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# Accessibility to Health Care Services for Children with Autism Spectrum Disorders

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Walden University
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Abstract

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Dissertation Submitted in Partial Fulfillment

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# Abstract

The study was an investigation into health care accessibility for children with autism spectrum disorder (ASD) following the transition to a private Medicaid system in the state of Florida. Pilot studies of managed Medicaid programs focused on costs and did not address how changes to the system impacted access to health care services. There were limited studies designed to understand how a change in the system, such as a privatization, would affect vulnerable populations such as young children with ASD. Additional concerns existed for children that were historically underserved by the health care system such as African American and Latino children because they typically had more difficulty accessing health care services in general. A modified version of the Consumer Assessment of Health Providers and System (CAHPS) Survey 4.0 was used in this study. The modifications to the survey included reducing the number of survey questions and adding open-ended questions. 86 participants were recruited from local organizations that supported children and families affected by ASD. Findings generated using nonparametric tests such as the Mann-Whitney U test and chi-square revealed delays in accessing therapeutic health care services that were pervasive in both private and public insurance groups. Furthermore, the qualitative analysis indicated that participants did not view their difficulties in accessing therapeutic health care services as related to race or ethnicity. Limitations of the study included the modifications made to the survey instrument. Implications for positive social change include a better understanding of the scope of the issue of therapeutic health care access for those advocating on behalf of children and families affected by autism.

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# Dedication

I wish to dedicate this study to all the caregivers who took time out of their busy schedules to document their daily struggles accessing health care for their children with autism.

# Acknowledgments

I would like to acknowledge my husband, family, and friends for all of the support that they provided and the sacrifices that they made so that I could complete this doctoral journey. I couldn't have done this without you. Additionally, I would like to acknowledge my committee for the guidance and support that they provided along the way.

Table of Contents

## List of Tables

# List of Figures

# Chapter 1: Introduction to the Study

## Introduction

Individuals affected by autism spectrum disorder (ASD) experience delays in social development and communication along with repetitive behaviors and interests (American Psychiatric Association [APA], 2013). In 2012, the United Nations estimated the global prevalence of ASD to be 62 cases per 10,000 births (Lin & Stella, 2015). The Maternal and Child Health Bureau (MCHB) defined Children with Special Health care Needs (CSHCN) as a child at risk of developing chronic conditions that require more health-related services than a typically developing child (Lin & Stella, 2015). Children with ASD are a unique subset of the CSHCN population with unmet health care needs. The ASD subset of the CSHCN population within the United States has unmet health care needs because they have historically had more difficulty accessing health care services (Chiri & Warfield, 2012). Children from diverse ethnic backgrounds who are historically underserved by the health care system are at an even greater risk for experiencing unmet health care needs (Lin & Stella, 2015).

The rising costs of health care in the United States have had particular significance for researchers and policymakers studying the unmet health care needs of individuals with ASD. Becerra et al. (2017) estimated that the cost of caring for all individuals with autism was $61 billion dollars per year. Of particular concern to those working with individuals affected by autism is the need to ensure access to a therapeutic intervention such as applied behavior analysis (ABA) early on in the child’s development. ABA is typically provided intensively until 3 years after birth (Jaffee, 2011). Becerra et al. (2017) found that 90.8% of the parent participants of children affected by ASD participating in a research study perceived ABA therapy to be beneficial to their child. Behavior therapy was highly desired by parents of young children with autism but very expensive.

ABA is a therapeutic intervention that significantly increases the cost of providing care for young children with ASD, and much of that burden of cost rests with the family and the community because private insurance companies have historically limited coverage of ABA (Hoffman, 2011). The health care industry takes the position that ABA is not medically necessary, and this ongoing debate over whether therapeutic interventions such as ABA are medically or educationally necessary and who is ultimately responsible for funding therapeutic interventions has resulted in considerable problems accessing health care services for young children with autism (Hoffman, 2011; Jaffee, 2013). Subsequently, the greatest unmet health care needs of children with ASD are consistently reported to be in the area of behavioral therapy (Farmer et al., 2014). Behavior therapy has positive effects on learning when implemented early on in the child's development (Jaffee, 2013).

As a result of the effectiveness of ABA, many families have transitioned their children to Medicaid programs so that the child's insurance provider is responsible for covering the cost of therapeutic interventions (Jaffee, 2013). Many of the children making the transition to Medicaid have private insurance, but they are unable to gain access to therapy despite having this type of coverage (Jaffee, 2013). Children most likely to transition to Medicaid are those with the most severe symptomology because

Medicaid is the largest provider of long-term services and supports for individuals with developmental disabilities such as autism (Merryman, Miller, Shockley, Eskow, & Chasson, 2015). State-run Medicaid programs are then responsible for providing the health insurance coverage and special education services to a growing number of individuals with more severe symptomology (Merryman et al., 2015). The burden of paying for health care services shifts from the private insurance company to that of state-run Medicaid programs and this impact trickles down to taxpayers in each state.

The purpose of the remainder of this chapter is to provide the reader with an understanding of what is happening at the state level to address the issue of health care accessibility as it pertains to children with ASD. The chapter includes the background, problem statement, purpose, and research questions that will guide the study. The significance and the social change implications are intended to increase awareness of the health care needs of the ASD population. A shift toward providing early intervention services to young children with ASD has the potential benefit of improving long-term outcomes for those individuals. Furthermore, it has the potential to save state governments a significant amount of money over the course of the individual's lifespan.

