

By recapitulating the lived experiences of parents in the implementation of the ACA and the purpose for its implementation in health care reform, participating individuals provided an account of their experiences in purchasing prescription drugs, hospital visits and stays, and other elements in caring for their child. Throughout this research, I was able to interpret their responses regarding their experiences and apply a

realistic and unbiased perspective regarding health care for chronically ill pediatric patients. This qualitative data provides detailed and previously uncovered research for an understudied population in the Southern state.

My supervising appointee, the founder and CEO of a nonprofit organization, reviewed the questions for participants prior to this study. I did not use surveys or other numerical tools for this research; hence, a quantitative approach was unnecessary or inapplicable to this study. I included no pilot or experimental study; therefore, a qualitative approach was an appropriate design. I applied Chenail's (2011) method of interviewing the investigator to assist me in creating procedures, revising interview questions with possible biases, and addressing other potential concerns.

### **Procedures for Recruitment, Participation, and Data Collection**

The recruitment, participation, and data-collection procedures for this phenomenography study were as follows:

1. I visited the nonprofit organization where I spoke to the CEO about soliciting participants for the study.
2. I e-mailed the CEO with an initial contact letter requesting to solicit potential participants for this study.
3. After receiving permission by e-mail with a signed letter from the nonprofit's CEO, I posted the criteria needed to qualify for this study on the parent information board in the facility.



4. Those parents who were interested in participating in the study contacted me by e-mail and at that time, I forwarded an informed-consent form to sign and return to me by e-mail.
5. Once I received the informed-consent form from the potential participant, I assigned them a pseudonym identifier that I e-mailed to the potential participant.
6. I sent additional information about the study to the potential participant suggesting a meeting place such as a local, public library's conference room, and availability times for them to confirm.
7. Following the meeting at the local library's secured conference room, I transcribed the audio-recorded interview on my HP desktop or laptop computer.
8. I followed up with the community partner, thanking them for their support and letting them know when all participants had been interviewed.
9. I contacted participants once all interviews had been transcribed for a debriefing session, seeking assurance that all information in their transcribed interviews was accurate and provided them with local organizations they could use for assistance or for support as they cared for their chronically ill child.
10. I shared the results of the study with the community partner but names remained anonymous to maintain participants' confidentiality.

## **Data-Analysis Plan**

When the interviews were completed, I reviewed the data and used NVivo software for qualitative research. NVivo is a software program that helps researchers organize and analyze qualitative data. NVivo assisted me with recording data to verify the reliability and validity of the study. I also analyzed all the interview transcripts by uploading the data into the computer software program to identify certain word frequencies. Searching for word frequencies allowed me to link and recover similar traits and characteristics participants identified. I used NVivo to record, link, code, and document similar words and phrases to form themes. I used descriptive coding to identify similar events and categorize the events into themes, based on ideas from Corbin and Strauss (2008), and I used NVivo to track ideas using charts and diagrams.

I reviewed all data entered in NVivo through my HP laptop. I used the suggestions by Sjostrom and Dahlgren (2002, as cited in Davies, 2015) as follows:

1. Familiarize myself with the material by reading over the interview transcripts.
2. Compile the answers from the participants and identify significant factors in participants' responses.
3. Condense individual responses identifying focal points in the lengthy responses.
4. Group similar responses while continuing to seek dissimilarities.
5. Compose categories to distinguish any boundaries in those categories.
6. Name the categories to identify and emphasize the essence of each.
7. Contrast and compare descriptions of similarities among different categories.

I sought key terms and similar phrases throughout the study, creating categories to assist in the coding process and to identify similarities and differences among participants.

Finally, I compiled and present the results from the data in Chapter 4.

### **Issues of Trustworthiness**

Issues of reliability and validity have been major concerns for researchers in qualitative research because the research is mostly inductive and focuses on understanding specific rather than generalized aspects of participants' worldviews. Because qualitative research focuses on participants' stories and similar phenomena rather than numbers and statistics, I needed a system to assess reliability. Guba and Lincoln (1994) created ideas about how to validate qualitative studies in ways that are equal to trustworthiness in quantitative studies, discerning that credibility equals internal validity. Guba and Lincoln suggested that researchers record data the same way for all participants, using a traditional method to record data that will lead to trustworthiness and reliability (Shenton, 2004). A traditional method could include the researcher building rapport and establishing relationships with the participants, which allows for open dialogue between participants and the researcher (Shenton, 2004).

Shenton (2004) cautioned researchers to refrain from getting caught up with transferability and risk the procedures of reporting data. Understanding transferability will lead to trustworthiness of the research project (Patton, 2002; Shenton, 2004). To achieve transferability, I used thick descriptions of findings from participants' experiences. The descriptions from participants' experiences allowed transferability of information to other individuals and situations, based on recommendations from Shenton.

Dependability is the counterpart of reliability (Shenton, 2004). Guba and Lincoln (1994) identified dependability and credibility as similar concepts. Researchers can validate credibility with dependability (Shenton, 2004). I used methods such as interviews and follow-up discussion to check for dependability (Creswell, 2013). I used detailed descriptions of how I conducted the interviews, and what implementation plans I used, based on views from Shenton (2004). In addition, I described how I collected data and how I reflected on the process to ensure dependability of the research project.

Conformability is like objectivity (Patton, 2002; Shenton, 2004). Patton (2002) suggested researchers follow certain steps to assure conformability in qualitative research. As the researcher for this study I took careful steps to ensure personal bias did not interfere with recording specific information provided by participants, based on ideas from Patton (2002). Moreover, according to Shenton (2004), I needed to review interviews and recorded data several times to check what participants reported and what I recorded. It is imperative that a researcher reports participants' experiences and ideas and not what the researcher may want to record (Shenton, 2004). For instance, researchers may have preconceived ideas about an experience. The experience reported by the participant may not be what the researcher hypothesized.

### **Ethical Procedures**

When conducting research that involves human subjects, all participants must consent to participate in the study by signing an informed-consent form. As the researcher for this study I informed each participant of the details of the study and each participant had the necessary mental capability to respond to the interview questions.

However, before interviewing any person for this study, I gained Walden University Institutional Review Board approval (Approval Number 11-01-18-0388739, expiration date, October 31, 2019). Additionally, before conducting the study and interviewing participants, I informed each participant of their rights to confidentiality and about the process of destroying any confidential information they may provide. I also informed participants about where I would store the data collected from them and informed them that I would be the only person with complete access to their confidential data. I also informed participants that they were welcome to cease participation in the study at any time.

I, the researcher and respondent, must ensure an extensive level of trust because the interaction between the respondent and me relies on accurate dialogue, articulated in writing, supplemented by a thorough, in-depth interview, preferably in a normal environment of the participant. A natural environment can be interpreted as the participant's office, church, or home; however, many participants may be in hospital locations. If the participant was willing to invite me into their natural environment, the overall inference is that they have already recognized a minimal level of confidence and trust.