## Background

A lack of action at the federal level of government regarding the issue of rising health care costs results in individual states inheriting much of the increased costs of caring for children with disabilities such as ASD (Hansel, 2013). Each state has addressed the problem of rising health care costs in its own way. Some states such as Florida transitioned to using managed care systems to lower the cost of insuring low-income participants and those with disabilities (Marcu et al., 2014). A managed care system places restraints on physicians in order to manage cost. The impact of this type of change on health care accessibility for young children with ASD was unknown when the change was first implemented (Reed & Meyer, 2004). Lavelle et al. (2014) estimated that 31% of children with ASD used some form of ASD related therapy such as ABA. State governments are experiencing challenges finding an appropriate balance between managing costs and providing adequate health care services to individuals with disabilities such as ASD (Hansel, 2013; Homan, 2012).

Programs such as ABA add to the cost of providing health care coverage for children with ASD because ABA therapy requires intensive one-on-one therapy with a trained provider (Roane, Fisher, & Carr, 2016). In the court ruling Garrido v. Dudek, the state of Florida mandated the coverage of ABA for children receiving Medicaid services (Barker & Noffsinger, 2014). The presiding judge in the case ruled that ABA was a medically necessary service for children with ASD and children who qualify should have access to the service until the age of 21 (Barker & Noffsinger, 2014). ABA is considered to be an effective intervention for children with ASD, but it contributes significantly to the rising cost of health care in the ASD population (Hoffman, 2011). Medicaid programs typically offered coverage for ABA services more intensively than private insurance companies, therefore, resulting in higher cost to provide health insurance coverage to a child enrolled in a state-run Medicaid program. The increased cost of providing the services led to state experimentation with new methods for enrolling participants into the Medicaid system.

Enrollment in Medicaid typically happens in one of two ways. The first approach is the traditional method in which the state contracts directly with providers to deliver a service (Hall, Yarbrough Landry, Lemak, Boyle, & Duncan, 2014). The second approach involves a capitated arrangement with a health management organization (HMO; Hall et al., 2014). To reduce costs, states such as Florida transitioned to using a capitated arrangement with HMOs (Hall et al., 2014). Capitated arrangements pay physicians per program enrollee rather than by paying per service rendered (Ruble, Heflinger, Renfrew, & Saunders, 2005). Reed and Meyer (2004) cautioned that managed care might not provide the best level of care to vulnerable populations. Ruble, Heflinger, Renfrew, and Saunders (2005) reported significant changes in health care utilization for children with autism within a Medicaid Managed Care program. In the spring of 2014, the federal government gave the state of Florida final approval to transition all Medicaid recipients to a private Medicaid system (Hall et al., 2014). Coupled with the implementation of the ACA, this time period was full of uncertainty for children with special health care needs and their families residing in Florida.

DeVoe et al. (2015) noted health care accessibility challenges for children following the implementation of the ACA in 2010. Furthermore, the Child and Adolescent Health Measurement Initiative (2013) indicated that Florida lagged behind national averages in terms of caring for children through the use patient centered medical homes (PCMH) prior to the transition to a private Medicaid system in 2014. A PCMH model is coordinated and family centered care (Golnik, Scal, Wey & Gaillard, 2012). The PCMH model of care is often preferred by caregivers and by state governments because they provide individualized care while also reducing cost (Hall et al., 2014; Harman, Hall, Lemak, & Duncan, 2014). Despite the fact that the PCMH model is preferred by families because it provides comprehensive family centered care, physicians rarely make use of a PCMH model when caring for those with autism (Golnik et al., 2012).

One of the positive outcomes of a successful implementation of the PCMH model is an increase in the number of well-child visits for children with special needs (Willits et al., 2013). The American Academy of Pediatrics provides physicians with guidelines for well-child visits called Bright Futures. Bright Future visits offer the physician an opportunity to assess growth and development and caregivers to raise any concerns they may have about their child (American Academy of Pediatrics, 2017). Well-child visits are often disrupted by gaps in health care insurance coverage. Gaps in health care coverage were problematic for children because the result was often a loss of the primary care provider which negatively affected the child's access to well-child visits (Leininger & Levy, 2015). For every month that the child is without health insurance coverage, there is a statistically significant increase in the likelihood that the child will not have access to well-child visits (Leininger & Levy, 2015).

Well-child visits are visits to the pediatrician for routine monitoring and screening for developmental concerns including autism. Children who missed well-child visits had a higher likelihood of developing long-term health related problems that were preventable with appropriate access to health care services. Further study is needed to understand the problem of accessibility for children with ASD. Improvements in accessibility are likely to lead to improved developmental outcomes for children with ASD.

## Problem Statement

The federal government has failed to enact legislation requiring private insurance companies to provide health insurance coverage to children with ASD for therapeutic interventions (Hansel, 2013; Jaffee, 2013). Thus, the responsibility of paying for health care services and providing coverage for therapeutic interventions for the ASD population is left to each state to mandate (Johnson et al., 2014). The cost of caring for a child with ASD is seven times higher than a child who does not have the disorder (Homan, 2012). Baio et al. (2018) reported that the prevalence of ASD has yet to stabilize in the United States so the cost of caring for these individuals is of growing economic concern. Private insurance companies frequently deny coverage for treatments deemed experimental and educational, whereas public programs such as Medicaid in the state of Florida are required to pay for treatments such as ABA (Barker & Noffsinger, 2014). As a result, children enrolled in private health insurance programs are enrolling in public Medicaid programs to gain access to treatments such as ABA (Jaffee, 2013; Wang, Mandell, Lawer, Cidav, & Leslie, 2013). The movement of ASD children with private insurance coverage to state Medicaid programs causes increased financial strain at the state level (Jaffee, 2013).

Consequently, the increased costs associated with caring for individuals with disabilities has resulted in the implementation of managed care systems (Reed & Meyer, 2004). However, the effect of the transition on vulnerable populations such as young children with ASD and especially those from diverse ethnic backgrounds who use community-based services are not well documented in the literature. Ruble et al., (2015) studied the impacts of the transition to a Medicaid Managed Care system within the state of Tennessee. The results of the study indicated changes in the patterns of health care utilization for children with autism including changes in the types of services rendered and the frequency of those treatments. Marcu et al. (2014) described the findings of a two-county pilot project in the state of Florida that was used to develop an integrated care system (ICS) that would reform the state Medicaid system. The ICS addressed reducing health care costs but did not delve into the quality of care that children received after implementation of the program. Marcu, Knapp, Brown, Madden, and Wang (2016) reiterated that the Medicaid system saves money using the ICS model but still did not answer the question regarding whether the ICS system impacts access to health care services for the CSHCN population in Florida.

Children with ASD experience positive long-term outcomes when they receive intensive therapeutic interventions during the first three years of life (Jaffee, 2013; Nickel & Huang-Storms, 2017). The annual costs for therapeutic interventions in the first three years of life are estimated to range from $6,000 to $36,000 (Johnson et al., 2014). An investment by the state in young children during the critical early years of development can, however, result in a reduction in the need for specialized services such as special education and rehabilitation services as the child transitions into adulthood (Dababnah et al., 2011). Delays in diagnosis caused delays in accessing therapeutic intervention services during the early childhood years (Siller, Reyes, Hotez, Hutman, & Sigman, 2013). On average, it took an increased number of visits to medical professionals for a child from a diverse background to gain the diagnosis of ASD (Mandell et al., 2009). Delays in access to therapeutic interventions in the early years affected the long-term prognosis for children of African American and Latino descent (Durkin et al., 2010; Mandell et al., 2009). African American and Latino children with ASD were at a disadvantage as they were not able to benefit from intensive early intervention services in the first 3 years of life because their diagnosis came later than their Caucasian peers (Mandell et al., 2009).

The transition to a private Medicaid payer system is likely to cause disruptions in service accessibility for young children with ASD, especially those from diverse backgrounds (Hall et al., 2015). Individuals of African American and Latino descent historically have had difficulty accessing health care services and were likely to be the most impacted by disruptions in their coverage (Bustamante, Fang, Rizzo, & Ortega, 2009). There was a gap in the literature related to how young children were affected by the changes to insurance payers in the state of Florida, especially those from diverse racial and ethnic backgrounds.

Recent statistics from the Centers for Disease Control (CDC) related to autism prevalence indicate that surveillance efforts in diverse communities are leading to more children from Latino and African American backgrounds being diagnosed with autism (Baio et al., 2018). As a result of more children being accurately diagnosed with autism in the Latino community, there is a need to study the needs of Latino families affected by ASD because Latino families access and use health care services differently their

Caucasian counterparts (Parish, Magaña, Rose, Timberlake, & Swaine, 2012a). When compared with Caucasian families, 32% of Latino participants v. 24% of Caucasian participants reported challenges using health care services (Parish et al., 2012a).

## Purpose Statement and the Nature of the Study

Although important findings were evident from previous research regarding the necessity for early therapeutic interventions for young children with ASD, I found no research examining how transitioning from a public payer Medicaid system to a private payer system would impact access to early therapeutic interventions for young children with ASD. Given such, further research was warranted to examine the problem of health care accessibility for young children with ASD and in particular, those from diverse ethnic backgrounds.

## Mixed Methods Design

The mixed methods study addressed health care accessibility for young children and families affected by ASD. The Consumer Assessment of Health Providers and System (CAHPS) Survey 4.0 was the instrument that was modified to collect the data for this study. Additional qualitative questions were added to the original survey to provide more information about any additional accessibility challenges that may exist related to race, culture, and or ethnicity. The questions on the modified CAHPS cross-sectional survey provided participants the opportunity to respond to questions in an open-ended, as well as a close-ended format. Only questions pertaining to the research questions in this study were included in the modified version of the survey.

For the quantitative research questions, there were two dependent variables. The first dependent variable was differences in access to therapeutic interventions based on insurance type. The second dependent variable was delays associated with accessing therapeutic interventions based on insurance type. These two variables of difference in access to therapeutic interventions and delays in access are dependent variables because this study attempts to determine if the independent variable of insurance type is the agent causing changes to those two dependent variables. Differences and delays are measured through the analysis of specific items on the modified CAHPS survey. The two dependent variables of differences in accessibility and delays in accessibility each had categorical and ordinal variables. Each item on the modified CAPHS was analyzed independently to answer a specific research question. The questions were answered with both categorical and Likert scale questions. Therapeutic interventions of particular interest included ABA, speech therapy, physical therapy, and occupational therapy. The two types of insurance groups, private and public were used as the independent variable to determine if they had an impact on access to therapy or caused delays in access to therapy for young children with autism.

## Research Questions and Hypotheses

Quantitative:

*RQ1:* What are the differences in accessing therapeutic health care services for children with ASD based on insurance type?

*$H_o1$:* There are no differences in accessing therapeutic interventions for children with ASD based on insurance type.

*$H_a1$:* There are differences in accessing therapeutic interventions for children with ASD based on insurance type.

*RQ2:* What are the differences in delays reported by caregivers of children with ASD in terms of accessing therapeutic services based on insurance type?

*$H_a2$:* There will be no difference in delays in accessing therapeutic services based on insurance type.