Because I used the qualitative method in this research, the discourse that derived from the individual declarations of participants must be authentic and presented in the essence originally intended by each contributing party. In the event a participant desired to remain anonymous, I had the duty to present the data in such a way that it represented the participant by using a numerical identifier or pseudonym assigned to each participant

throughout this study. The participant used the identifier to sign documents or in any communication throughout the study. I did not give incentives to any participant and continue to keep all information in a password-protected computer file.

### **Summary**

Chapter 3 presented the methods to obtain data to address the problem and purpose of the study. This chapter also represented the data collection, recruitment, and participation processes that aligned with the design and method used for this study. This chapter pointed out how I attained significant viewpoints that parent interviewees experienced. This chapter included the sampling process as well as the ethical considerations used throughout this study. In Chapter 4 I describe the data collected and the data analysis.

## Chapter 4: Results

Members of the U.S. Congress enacted the ACA to increase the portion of the population protected by health insurance (Rosebaum, 2011). Health care in the Southern state is a controversial topic about which state policymakers continue debate on modifications. According to Mulligan (2013), former President Obama built the ACA, based on former Republican Massachusetts governor Mitt Romney's health care plan, implemented for Massachusetts state residents. Governor Romney implemented Romneycare so that all Massachusetts residents would receive a minimum level of health insurance coverage (Mulligan, 2013). Moreover, residents would receive free health care if they earned less than 150% of the FPL, and employers with more than 10 full-time employees would have to provide health care (Mulligan, 2013).

I investigated the health care policies in the Southern state and explored the decision-making processes used during the 2016 and 2017 legislation sessions to gain the necessary information to help answer the central question: How do parents with chronically ill children in the Southern state perceive their experiences with the ACA? This chapter includes a presentation of the research results. The chapter also includes a description of the research setting and the demographics of the participants. Moreover, the chapter includes details about the procedures used for the collection of data, data analysis, identification of themes from the data, and the issues of trustworthiness. To conclude this chapter, I provide a brief summary.

### **Setting**

Individual participant interviews occurred face-to-face or through Skype which is a form of audio-visual telecommunication. I met with participants in a local library's meeting room, which provided a private space for the interviews. The interviews took place during weekend hours to avoid conflicts with participants' work schedule. Participants who could not meet with me face-to-face completed their interviews using audio-visual telecommunication.

### **Participant Demographics**

The 12 participants shared some common experiences. All participants were parents, residents of the Southern state who cared for chronically ill children, and individuals who received health care through the health care marketplace designed under the ACA. Additionally, participants used prescribed pseudonyms and created anonymous e-mail accounts to maintain their confidentiality when communicating with me, as a criterion for this study. All participants were caregivers of children with chronic illnesses under the age of 18. Participants' demographics appear in Table 1.

### **Data Collection**

To collect data for this study, I interviewed participants face-to-face or used an audio-recorded telecommunication application. Participants included 12 parents who were caregivers of chronically ill children receiving health care under this southern state's health care marketplace. Each participant answered the five questions listed in the interview protocol. I used follow-up questions, as necessary, to keep participants engaged and to gain more information about their perceptions and experiences with health care in



southern state. I audio recorded and transcribed all interviews with software to capture participants' verbal responses. I followed the data-collection plan described in Chapter 3. No unexpected circumstances arose during the data-collection process.

Table 1

*Participant Demographics*

Participant	Gender of caregiver	Relationship to child	Children's age
1	Female	Mother	16, 13, 11, 6
2	Female	Mother	8
3	Female	Mother	12
4	Female	Mother	6
5	Female	Mother	15
6	Female	Mother	12
7	Female	Aunt	10
8	Female	Grandmother	8
9	Female	Mother	17, 14
10	Female	Mother	9
11	Female	Mother	11
12	Female	Mother	14

I created interview questions to focus on the experiences of parents with chronically ill children receiving health care under the ACA. I did not ask additional questions to allow each participant to independently respond to each question without persuasion from me. I wanted participants to respond to the interview questions without assistance; however, I had to clarify to six of my participants that Obamacare and the ACA were the same.

### **Data Analysis**

After reviewing the transcribed interviews, I began data analysis using the process described by McMillan (2009) to understand the why, what, and how of these parents' lived experiences. This process included the following steps:

1. Extract what is central, essential, or generic by reading the interviews. I read transcripts in their entirety while taking notes to document central, essential, and generic themes used throughout the transcripts.
2. Chunk the units of representation or compile all respondents' answers. I created a separate document for each of the five interview questions into which I copied and pasted interview responses for individual questions from each participant into the conforming document, which allowed me to chunk similar themes.
3. Generalize from what has been learned in the past to new learning. In these documents, I summarized participant responses to each question to generalize what had been learned in the past to new learning about health care in southern state and to refine substantial, evolving components.
4. Transfer these generalizations from one context to a different context. After highlighting similar themes with a highlighter and combining those elements of the data that were similar, I reviewed and compared themes while discarding themes that arose only once. The final step was confirming the accuracy of all themes defined in the transcripts.

After I completed these steps, I assessed the themes and theme fields to consider participants' areas of perception for each response. I also evaluated the implications of words and phrases used in participant interviews. By considering the frequency of use with terms and phrases, I was able to develop subcategories that described participants' experiences. The purpose of developing subcategories was to determine potential connections to the perceptions and experiences of participants. I identified, coded, and used central phrases and words to locate patterns, themes, and similar perceptions.

I used phenomenographic content analysis to identify resemblances and dissimilarities among participant responses. I identified changes in the themes or patterns as they occurred during the analysis process. Additionally, I used NVivo 12 Plus software to search for comparable connections that may have not emerged in the manual-coding process. I did not find any significant inconsistencies after searching for discrepant data through manual-coding procedures. Table 2 provides an illustration of the primary organization of participant responses that helped me identify overall themes in the study.

### **Evidence of Trustworthiness**

To maintain and show evidence of trustworthiness, I strictly followed the trustworthiness strategies noted in Chapter 3. During the interview and analysis process, I upheld a state of spontaneous thinking to link my assumptions, obtain a vivid comprehension of the data, and preserve an awareness of prejudices that could inhibit my analysis. By journaling throughout the research process, I was able to identify themes in my data and categorize them as needed.