*$H_a2$:* There will be differences in delays in accessing therapeutic services based on insurance type.

Qualitative:

*RQ3:* What are the unique challenges, if any that African American and Latino families face when accessing services for young children with ASD enrolled in a Medicaid program?

## Conceptual Framework

The conceptual framework for the project developed from components of four theories. Elements from two of the theories were used to create the structure of the literature review while elements from the remaining two theories were used to develop the methodology for the project.

The first theory that contributed to the framework of the literature review was Anderson & Aday's Behavioral Health Model (BHM). The BHM model provided a means for determining if the policies designed to increase access to health care services and increase consumer satisfaction are actually working as intended. The second theory that contributed to the development of the literature review was the social disability theory. The social disability theory helped enhance the researchers understanding of how societal barriers prevent individuals with disabilities from reaching their full potential.

The additional two components of the conceptual framework shaped the development of the methodology. Those components were the critical communications methodology (CCM) and the soft systems methodology (SSM). CCM uses adjustments in the research design to give a voice to the participants. CCM uses the participant's experience with social exclusion as a means to uncover the mechanisms that can lead to a transformation. Soft Systems Methodology (SSM) emphasizes the reality that problems are not stagnant and that systems are constantly evolving. The solutions that develop from this framework must be culturally feasible to the group that is affected by the particular problem if there is going to be a sustained impact. Typically, a knowledgeable individual such as a researcher leads the process of implementing solutions. However, when using the SSM methodology, the individuals embedded in the situation are the ones charged with implementing the solution (Checkland & Poulter, 2010). Elements of these four theories help to frame the literature review and the development of the methodology.

## Operational Definitions

*Autism spectrum disorder (ASD):* Persistent deficits in social communication and interactions across multiple contexts that interfere with the development of social relationships and can negatively impact academic or occupational performance (APA, 2013).

*Children with Special Health care Needs (CSHCN):* A child at risk of developing chronic conditions that require more health-related services than a typically developing child (Lin & Stella, 2015).

*Bright Futures – Well-Child Visits:* Guidelines for pediatricians to follow when assessing the growth and development of children (American Academy of Pediatrics, 2017).

*Critical Window of Development:* A period of heightened plasticity within the brain in which environmental input is necessary for development (Braddock & Twyman, 2014; Vivanti, Barbaro, Hudry, Dissanayake, & Prior, 2013).

*Critical Communication Methodology (CCM)* – A methodology that uses adjustments in the research design to give a voice to the participants.

*Soft Systems Methodology (SSM)* – SSM is a methodology that emphasizes the reality that problems are not stagnant and that systems are constantly evolving (Hodges, Ferreira, & Israel, 2012)

## Assumptions

The assumptions associated with the chi-square test were that the observations were from a random sample and that the sampling distribution was made to approximate a chi-squared distribution by making the sample size large enough. The assumptions associated with the Mann Whitney U test were that the continuous distributions for the test variables were exactly the same for the two populations and that the scores on the test variables were independent of each other.

## Limitations

Modifying the CAHPS survey posed a clear threat to the internal validity of the study. As a result of an internal threat to validity, it was difficult to determine if the independent variable was the clear reason for the changes in the dependent variable. The risk to the internal validity of the study was accepted because there were no other known instruments to date that had been determined to be reliable and valid measures of assessing health care accessibility for young children with ASD.

## Delimitations

The delimitations that threatened the external validity of the study included the selection of a sample from a relatively small geographic area. The external validity was threatened by a sample from a specific geographic area because it makes it difficult to generalize the results to participants living in different locations. Also, only caregivers who spoke fluent English had an opportunity to participate in the project. Nonnative speakers may have provided additional key insights into the challenges associated with health care accessibility, especially for populations of interest such as young children from the Latino community. Due to the delimitations in the study, there was limited generalizability of the quantitative findings of the study to populations of young children under the age of 8 living in the state of Florida. The qualitative findings also had limited transferability because triangulation of the data is beyond the scope of the current project. Triangulation was beyond the scope of the study because it would have required the inclusion of additional methods of data collection.

## Significance and Implications for Social Change

### Knowledge Generation

The study was designed to collect data on the topic of health care accessibility for young children diagnosed with ASD. The knowledge generated was collected directly from the caregivers of young children impacted by the transition to a commercial private payer Medicaid system. As a result, the findings provided insight into how a transition to a commercial private payer Medicaid system affected a growing subset of the CSHCN population in the state of Florida. The knowledge was used to generate discussion around access to health care for young children with ASD in the state of Florida.

### Professional Application

An approach that includes caregivers, professionals, and lawmakers is needed in addressing rising health care costs for the CSHCN population in Florida. Action is needed at the state level to address the fact that the burden of caring for individuals with ASD has shifted to individual states rather than private insurance companies. The findings from the research project could be used to help policymakers manage health care costs and maintain the quality of health care for the ASD population. The findings can be the basis for a policy debate regarding the need to provide intensive early intervention services to mitigate long-term costs of care for the ASD population.

### Positive Social Change

There are several potential avenues in which the research can contribute positively to the social change movement within the autism community. Building awareness of the problem of health care accessibility can lead to changes in the way that children are identified for autism screenings. Thus, the project's specific emphasis on children from diverse backgrounds may increase the chances that young children from diverse backgrounds receive an earlier diagnosis. Additionally, building awareness within the community regarding health care accessibility can generate a sense of empowerment amongst caregivers of children with ASD that are experiencing the problem. This empowerment may lead to the development of organizations that can apply increased pressure on lawmakers to take action on the issue. It is possible that the awareness raised by this project could lead to improved health care accessibility for those within the autism community. The findings from the dissertation are a first step in the process of making social change for the autism community.