Table 2

*Terms/Phrases in Participant Responses*

Question number	Question	Terms used (Participant frequency)
1	What do you believe the enactment of the Affordable Care Act was designed to do for those who receive health care?	Access (8) Affordable (12) Healthcare (12) Receive (7) Poor people (2) Can't afford health insurance (10) Need Insurance (12) Obamacare (9)
2	Since the enactment of the Affordable Care Act, what changes have you seen in any out-of-pocket expenses for your child who has been diagnosed with a chronic illness?	No changes (8) None (4) Same (10) Prescriptions (2) Can't afford (3)
3	Based on your experiences and perception, what do you believe is the least considered when public officials decide on health care policies?	Income (10) Works (5) Poor (6) All children (2) Child becomes an adult (2) Expenses (8) Knowledge (9) Accessibility (12) Availability (12) Aspect (6) Constituents (10) Stress (4) Moving (1)
4	Based on your experience and perception, what do you believe should be considered when public officials are drafting health care policies relative to children with chronic illnesses?	Income (9) Working (7) Poor (8) Preconditions (12) Household (4) Politics (4) Rich people (3) Conditions (10) Expansion (9) Lawmakers (9) Opportunity (11) Accessible (10)
5	Since the enactment of the Affordable Care Act, were there any medical services added or taken away from the services provided for your chronically ill child? If services were added or taken away, please explain what those services were and what has been the effect of that service being either added or taken away.	No services were added (12) Decrease in prescriptions (2) I don't know (10) Expenses (6) Changes (7) Medicaid (8) Prescription (12) School (2)

I thoroughly examined each participant's responses from the substantial data collected, which ensured reliability. I also encouraged participants to provide as much detail as possible about their experiences with their southern state's health care and their perceptions of the ACA, using specific examples and individualized lived experiences when applicable, helping me create a better description of participants' experiences, with richer context when comparing and categorizing data. However, I did not seek documentation, names, or other information that could have jeopardized the anonymity or confidentiality of participants.

This study's resources only included the following: e-mail correspondence with the participants using assigned pseudonyms, audio recordings of each interview and the transcription of each interview, the preliminary data grouping described earlier, manual analysis of the data, described earlier, on a separate document to categorize themes, and NVivo analysis, which allowed for clearer transferability. To further ensure evidence of trustworthiness, I allowed participants to review the transcripts to ensure that all information from their transcribed interviews was accurate. Allowing participants to review the transcripts and my interpretations of the data, they could see that the transcripts were accurate representations of their responses regarding their lived experiences with health care in southern state. No participants expressed concerns about their transcripts or if they felt misrepresented in their proposed interaction.

## **Results**

Several themes surfaced during the analysis and coding of the participant interviews (see Table 2). These themes included access to health care, affordability, gross

versus net income being used to interpret what is affordable, taking care of a chronically ill child who may become a chronically ill adult, and politics. I discuss each theme further on the pages below and provide a breakdown of each interview question, which corresponded with each theme or frequently cited phrase.

### **Patterns/Themes for Individual Interview Questions**

**Interview Question 1.** “What do you believe the enactment of the Affordable Care Act was designed to do for those who receive health care?” Participants responded similarly to this question with eight significant themes emerging. All participants had some knowledge of what they perceived the ACA was designed to do, but Participants 3 and 6 were unaware that the ACA and Obamacare were the same, whereas Participants 1, 2, 4, 5, 7, 8, 9, 10, 11, and 12 appeared to be more aware of what the ACA was designed to do. Four of the 12 participants (Participants 3, 4, 7, and 9) did not know the term “Affordable Care Act,” so I had to use the term Obamacare for them to effectively respond to the question. Participants 1, 2, 5, 6, 8, 10, 11, and 12 appeared to know that the ACA and Obamacare were the same. Participants 2, 6, 8, 9, and 11 had little knowledge of the purpose of the ACA and had only heard about it on television, whereas Participants 1, 3, 4, 5, 7, 10, and 12 appeared to be knowledgeable. Participant 5 voluntarily shared working for a health care facility, so knew more about the act. Participants 3 and 7 stated they wished they knew more about the act, so they could better understand how the act could best benefit their chronically ill child. All 12 participants stated they were glad preexisting conditions did not interfere with coverage and understood that the ACA allowed their children to receive coverage after the age of 19.

**Interview Question 2.** “Since the enactment of the Affordable Care Act, what changes have you seen in any out-of-pocket expenses for your child who has been diagnosed with a chronic illness?” Participants 2 and 11 each experienced a decrease in out-of-pocket expenses for prescriptions; however, the other 10 participants all stated they saw no changes in out-of-pocket expenses. Participant 6 “had a hard time gaining health care through the Affordable Care Act because the insurer’s representative stated that her income was above poverty level.”

**Interview Question 3.** “Based on your experiences and perception, what do you believe is the least considered when public officials decide on health care policies?” Participants 1, 3, 6, and 12 said that gross income should not be considered whereas Participants 2, 4, 5, 7, 8, 9, 10, and 11 did not mention if a person’s net income should be considered. All participants said income should be considered, but Participants 1, 3, 6, and 12 were specific about which type of income. Participant 1 stated that public officials should consider the composition of the entire household, such as other children, utilities, food, and transportation for the chronically ill child whereas the other 11 participants made no mentioning of policymakers considering the makeup of the entire household.

Participant 6 mentioned, “...there must be medical providers within a certain radius of residential areas to provide medical care, so transportation costs should be factored in their decision-making processes.” Participant 12 stated, “Political parties should not overpower the decision to side with voting for health care policies at all.” Participant 12 noted that former President Barack Obama drafted the ACA using Republican principles which was why many Americans did not understand why

Republican congressmen were fighting against it. This participant also stated, “There was not a concern about getting rid of the Affordable Care Act since it has already been upheld by the United States Supreme Court.”

Participant 1 elaborated on the levels of stress experienced with all the changes in health care for the participant’s child. This participant stated that every time the child goes to an appointment or gets a prescription, “it is unknown if there will be any out-of-pocket expenses or not.” Participants 1, 3, and 4 mentioned stress as a factor when caring for the child and ensuring that full to mostly full coverage is available for their chronically ill children.

**Interview Question 4.** “Based on your experience and perception, what do you believe should be considered when public officials are drafting health care policies relative to children with chronic illnesses?” Participant 10 stated, “Public officials should consider that children with chronic illnesses become adults with chronic illnesses.” This participant also noted that there should be an “increase in what is given financially by the government to pay for prescriptions and health care management for chronically ill individuals so that when the children become adults, their illnesses will not be neglected.” Participant 10 stated,

mental illness is a chronic illness and public officials should understand the importance of managing the mentally ill health, so that they can become productive citizens who give back to their communities, instead of mentally ill patients who have to be hospitalized.



Participant 6 mentioned that “public officials should consider paid transportation, being paid for through health insurance, when their chronically ill child may have to go to an out-of-state facility for treatments or health care management.” Participants 1, 2, 3, 4, 5, 7, 8, 9, 11, and 12 did not state discuss transportation or children who may possibly become adults with mental illnesses, but these 10 participants all did cite that policymakers should consider the region in which they are located with regard to the median salaries given in their career fields and the cost of living.

**Interview Question 5.** “Since the enactment of the Affordable Care Act, were there any medical services added or taken away from the services provided for your chronically ill child? If services were added or taken away, please explain what those services were and what has been the effect of that service being either added or taken away.” All participants stated they were unaware of any services added to or taken away from their health insurance packages. The only medical services noted were that Participants 6 and 8 said prescription costs went down.

Participant 3 “wanted the government to just leave health care alone and stop taking from health insurance and education every time they need money somewhere else.” Participant 12 stated that “health care under the Affordable Care Act would not be an issue if it were a White, Republican president who drafted it first.” This same participant also stated that “if more minorities and underprivileged people were not helped under the act, they believed there would not be so much debate about it.” Participant 4 stated, “Can any services be added to or taken away from my baby’s health care with the Affordable Care Act? Because, I don’t need no more surprises.” The

participant was concerned about losing a benefit received for the participant's child.

Participants 1, 2, 5, 7, 9, 10, and 11 only stated that their child had no services added or removed, without adding further dialogue.

### **Categorizing and Developing Themes**

Four relevant themes emerged during the interview process. The first theme was about the general knowledge of the ACA and access to health care; generally all participants were aware of this general knowledge. The second theme was about affordability: participants frequently used this word or discussed who decided what was affordable and for whom. The third theme was how the chronically ill child's health is managed throughout adulthood: several participants mentioned this concern even after the child turns 27 (the ACA guarantees coverage up until the age of 26). The fourth theme regarded political views: political views appeared to overshadow what was needed in health care when deciding on health care policies.

**Access to health care.** I validated this theme by analyzing it with all participants through the NVivo software and by manually analyzing the data. This validation allowed me to see that 100% of participants stated they believed the ACA was designed to provide access to health care, regardless of preconditions; however, 40% of participants believed access to knowledge of the ACA was not readily available for those who care for chronically ill children.

**Affordability: Gross income versus net income.** Participants 1, 3, 4, and 12 mentioned that because they do not have access to their gross income, it is unfair for it to be considered when discerning what is affordable for most households about health care.

Participant 1 cited, “There are other obligations in the household including four other children and a chronically ill spouse, so to use gross income is negligent to the needs of the average American household.” Participant 12 stated that, “If the net income is considered, policymakers in southern state should know that the average household in this state does not make a six-figure income, so consider what is affordable to those who make much less.” Participant 12 also “did not understand how America was the richest country in the world, yet residents have to pay for health insurance while other countries in the world have free health care.”

**Taking care of the chronically ill child who may become a chronically ill adult.** Participants 10 and 12 mentioned addressing mental-illness issues themselves as an adult or with a spouse. Their concerns were whether their children who have mental illness would be covered through the same health care into adulthood. Participant 12 mentioned concern for the child, with one political party having more seats than the other in Congress. Because of the nature of this study, I could not and did not provide my political party preference; however, I did allow participants to elaborate on their concerns for their child’s health care into adulthood. It appeared that most participants were comfortable speaking about it, whereas four participants seemed to become tense the more it was discussed.

### **Why Politics Appear to Overshadow Decisions in Health Care**

Participant 11 stated, “It seems like the public officials be in their feelings about laws when it comes to helping people.” Participant 12 stated, “Because most of them are millionaires, they will never understand what we go through just to stay healthy.” Most

participants did not go into detail about politics; however, Participants 1, 6, 11, and 12 believed that politics played a major role in the decision-making processes regarding health care and felt this politically based decision-making is unfair to children diagnosed with the chronic illnesses.

### **Discrepant Cases and Nonconforming Data**

Based on interviews with the 12 participants, at least two discrepant case arose, with Participants 3 and 6 presenting nonconforming data. These participants did not know the ACA was the same as Obamacare, nor were they familiar with what the act entailed. All participants were familiar with needs for health care. When the topic was what policymakers should consider when drafting health care policies, Participant 1 voluntarily shared that her four children and spouse all had chronic illnesses that needed sufficient health care.

All participants appeared sincere about the need for their southern state's government to provide health care for low-income households, but Participant 12 appeared to be knowledgeable of health care under the ACA more than the other 11 participants. This participant had current knowledge of the changes in government and education through cable television, whereas some participants mentioned they did not know much about the ACA because they do not watch television, have cable, or have access to the World Wide Web. Participant 1, who was knowledgeable about the act, stated, "I am scared to work more hours because I don't want to lose my health insurance." This participant, as well as Participants 4 and 6, stated that if they make more money, they will lose certain benefits from the government such as food stamps and low-

income housing vouchers. Living in low-income apartments or with family members was the only way Participant 1 could provide for the family with health care and Supplementary Nutrition Assistance Program benefits. Participants 1 and 6 voluntarily shared they work as registered nurses part time, only to ensure health care would be affordable for all of their household dependents.

### **Summary**

Chapter 4 included the findings of 12 participants who receive health care under the ACA, reside in southern state, and care for children who have been diagnosed with chronic illnesses. The results of this study provide substantial insight into the central research question: How do parents with chronically ill children in the Southern state perceive their experiences with the ACA? Major themes that emerged were access to health care, affordability, gross income versus net income, caring for the chronically ill child who may become a chronically ill adult, and why politics appears to overshadow decisions in health care. Participant interviews were conducted face-to-face or online, were audio recorded through technology, and were saved on a password-protected hard drive. The interviews revealed a variety of opportunities for forthcoming research, presented in Chapter 5.

## Chapter 5: Discussion, Conclusions, and Recommendations

According to Kantarjian, Steensma, and Light (2014), the ACA may save 90,000 lives per year. According to findings in the current study, low-income One southern state participants may not be very knowledgeable about the ACA and may have no direct access to knowledge about one southern state's health care and the ACA. The purpose of this phenomenographic study was to gain greater insight and knowledge about how the implementation of the ACA affects parents with chronically ill children in the Southern state. Although every experience is unique, similarities emerged in participants' perspectives regarding affordability, access to health care, and politics. Many participants mentioned the stress they experience in caring for their child, whereas other participants mentioned the stress they experience when they hear about health care in southern state or the United States. In addition, many participants mentioned they experienced stressed and concern about their children losing health care benefits as they become adults, which could hinder them from being able to take care of themselves.

One southern state policymakers may gain insight and knowledge from this study and intervene with health care providers to provide fair, sufficient, and adequate health care for every citizen with chronic illnesses, regardless of income, background, or political party. I evaluate the results of this study, discussed in this chapter, to provide suggestions for this southern state's policymakers in their decision-making processes for health care for chronically ill children. Further, policymakers may glean information from this study when determining whether they should consider Medicaid expansion as an aid to families with low incomes who need health care.

All participants believed the ACA was designed to assist people with affordable health care. However, all mentioned income and other children in the household they believed were not considered when drafting health care policies, and especially policies for children with chronic illnesses. Participants were concerned that public officials did not understand how the average state's residents' household income is disbursed. Further, participants were concerned that political figures allowed their political parties to be in the forefront of their decision-making, rather than the needs of impoverished families, when making decisions about health care supplements. Data indicated that all but two participants saw no personal benefits, such as a change in prescription costs, in their child's health care packages, following the enactment of the ACA; those who did see the benefit mentioned they believed the act should not be eliminated but modified to assist all families.