## Summary and Transition

The increasing prevalence of ASD along with the rising costs of health care have the potential to result in a public health crisis. This research project examines how transitioning to a managed care system impacts accessibility to health care services for young children with ASD. Previous research indicated that implementation of a managed health care system keeps cost down. It remains unclear, however, how these systems affect accessibility to health care services, especially for young children with ASD.

The current study aims to use a modified version of the CAPHS survey. The use of the CAHPS survey provides an opportunity to gain specific information regarding health care accessibility for young children with ASD. The state of Florida recently transitioned to a private Medicaid system, which is intended to save the state money by transitioning special needs patients to HMO plans (Marcu et al., 2014). The changes in the Medicaid system in Florida make it an important state to study. Families are dual enrolling their children in Medicaid and private health insurance plans to gain access to the best therapeutic interventions (Jaffee, 2013). The increase in the number of children enrolling in Medicaid will increase the cost of providing health care services. Challenges in accessing health care services early in the course of treatment for ASD can delay the initial diagnosis for young children (Siller et al., 2013). An early diagnosis of ASD for a child can mean improved long-term outcomes. The implementation of early therapeutic interventions can increase the chances of children developing on a normal developmental trajectory as they transition into elementary school. Even with early intervention services, however, children with ASD still have difficulty accessing appropriate health care services (Siller et al., 2013).

A balance between providing health care and maintaining costs is needed. When all players in the insurance industry, including public and private, work together, that is when a solution to the problem will emerge.

## Organization of the Study

The dissertation is divided into five chapters. Chapter 1 includes the background, the rationale and the significance of the study. Chapter 2 reviews the literature about the topic. Chapter 3 includes a review of the methods used to collect and analyze the quantitative and qualitative data. Chapter 4 discusses the findings from the analysis. Chapter 5 will discuss the findings of the study and make recommendations for future research on the topic. Also, Chapter 5 will discuss implications for how the research can be used to cause social change for those affected by ASD.

# Chapter 2: Literature Review

## Introduction

The purpose of this mixed methods study was to explore the issue of health care accessibility for children with ASD. Young children with ASD, especially those from diverse backgrounds, have difficulty accessing therapeutic interventions. Delayed entry into therapy can have a negative impact on overall developmental trajectory for the child.

The purpose of this chapter was to draw parallels between health care accessibility and long-term outcomes for the ASD population. The barriers to health care accessibility and the impact of those of barriers on the child with ASD are addressed within the literature review. Literature that explored the impact of racial disparities on accessibility to health care in the ASD population received additional attention. The literature review concluded with a discussion regarding the need for a mixed methods study.

The majority of articles selected for inclusion were published within the past 5 years. Articles published more than five years ago were included if they made a significant contribution to the literature. All articles selected for inclusion derived from peer-reviewed scholarly publications. The scanning process for inclusion included first reading the abstract and the discussion sections of peer reviewed articles.

The literature review is divided into six sections. The first section discusses the conceptual framework as it relates to the topic. The second section explores changes in the health care payer system that are relevant to health care access for children with autism. The third section summarizes the specific health care needs of the ASD population. The fourth section explores patterns of use and the issue of accessibility for children with the designation CSHCN. The fifth section provides a brief history of changes specific to the Florida Medicaid system and the final section provides implications for how health care changes affect specific subsets of the ASD population such as children of African American and Latino descent.

## Literature Review Strategy

Several databases were accessed to complete the literature review for the proposed project. The databases included ABI/INFORM Complete, Academic Search Complete, Business Source Complete, CINAHL, Expanded Academic ASAP, Google Scholar, Medline, ProQuest, PsycArticles, PsycINFO, PubMed, and SocIndex. The majority of the literature review consisted of articles published between 2013 and 2018. Some of the keywords used to search the databases included: *Affordable Care Act* (*ACA)*, *Applied Behavior Analysis (ABA)*, *Anderson & Aday behavioral health model (BHM)*, *autism spectrum disorder (ASD)*, *children with special health care needs (CSHCN)*, *critical communicative methodology (CCM)*, *critical periods of development*, *disparities in health care accessibility*, *early intervention*, *Express Lane Eligibility (ELE)*, *family burden*, *federal Autism mandates*, *financial cost*, *Federal Medicaid*, *Florida Medicaid*, *health care accessibility*, *health insurance*, *health care utilization*, *managed care plans*, *patient centered medical home (PCMH)*, *public health care*, *private health care*, *soft systems methodology*, and *unmet health care needs*.

## Conceptual Framework

This section of the review described the theoretical elements that contributed to the conceptual framework of the project. The social model of disability, Aday and Andersen’s BHM, critical communicative methodology (CCM), and soft systems methodology (SSM) each made a significant contribution to the conceptual framework on the topic of health care accessibility for children with ASD. The conceptual framework supported the construction of the literature review and the case for the use of a specific methodological framework.

## Support for the Development of the Literature Review

The social model of disability focused on reducing socially constructed barriers that impede the ability of individuals with disabilities to fully integrate into society (Barnes & Mercer, 1997). The use of model helped to guide the study in the direction of improving access to therapeutic health care services so that individuals with ASD have the potential to develop as much independence as possible in adulthood. The project aimed to increase the understanding of the needs of young children with ASD and how therapeutic health care services at an early age can improve long-term outcomes over the lifespan for those in a position to make change on this issue.