One of the most significant findings in the data came from Participants 1, 6, and 12, who discussed being unemployed. These participants were told that because they had no income, they could not receive health care under the health care marketplace and to apply for Medicaid instead. When these applicants applied for Medicaid, they received health care for their children but not for themselves. Participants were concerned with addressing the stresses of caring for their chronically ill children and possibly becoming sick themselves, which would not be beneficial for the child's care. They worried that they might become sick and unable to care for the themselves, the chronically ill child, or other children in their home. In the following sections, I examine study results in the context of the literature examined in Chapter 2.

### **Interpretation of the Findings**

The four themes that emerged from the coding process reflected how the 12 participants described their experiences with the ACA: (a) general knowledge of the ACA and access to health care, (b) affordability, (c) health care as the chronically ill child reaches adulthood, and (d) the impact of politics on the provision of sufficient health care. This study focused on how the participants perceived their experiences with the ACA while caring for a chronically ill child. Participants reported their experiences by expressing how they valued health care as a whole in the Southern state and the practices undertaken to ensure that children up until the age of 26 have health care coverage, without regard to preexisting conditions.

Interpretation of findings for participants' experiences with health care was in alignment with literature reviewed in Chapter 2. Also in alignment was Argyris's (1970) intervention theory, which I used to address intervention methods by one southern state's policymakers, health care as a social safety net for the public, health care access, health care equity, and Medicaid expansion. Because such a marked division exists on views of health care among those who may be labeled as impoverished and those considered affluent, in this study, I only included individuals falling between 150 and 300% of FPL, aligned with the health care marketplace income requirement.

The 12 participants in this study discussed their experiences and perceptions about health care following enactment of the ACA and the health care they receive under this act. Participants 2 and 11 remembered experiencing a reduction in prescription costs; the remaining participants cited no changes in services added or taken away from their



health care plan compared to prior to the enactment of the ACA. Six participants mentioned that politics was a factor in health care policymaking, whereas the other six participants mentioned consideration of income and the accessibility of health care knowledge as obsolete. The 12 participants were all working adults who decided to use health care under the health care marketplace because health care provided by their employer, if available, was too expensive.

Participant 1, who has multiple children diagnosed with chronic illnesses, reflected on the discussion of the ACA when former President Barack Obama was in office. This participant noted the satisfaction received when thinking about lowering costs for health care for the entire family. Following ACA enactment, this participant expressed great disappointment when one southern state's governor and other public officials who make decisions on expanding Medicaid did not adopt the idea of Medicaid expansion. By not adopting Medicaid expansion, this participant was left to pay more out-of-pocket expenses and to decide between paying for food or paying for prescriptions for chronically ill children.

The inequity of health care can place a strain on impoverished people when needed financial resources are not accessible (Ballotpedia, 2017). Participant 2 received health care following the ACA after paying money considered expensive through her employer's health care plan. This participant stated that the monthly amount deducted from her paycheck was not costly, but the deductibles were financially challenging. Participant 2 was born and raised in the southern state's Delta region and recalled that many specialists needed for her child's care had offices at least 100 miles away. Due to

transportation issues, the participant's child had missed appointments and prescriptions were not filled on time. With missed prescriptions, the child suffered in school and the participant would have to stay home with the child most days because the school was unable to receive a child who had to obtain so much medical attention throughout the day.

This participant mentioned that she understood the intent of the ACA but wished it would have included modifications to health care where caregivers could receive transportation assistance that is financially satisfied through health care plans, specifically for those with chronically ill children. As Grant et al. (2016) noted, one southern state ranks as the poorest state in the United States and has a significant number of parents who care for chronically ill children with little or no income. Obtaining transportation is critical for appropriate access to health care services. Grant et al. also noted that economically vulnerable children experience health disparities, including higher occurrences of acute and chronic conditions, higher mortality rates, and difficulty accessing services.

Participant 3's responses aligned with research by Steenhuisen (2013), who noted that one southern state's governor rejecting the Medicaid expansion, turned down an estimated \$426 million in federal funds for 2014. This participant noted that although the household was a two-income household, the parents still struggled to care for a child with a severe chronic illness. The child received no changes in health care services, but the child without a chronic illness was neglected in some ways because so much time and energy had to be given to the chronically ill child. This participant also desired programs

for siblings of chronically ill children that could be supported by local community centers or programs that focus on their needs, or help for parents at home to care for their chronically ill child.

Participant 4 must address health care services for a chronically ill spouse who is over the age of 26 and a chronically ill child. This participant's response aligned with the findings of Trish et al. (2016), who noted that the coverage gap affects most adults, as they could still face large out-of-pocket burdens. As the participant mentioned, having little income while having to take care of other financial obligations, such as utilities and food, the costs for health care rates under \$20 per month could still be unaffordable. This participant noted the family already lived in a neighborhood with high crime rates and the children attended a low-ranking school district, which added to a sense of guilt for having to survive under such conditions; now, the costs of health care had become an additional burden for the family. Although the participant was over the age of 21, medical care was not accessible to the family because the participant's household income was said to be over the amount needed to receive state-assisted health care, causing them to postpone their own medical care because of costs. This response aligns with the study by Garfield et al. (2014), who specified that the result of not expanding Medicaid may cause individuals who become ill to postpone medical care because of costs.

Participant 5 has a career in the medical field and received information on changes in health care often. This participant has a child with a chronic illness and was elaborate in detailed knowledge of the ACA and its purpose. This participant not only cared for a chronically ill child, but shared experiences with others who had been caring

for a chronically ill child. To focus the interview on the participant's experiences, I asked how the experiences of those caregivers differed from her own. The only difference the participant discern after the enactment of the ACA was that access to knowledge of health care was different due to the participant's career choice. This participant showed concern about the accessibility of health care under the ACA for those who lived in rural southern state regions. This participant's responses align with Scal (2016), who noted that too many adolescents and young adults already have chronic illnesses and are not receiving the medical care they need.

Participant 6 had not addressed having a chronically ill child until an illness fell on the child suddenly. Previous to that experience, the participant had not noted health care changes, nor did Participant 6 realize the effects of one southern state's government not expanding Medicaid. However, after the child became ill, this participant discussed the decrease in prescription costs following the ACA and the willingness of health officials to find health care supplements to aid in the care for her child. However, the participant also noted that health care was based on gross income and not a person's net income. The participant held concern about the child growing into their adult years. In a study conducted by Campbell et al. (2014), the authors opined that investing in a child's health could improve their lives in the school-age years and could also yielding adults with good health.

Participant 7 was very clear about understanding of the ACA, but was unaware that the ACA and Obamacare were the same. This participant believed insurance was designed under the ACA to assist low-income families needing health care but, like other

participants, cited that gross income should not be considered when designing individual health care plans. This participant also mentioned that information about the ACA was not prevalent; for example, in their children's health care provider's office, no literature was readily available for caregivers to gain more knowledge. Following the ACA, this participant had to make a change in health care providers for her child because the provider no longer accepted Medicaid or any provider under the health care marketplaces. Fedele et al. (2010) held concern for the well-being of the caregiver of chronically ill children; similarly, this was also a concern of Participant 7. This participant's responses also aligned with Cousino and Hazen's (2013) research about how, with escalation of chronic illnesses in children, "parenting stress should be targeted for future intervention and specific measures should be used for future studies" (p.809).

Participant 8 mentioned that the school the child attends was not supportive with her child's chronic illness for assignments missed if the child was hospitalized for extended periods of time. This was the only participant who noted academics as an issue pertaining to caring for a chronically ill child. When asked about services being taken away or added to their health care plan, the participant stated that overall, they had not experienced a great change; however, Participant 8 suggested decision-making officials mandate programs or plans to assist caregivers with chronically ill children so the child will not have to repeat a grade. One southern state abides by federal laws such as requirements for Free Appropriate Public Education and the Individuals and Disabilities Education Act (U.S. Department of Education, 2010), that support parents who are caregivers of chronically ill children. Accessibility to the rights of this participant

regarding education appeared to be unavailable at her child's school, so in the debriefing process of the interview, I suggested she present both acts to her child's school principal. Teachers are obligated to have lessons available and accessible to children with chronic illnesses.

Participant 9 is a traveling nurse with several children, one with a chronic illness. The participant mentioned it is difficult to travel for a job and take care of a family with a chronically ill child. Access to health care providers under their network when out of one southern state seemed challenging and the ability to travel with a chronically ill child altogether was demanding. This participant knew about the ACA, was unaware that Obamacare and the ACA were the same, and believed that politics played a role in decision-making processes when legislators make health care policies. Participant 9 noted, like Herrmann et al. (2015), that medical education must be readily available about the ACA and physicians must be clear on the impact, development, intervention processes, and ability to translate their knowledge to their patients.

Participant 10 was unaware of benefits tied to the ACA but was aware of the purpose of the act and what low-income households could gain. This participant also believed it to be unfair to use gross income rather than net income to decide what health care a family could receive. Out-of-pocket expenses were costly to obtain the medicines the health care provider considered best for the child. Prescriptions covered by Medicaid or health care under the marketplaces appeared to be of low quality and less effective, but affordable. This participant also believed race was a factor and stated, "it seems Black folks are always having to suffer and fight for our kids when everybody else get what

they need.” I asked what the participant thought public officials considered least when drafting health care policies. The participant’s response was in alignment with findings from a Garfield et al. (2014) study, which showed that “those states that decided not to expand Medicaid disproportionately affected those people of color.”

Participant 11 recalled the child’s desire to participate in sports but was unable to participate due to the chronic illness. This participant found it stressful to see the child deal with the illness, but equally stressful for the participant to deal with the child not being as social as other children for fear of experiencing negative symptoms or episodes from the chronic illness. When I asked the participant what should be considered when drafting health care policies, like other participants, a major issue was about how the child would manage their health care as an adulthood. This participant mentioned not wanting the child to grow up as an adult who continued to be unable to participate in sports or other physical activities due to lacking certain treatments, forms of therapy, or prescriptions that were unaffordable. Keller and Chamberlain (2014) noted that, “Although the ACA may improve access to health care and health care quality, this enactment was not designed with the needs of children in mind and will need to be adapted to address these needs” (para. 1). This participant’s response collaborated with Keller and Chamberlain study, which extending concern to the child health care quality being more equitable in the adult years.

Participant 12 was quite familiar with the ACA, why it was designed, and the benefits received while receiving health care following its enactment. This participant did, however, note that because the U.S. Supreme Court upheld this enactment,

modifications should come about regarding health care management into adulthood with mental health at the forefront in health policymaking for all ages, and a separation of politics from decision-making processes. The participant averred preventative measures for specific illnesses are important, such as counseling or support services for adults caring for children with chronic illnesses. These measures should be prioritized when health insurance companies decide which medical services and prescriptions they will cover. Findings from a 2012 study conducted by members of the American Public Health Association aligned with this participant's response, stating that only 3 cents of each health care dollar is spent on prevention. The participant mentioned increased stress as a single parent caring for a child with a chronic illness and believed some policymakers failed to include single parents in their decision-making. Single parents caring for a chronically ill child should be more at the forefront of policymakers' views. This participant stated that instead of policymakers looking at what is in their own bank accounts, they should consider those who were not presented with the same opportunities to live affluent lifestyles and recalculate what they believe to be affordable.

### **Limitations of the Study**

Some limitations emerged while pursuing this study. One limitation a parent unexpectedly mentioning having a child with a chronic illness who, after battling with the illness for 5 years, passed away. Participant 8 insisted on speaking about the matter; I steered the conversation to the living child who was diagnosed with a chronic illness to avoid a vulnerable or stressful setting. The exclusion of participants who were receiving insurance through their employer presented another limitation because during the



recruitment process, some potential participants e-mailed me to be a part of the study. When I assessed their credentials to be a valid participant, it appeared they did not fall under the guidelines to be a recipient of health care provided under the ACA. Finally, bias arose in the interviews as participants described their political beliefs and positions related to race. Nevertheless, to maintain a credible study, I steered the interviews toward the topic at hand. All anticipated limitations were mitigated.

### **Recommendations**

I have several recommendations for action and future study, based on this study's findings. These recommendations require policymakers, health insurance providers, and health care providers to recognize that parents who are caregivers for chronically ill children have different needs from those of parents with children who are considered "healthy." In support of health care policies, policymakers must gain greater understanding of lower income families and intervene in the lives of constituents. These families must maintain households with food and utilities and may have to cater to the additional needs and expenses of chronically ill children in areas such as transportation, at-home medical equipment, or prescriptions that may not be covered under their health care. I believe that by expanding Medicaid in southern state, costs for prescriptions or other health-related resources would be more accessible and many parents would experience less stress when caring for their chronically ill children. Politics should not be a factor when drafting policies for the sake of human life.

Participant 1 recommended that when seeking government assistance for health care, net income should be considered rather than gross income because gross income

does not reflect available funds. This participant believed it unfair to base government assistance allowed on income that is only seen and not touched. When policymakers draft health care laws, Participant 1 thought they should consider that chronically ill children will one day be chronically ill adults and should be confident that their health will be properly managed throughout their lives to become committed, tax-paying citizens. This participant would consider migrating to a state where Medicaid was expanded to provide better health care for her child. If a major goal for this act is to “improve access to affordable health coverage for everyone and protect consumers from abusive insurance consumer practice” (White House, 2015, para. 2), then the accessibility of knowledge of this act could be more apparent in health care facilities and even local businesses to educate health care recipients.