The use of Aday and Andersen’s BHM helped the study to generate outcomes consistent with the social model of disability. The BHM model provided a means for evaluating the effectiveness of policies designed to increase access to health care services and increase consumer satisfaction (Aday & Andersen, 1974). The social model of disability calls for better measurement of the barriers to full inclusion for individuals with disabilities in society (Barnes & Mercer, 1997). According to Aday and Andersen (1974), it is important to have a method for evaluating the outcomes of health care initiatives. Evaluating the outcomes includes answering questions related to whether people with health care needs can enter the health care system and what their level of satisfaction is once they are in the system (Aday & Andersen, 1974). Aday & Andersen (1974) noted that the model divides consumer characteristics that drive health care utilization into predisposing, enabling, and need components. After studying the model, it is possible to consider factors impacting entry into the health care system and level of satisfaction once the consumer is in the system. Aday and Andersen's BHM model can be useful for describing the health care utilization patterns within the ASD population and the level of consumer satisfaction within the health care system. The use of the BHM model can generate information that can be used to determine if individuals with ASD are gaining access to the services that they will need to reach their full potential as adults. The use of the model is critical for evaluating access to care for individuals from Latino and African American backgrounds.

## Support for the Development of the Methodology

There are two additional theoretical components of the framework that support the development of the methodology for the current study. Those two theories are the CCM and SSM. A review of the literature revealed considerable large scale efforts to study the issue of accessibility of health care for children with special needs using data from national databases (Lin & Stella, 2015; Parish, Thomas, Rose, Kilany, & Shattuck, 2012c; Szilagyi, 2012). There are, however, limited attempts to devise creative methodological solutions to increase the inclusion of children and families of Latino and African American backgrounds in research studies. Historically, individuals from Latino and African American backgrounds have had different experiences accessing health care services compared to Caucasian individuals (Bustamante et al., 2009; Lopez, 2014; Magaña, Parish, Rose, Timberlake, & Swaine, 2012; Parish et al., 2012a; Zuckerman et al., 2014b). Within the literature reviewed for this study, there are several potential theoretical components that apply to the study of health care accessibility that respect and incorporate the participants' experiences into the development of a solution to the problem of health care accessibility. Incorporating elements of CCM and SSM into the methodology has the potential to lead to solutions to that are valued by the autism community, and there is increased buy in from the community as a result.

CCM seeks to overcome inequality by making methodological adjustments in the research design that give a voice to the participants (Gómez, Puigvert, & Flecha, 2011). CCM uses the participants' experiences with social exclusion as a means to uncover the mechanisms that lead to new understandings of social problems (Gómez et al., 2011). By applying the CCM methodology to the social problem of access to health care for young children with ASD, there is the potential that parents of young children with ASD will have creative solutions to the problems preventing access to health care for their children. Including the individual affected by the social problem being studied is essential to the development of a solution (Checkland & Poulter, 2010).

The SSM framework developed by Checkland and Poulter (2010) helped to frame the problematic social situation that exists as a result of health care disparities. SSM has been used broadly in some areas including revamping a community model for adolescent mental health care (Hodges, Ferreira, & Israel, 2012). Creating a new model is beyond the scope of the current dissertation project because this project is focused on understanding the problem and making recommendations for future studies, but there is much to be gleaned from understanding the steps taken to develop effective solutions to complex social problems.

The soft aspect of the SSM methodology emphasizes the reality that problems are not stagnant and that systems are constantly evolving (Hodges et al., 2012). Banathy (2013) described how the SSM methodology uses a systematic approach to inquiring into the system. The world is not well ordered, and situations are in constant flux (Checkland & Poulter, 2010). The solutions that develop from this framework must be culturally feasible to the group that is affected by the particular problem if there is going to be a sustained impact. Typically, a knowledgeable individual such as a researcher leads the process of implementing solutions. However, when using the SSM methodology, the individuals embedded in the situation are the ones charged with implementing the solution (Checkland & Poulter, 2010). According to the limited information collection principle, more time should be spent on generating a solution to the problem rather than on collecting data about the problem (Banathy, 2013).

The development of root definitions and rich pictures is a means of developing effective solutions to complex social problems (Hodges et al., 2012). The application of CCM developed for this project included the use of root definitions and rich pictures. Root definitions are statements about the system that are used to facilitate problem solving and the development of hypotheses (Hodges et al., 2012). Rich pictures are the researcher's compilation of stakeholder experiences (Hodges et al., 2012). Root definitions and rich pictures are intended to ensure that the change effort is grounded and has applicability to real-world settings (Hodges et al., 2012). The incorporation of CCM into the framework of this project will help to organize the responses to open-ended questions provided by the participants.

The SSM methodology stands to help systematize the researchers thinking regarding the problematic situation resulting from the difficulties that children with autism spectrum disorder (ASD) have accessing health care services. Soft systems methodology (SSM) that helps to support the use of a mixed methods study (Hodges et al., 2012). The conceptual framework supports the development of a mixed methods study that validates the perspective of the research participants and maintains the social model of disability perspective.

There is a lack of evidenced based research detailing the outcomes of transitioning children with ASD to a managed care system that is operated by a private commercial health insurance company. The current literature review will synthesize the results of previous research related to the topic to build a justification for a mixed methods study to examine how the recent change to a private payer system for Medicaid in Florida has impacted accessibility to health care services for young children with ASD. An important component of this literature review is the analysis of the methodological approaches necessary to address the issue of health care accessibility and the specific methodological flaws that undermine the quality of the research studies associated with the topic.

## ASD and Health Care Accessibility

This section of the literature review provided a meta-analysis of the current research on the topic of health care accessibility for children with autism spectrum disorder (ASD). Articles are compared and contrasted based on the type of study completed, the outcome of the study, the type of analysis completed, and the quality of the overall study.

### The Importance of Health care Coverage – Early Diagnosis

Children receiving an early diagnosis of autism have improved developmental outcomes over the course of their lifetime because they can access therapeutic interventions at a time of optimal brain development (Braddock & Twyman, 2014; Vivanti et al., 2013). Thus, the cost to families and to the government is substantially lower over the course of the lifetime for those individuals who received intervention at an early age (Dababnah et al., 2011). The effectiveness of early intervention programs for children with autism is noted through improved cognitive and social skill functioning (Campbell et al., 2014). The benefits were long-term with study participants having benefits noted into their mid-thirties (Campbell et al., 2014).

Gaps in health care coverage can be particularly harmful to young children with ASD who require a medical diagnosis to access therapeutic interventions because without a diagnosis these children are not able to start therapy. Lengthy gaps in health insurance coverage and the resulting effect of churn can cause a delay in diagnosis affecting accessibility to early intervention services during a critical period of development (DeVoe et al., 2011a; Emerson, Morrell, & Nice, 2016; Gourdine, Baffour, & Teasley, 2011; Vohra, Madhavan, Sambamoorthi, & St Peter, 2014). The significant delay in accessing the diagnosis affects long-term treatment outcomes resulting in children needing longer courses of therapy (Gourdine et al., 2011). Consistent health care coverage for children with ASD is desirable because it results in fewer unmet health care needs (Cheak-Zamora & Farmer, 2015; Devoe et al., 2015; Emerson et al., 2016).

Gaps in coverage are particularly problematic for young African American children and Latino children because they have historically received a diagnosis of ASD later than Caucasian children (Gourdine et al., 2011). The combination of delays in diagnosis and access to therapeutic services can result in the Latino, and African American population of children with ASD starting elementary school at a disadvantage from their Caucasian peers (Dababnah et al., 2011; Mandell et al., 2009).

Improved screening measures have helped to get African American and Latino children diagnosed at an earlier age (Emerson et al., 2016; Jo et al., 2015). The improved screening measures have resulted in fewer incorrect diagnosis and fewer return trips to the physician’s office to get the correct diagnosis for Latino and African American children (Emerson et al., 2016: Jo et al., 2015). Despite the improvements in age of diagnosis, there are still other factors delaying diagnosis such as health insurance coverage for Latino and African American children because specialists often refuse to see children with public insurance (Emerson et al., 2016). Doshi, Tilford, Ounpraseuth, Kuo, and Payakachat (2017) found that Caucasian children had better access to coordinated care and family centered care than their non-Caucasian counterparts. Therefore, access to care is still impacted by the race of the child and there is more that needs to be done to help these children to gain access to much needed services.

## Family Income

Family income level can have a profound impact on accessing consistent health care coverage for children with autism spectrum disorder (ASD). Fluctuations or churn in parent income level can result in frequent changes in health insurance coverage for the child with ASD regardless of whether the insurance is through a public payer or private payer system (DeVoe et al., 2011a). Parent income level fluctuations in insurance coverage impact the child with ASD's ability to access consistent health care services. Children from middle income families experience more gaps in health coverage than children residing in families far below the poverty line because the effects of income fluctuations on insurance are particularly harmful to middle income families (DeVoe, Tillotson, & Wallace, 2011b). Middle income families experience the greatest fluctuations in health care coverage because they make too much money to qualify for government programs, but not enough income to pay for services out of pocket (Crocetti, Ghazarian, Myles, Ogbuoji, & Cheng, 2012).

Children from middle income families and those closest to the federal poverty line (FPL) do not have the health care safety net that is available to children far below the poverty line (Crocetti et al., 2012; DeVoe, Wallace, Selph, Westfall, & Crocker, 2011c). Obtaining insurance coverage was perceived as a problem by parents regardless of their level of socioeconomic status (Pickard & Ingersoll, 2015; Walker, Alfonso, Colquitt, Weeks, & Telfair, 2016). A public payer system such as Medicaid provides protection to low-income children from the effects of churn and ensures their ability to access consistent health care coverage (DeVoe et al., 2011a). Low-income children without Medicaid are also subject to gaps in coverage due to a provision within the ACA that exempts families from purchasing health insurance coverage if they do not earn enough income (DeVoe et al., 2015). Instability in family income raises the risk of exposing children with ASD to the harmful effects of having inconsistent health care coverage.

Not surprisingly, families experiencing gaps in insurance coverage are susceptible to increased out of pocket expenses related to their child with ASD's medical and therapeutic needs. Increased out of pocket expenditures lead to financial difficulties for the families of children with autism (Parish, Thomas, Williams, & Crossman, 2015; Thomas, Williams, & Morrissey, 2016). Medicaid health insurance programs offset out of pocket cost for low-income families (Parish et al., 2012c; Thomas et al., 2016; Wang et al., 2013).

## Health Care Utilization

Just as churn is a problem for children with autism spectrum disorder (ASD), so is underutilization of available health care services. Children with special health care needs (CSHCN) population diagnosed with autism spectrum disorder (ASD) have more intensive medical needs requiring greater health care service utilization (Wu, Kung, Li, & Tsai, 2015). Health care utilization is an important factor to consider in addressing health care accessibility because health care services are not always adequately used (Emerson et al., 2016). Underutilization is of concern with children with ASD because it can be an indication that more children are experiencing gaps in health care coverage. Any gap or underutilization of service has the potential to impact the overall quality of health for the child with ASD (Parish, Rose, Yoo, & Swaine, 2012b).