I recommend that this southern state and its policymakers gain the same momentum for providing health care policies, expanding Medicaid, and providing knowledge about changes in health care that they gain during election seasons. Health care policies are not addressed such that affluent and less affluent people are equally aware of the benefits of the ACA. Public officials should engage with families to establish a sense of obligation without prejudice when deciding on health care policies. Additionally, public officials should distribute resources to constituents without constituents having to rely on the Internet to learn about modifications to health care.

Health care providers take the Hippocratic Oath to treat those who are ill to the best of their ability (Shiel, 2018). In treating these patients, the responsibility of sharing the knowledge of health care options should also be an obligation of medical staff.

Medical staff can share medical knowledge with monitors set up throughout the medical facility that constantly share information about medical and health care. Just as billing and intake processes are priorities, so should health care options be a priority with regards to prescriptions, surgeries, treatments, and management.

Regardless of one's choice of political party, health care policies should be decided with a nonpartisan mindset. Votes or decisions made on health care policies should be motivated by the needs of families and not by the political opinion of decision-makers. Personal biases that outweigh the benefits of good health care can prevent the appropriate treatment of children with chronic illnesses. Moreover, transportation costs should be covered through health insurance. This southern state's insurance commissioner, top medical administrators, and state public officials should intervene by collaborating and formulating a think tank to draft a holistic plan in health care management, accessibility, equity, and affordability for the care of chronically ill children and adults.

Study participants did not mention if they were registered voters, but Participants 6, 11, and 12 mentioned they believed public officials think more about their own financial stance than the income of the average or low-income constituents when making decisions. Participants expressed a disconnection in communication with their local leaders and somewhat of a similar disconnection with their medical providers regarding health care. Following this research and discussions with participants, all agreed this southern state should adopt Medicaid expansion as it is one of the most impoverished states in the nation.

Researchers could consider further and more thorough studies on single parents who care for children diagnosed with chronic or catastrophic illnesses who fall into the coverage gap following the enactment of the ACA. Those who fall below the FPL should be covered under policies that are realistic, aligned with their incomes and lifestyles. Future researchers should consider analyzing the levels of stress people can encounter while parenting and providing care for chronically ill children and resources that are available to support them mentally, socially, and physically. Although some researchers included information about parents' support and coping skills, future researchers should explore the impact, perceptions, and lived experiences of siblings of chronically ill children who receive caregiving efforts from their parents. I recommend research on support efforts, resources to manage their own emotions while witnessing caregiving efforts, and the social attitudes of these children. I also recommended study to discern if geographic location is a factor that contributes to a knowledge gap between medical providers, state policymakers, and health care recipients. Last, researchers who analyze income in this southern state should examine the monies distributed by the Social Security Administration, their decision-making practices when deciding the amount for each family who files a claim for disability, and what the deciding factors are for granting or denying benefits for those caregivers who care for children with chronic illnesses.

### **Implications**

A variety of implications developed from this research. First, through this study, I revealed that the social safety net designed to help those families that are impoverished would provide better health care had Medicaid been expanded in this southern state.

Moreover, if Medicaid had been expanded, families would have more and higher quality prescriptions and medical services when caring for chronically ill children. By opting out of expanding Medicaid, nationally, at least 3.6 million fewer individuals would be insured, and by 2016, state spending and uncompensated care would increase by \$1 billion (Price & Eibner, 2013). One southern state, according to Tavernise and Gebeloff (2013), has the largest percentage of poor and uninsured people in the country.

In the United States, some poorer citizens earn more than the level designated for poverty and are not considered for free or affordable health care. The ACA should be modified to assist those without health care to receive some sort of assistance rather than being told they have too much or too little income for government or state subsidies. Members of the federal government spent millions of dollars on the enforcement of state seatbelt laws (Houston & Richardson, 2005), but took millions of dollars away from health care (Tavernise & Gebeloff, 2013) when they both save lives.

Regardless of background or political beliefs, public officials should be catalysts for social change when it comes to the health and well-being of all the American people. Parents rely on crucial health care benefits provided for children and should be knowledgeable of all benefits accessible to them. Not only is accessibility priority, but the equity of the health care and knowledge of are equally imperative. Health care should be a certainty and not a concern for any constituent in this southern state. It is critical that those who make the decisions on health care policies should not be contributors to children having escalated lifelong challenges; rather, they should ensure children get the needed services for their diagnoses or prescriptions for health care management. A

reduction in uninsured pediatric residents in this southern state may ensue if policymakers do not mitigate the knowledge gap but instead work to educate the public about what is accessible for health care. I believe that missed appointments for chronically ill children and their prescriptions being left unfilled would decrease with greater accessibility to health insurance. Members of the government, nationally and statewide, should stand with all Americans in need of health care, rather than turning their backs on those in need.

### **Conclusion**

Findings from this study provided perceptions and experiences of parents who care for chronically ill children, following the enactment of the ACA. The study added new knowledge to a body of literature as it included information about how the ACA affects parents who have chronically ill children, who may experience limited health care. This study's findings showed that policymakers should reconsider income as a deciding factor for the type of insurance parents can receive for their children. Furthermore, research findings displayed how this southern state's governor, by opting out of expanding Medicaid in the state, caused parents to suffer by not being able to get adequate health care for their chronically ill children.

Data from participant interviews indicated significant issues of equity and accessibility in health care marketplaces and inconsistencies in the ACA regarding to whom health care is accessible. Policymakers' failure to communicate with and be accessible to constituents in this southern state also appeared to be capricious, as most participants were unable to reach public leaders in their areas. Policymakers should

consider how to eliminate the coverage gap, nationally and statewide. Moreover, to ensure that chronically ill children receive the coverage they need, expanding Medicaid could decrease the numbers of those who receive limited services and improve those services already provided to them. In many cases when considering participants' interview responses, Medicaid and the health care marketplaces under the ACA are the only safeguards they have. Physicians and policymakers alike, if they consistently intervene regarding health care policies, could have an equitable impact. If Medicaid was expanded in this southern state, and with minimal modifications to the ACA, health care could be accessible to all individuals, regardless of preexisting conditions, so caregivers of chronically ill children would not have to stress about affordable health care.

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## Appendix A: Ethical Certificate

## Certificate of Completion

The National Institutes of Health (NIH) Office of Extramural Research certifies that Kimberly Bracey successfully completed the NIH Web-based training course, “Protecting Human Research Participants”

Date of completion: 09/14/2013

Certification Number: 1267579

## Appendix B: Initial Contact Message and Criteria

To Whom It May Concern:

My name is Kimberly V. Bracey, and I am a Walden University doctoral candidate living in a central southern state. I am in search of research participants. I would like the assistance of parents caring for children with chronic illnesses in the southern state. To participate in this study, you must meet the following criteria:

Be a parent caring for a chronically ill child;  
Be a parent receiving state assistance (CHIP or Medicaid) for a chronically ill child;  
Must be willing to use a prescribed pseudonym for confidentiality and anonymity'  
Must be willing to schedule a 30 minute interview with the researcher;  
Must be willing to meet with the researcher at least twice, within a 30-day period, for a scheduled 30 minute face-to-face interview in a private room at the local public library, in a designated private conference room at the center, or an electronic interview using a telecommunication application for video chat (Skype, Facebook Messenger, ...), and for a potential 30-minute follow-up interview to discuss and clear up any discrepancies or confusion from the interview transcript, based on your responses to the interview questions.

If you meet the criteria and are interested in assisting me with this study, please contact me via email at [REDACTED] Thank you for your consideration.

Sincerely,

Kimberly V. Bracey  
Walden University Doctoral Student

## Appendix C: Letter of Cooperation from Community Partner

[REDACTED]

[REDACTED]

April 22, 2018

Dear Kimberly V. Bracey,

Based on my review of your research proposal, I give permission for you to conduct the study entitled Implementation of the Affordable Care Act and the Experiences of Parents with Chronically Ill Children within the [REDACTED]. As part of this study, I authorize you to randomly recruit 12 participants from a list of clients who will remain anonymous. You will explore the experiences and perceptions of those participants obtaining health care [REDACTED] for children with chronic illnesses, while investigating if a limited amount of treatment is available for any recipient of state-mandated or non-state-mandated insurance since the implementation of the ACA. Individuals' participation will be voluntary and at their own discretion.

I understand that the student will not be naming our organization in the doctoral project report that is published in ProQuest.

I confirm that I am authorized to approve research in this setting and that this plan complies with the organization's policies.

I understand that the data collected will remain entirely confidential and may not be provided to anyone outside of the student's supervising faculty/staff without permission from the Walden University IRB.

### Appendix D: Interview Questions

The researcher will ask participants the following questions to collect data pertaining to their Affordable Care Act of 2010 experiences when getting health care for children who are chronically ill.

1. What do you believe the enactment of the Affordable Care Act was designed to do for those who receive health care?
2. Since the enactment of the Affordable Care Act, what changes have you seen in any out-of-pocket expenses for your child who has been diagnosed with a chronic illness?
3. Based on your experiences and perception, what do you believe is the least considered when public officials decide on health care policies?
4. Based on your experience and perception, what do you believe should be considered when public officials are drafting health care policies relative to children with chronic illnesses?

Since the enactment of the Affordable Care Act, were there any medical services added or taken away from the services provided for your chronically ill child? If services were added or taken away, please explain what those services were and what has been the effect of that service being either added or taken away.

## Appendix E: Debriefing Document

The researcher designed this document to provide participants with resources that may assist them, if they need someone to communicate with, before, during and after the study. It is understandable and normal for participants to experience levels of discomfort, which might cause undue stress. As the researcher for this study, it is my goal to keep your (participant) identity confidential, protect your anonymity, and to alleviate as much stress as possible, potentially caused by the study, as to not cause harm to you, the participant. Below is a list of resources and referrals for you to access, if you need assistance. You can also contact me by e-mail at [REDACTED]

### **Resources**

The National Organizations with Support Groups in [REDACTED] at [REDACTED] includes a large amount of helpful resources: - resources from the website are as follows:

#### **One southern state Agencies & Advocacy Organizations**

##### **State CHIP Program**

(health care for low-income uninsured children)

One southern state Health Benefits

Division of Medicaid

[REDACTED]

##### **Coalition for Citizens with Disabilities**

[REDACTED]

##### **EMPOWER Community Parent Resource Center**

[REDACTED]

**F.A.C.T.S.  
Families Advocating Collaborating Teaching and Supporting for  
Children's Mental Health, Inc.**

[REDACTED]

**First Steps Early Intervention System (children 3 and under)  
One [REDACTED] State Department of Health (MSDH)**

[REDACTED]

**One [REDACTED] Parent Training and Information Center**

[REDACTED]

**Parents for Public Schools of [REDACTED]**

[REDACTED]

Parent Teacher Association (PTA)

[REDACTED]

Parents United Together (PUT)

[REDACTED]

**Programs for Children with Special Health Care Needs**

Children's Medical Program

Board of Health

[REDACTED]

One [REDACTED] Protection and Advocacy System, Inc.

[REDACTED]

**Special Kids Family Network**

Family YMCA

[REDACTED]

One [REDACTED] Support Groups

The Arc of Lowndes County

Norma Jones or Leslie Junkin



#### Online Support Communities

[wrightslaw.com](http://wrightslaw.com) --- Wrightslaw provides reliable information for parents, educators, and advocates about special education law, education law, and advocacy for children with disabilities.

[yellowpagesforkids.com/help/ms.htm](http://yellowpagesforkids.com/help/ms.htm) --- Find educational consultants, psychologists, educational diagnosticians, health care providers, academic therapists, tutors, speech language therapists, occupational therapists, coaches, advocates, and attorneys for children with disabilities on the Yellow Pages for Kids. You will also find special education schools, learning centers, treatment programs, parent groups, respite care, community centers, grassroots organizations, and government programs for children with disabilities.

#### Parents United Together (PUT)

[parentsunitedtogether.com](http://parentsunitedtogether.com)

#### Quitman P.A.W.S. (Parent Advocates Working for Solutions)

[health.groups.yahoo.com/group/ms\\_paws\\_and\\_puzzles](http://health.groups.yahoo.com/group/ms_paws_and_puzzles)

Quitman PAWS is a parent-run and parent sponsored support group for special needs children and their families and caregivers in the Quitman, MS school district. The Mission of PAWS is to provide awareness, advocacy and education to those serving and caring for our special kids.



## Appendix F: Emailed Statement from Kaiser Family Foundation Granting Permission for

## Resource Citation

From: Kimberly Jones  
 Date: Wednesday, March 16, 2016  
 Subject: RE: Kaiser Family Foundation Question/Comment  
 To: Kanani Kauka  
 Awesome-thanks!  
 On Tuesday, March 15, 2016  
 Hello. Thank you for your query.  
 As long as you follow the reprint and citation guidelines here: <http://kff.org/cite-and-reprintkff/>,  
 consider permission granted.  
 Please let me know if you have questions.

---

Kanani Kauka | Web Development and Production Associate  
 KAISER FAMILY FOUNDATION | MENLO PARK, CA

Have you seen our latest animation? *Health Insurance Explained: The YouToons Have it Covered*

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From: KFF Contact Us [<mailto:no-reply@wufoo.com>]

Sent: Friday, March 11, 2016 2:16 PM

To: Kaiser Family Foundation Help

Subject: Kaiser Family Foundation Question/Comment

Full name \* Kimberly V. Bracey

Choose one \* Reprinting or Citing KFF Work

Enter your question or comment

below. \*

Hello- I am a doctoral student that's performing a study on the Affordable Care Act and Single-Parent Caregivers of One southern state Children with Leukemia. There are several of your figures that are relevant for my study and I wanted to know if I could gain permission to use them? Thank you in advance for your time.  
 Sincerely, Kimberly V. Bracey