## Comorbid Conditions

Health care utilization is highest among children with ASD that also have intellectual disability or who have a comorbid psychiatric condition (Zablotsky et al., 2015). There is evidence to suggest that increased health care utilization is driven by high quality health care (Magaña et al., 2012; Parish et al., 2012a). An element of that high quality care is parent perceptions of interactions with health care providers (Magaña et al., 2012; Parish et al., 2012a). Children with co-morbid conditions are likely to need more services and their parents are likely to seek those services when they perceive their relationship with the child's health care provider in a positive manner.

## African American and Latino Families

African American and Latino families were often reported to use lower levels of health care services. The physician's ability to act in a culturally competent manner is implicated in lower health care utilization rates among children with autism spectrum disorder (ASD) from diverse backgrounds (Gourdine et al., 2011; Janvier et al., 2015; Parish et al., 2012a). Factors such as poor interactions with health care providers lead to decreased health care utilization rates among African American and Latino children and their families (Parish et al., 2012a). Through a qualitative case study, Gourdine, Baffour, and Teasley (2011) described how families of children with ASD often experienced "racial slights" and left the patient's family feeling less competent in their ability to care for their loved one with ASD. Repeated negative experiences with the physician result in mistrust on the part of the parent resulting in poor use of health care services for the child with ASD.

### Strengths and Limitations

A strength of many autism studies is that they generate data from large national datasets. Through the analysis of large national datasets such as the MAX data files, it is possible to demonstrate differences in health care utilization based on the age of the individual (Cidav et al., 2013). Unfortunately, a limitation of these datasets is that the direction of a relationship between variables cannot be determined from studies using pre-established variable (Zablotsky et al., 2015). The researcher interested in interpreting the data is limited to using regression models to predict the relationship between pre-established variables. There are few studies with a purely qualitative or mixed methods approach to the issue of health care utilization. The topic of health care utilization among children with ASD deserves further investigation employing the use of quasi-experimental approaches that answer specific research questions using primary sources of data.

## Unmet Health Care Needs

Despite having higher health care utilization rates, the parents of children with autism report their children had unmet health care needs in numerous studies (Cheak-Zamora & Farmer, 2015; Chiri & Warfield, 2012; Farmer et al., 2014; Zablotsky et al., 2015; Zuckerman, Lindly, Bethell, & Kuhlthau, 2014a). Some of the factors suspected of increasing the likelihood of a child with ASD having unmet health care needs included missing a well-child visit, a transition to a managed care system, family income level, unmet family mental health needs, inconsistent health care coverage, and the use of multiple therapeutic services (Benevides, Carretta, & Lane, 2015; Cheak-Zamora & Farmer, 2015; Chiri & Warfield, 2012; Litt, & McCormick, 2015).

## Therapeutic Need

Despite estimates of over 97% of children with autism using, at minimum one therapeutic service, there are high levels of unmet need for therapeutic and specialty care services among this population (Cheak-Zamora & Farmer, 2015; Zablotsky et al., 2015). Multiple studies reported over 30% of parents with a child with autism reporting an unmet need (Cheak-Zamora & Farmer, 2015; Farmer et al., 2014; Zablotsky et al., 2015). Behavior therapy was a particular therapeutic intervention that parents reported having the most challenges accessing for their child with autism (Farmer et al., 2014; Litt, & McCormick, 2015). A limitation of secondary data sources when attempting to understand unmet need is the original questionnaire may not include questions about accessing behavior therapy. Moreover, the need for behavior therapy may be grossly underestimated when using secondary data sources (Cheak-Zamora & Farmer, 2015).

An examination of the available literature indicated that the increasing cost of health care over the past decade has not led to improved accessibility to health care services for children in the United States. Several studies examined accessibility to health care services for the CSHCN population over the last decade (Crocetti et al., 2012; Newacheck et al., 2009; Szilagyi, 2012; Winitzer, Bisgaier, Grogan, & Rhodes, 2012; Zuckerman et al., 2014a). Much of the research completed on the topic of health care accessibility has historically developed from research studies with a quantitative methodology. The limited qualitative studies that are available on the topic are important in that they can bring attention to the problem of accessibility from the parent's perspective.

Regardless of the methodology selected to study the problem of accessibility to health care , the literature on the topic revealed that the parents of children with autism report unique challenges in accessing referrals and specialty care services (DeVoe et al., 2011c; Farmer et al., 2014; Parish et al., 2012a; Winitzer et al., 2012). The problem appeared to be more pronounced for those children with public health insurance plans and children with disabilities such as autism (Benevides et al., 2015; Chiri & Warfield, 2012; DeVoe et al., 2011b).

## Strengths and Limitations

The literature associated with unmet health care needs of children with autism included the use of mixed methods methodologies to examine which needs were unmet for children with autism (Brown, Ouellette-Kuntz, Hunter, Kelley, & Cobigo, 2012; Farmer et al., 2014). Examining the issue of unmet need through a mixed methods approach had the potential to disseminate research faster by allowing for the publication of findings in one study. Eliminating the publication process for the second study increases the speed at which evidence based research can drive solutions to the complex problem of unmet health care needs for children with autism.

The use of secondary data sources limited researcher control over confounding variables (Zablotsky et al., 2015). Benevides, Carretta, and Lane (2016) speculated that the increase in unmet need might be due to some additional variables including more individuals entering the system as a result of the increased prevalence of the disorder, policy changes such as autism insurance mandates and or the availability of providers to care for individuals with ASD.

The format for my dissertation mirrored the design of Brown, Ouellette-Kuntz, Hunter, Kelle, and Cobigo (2012) in hopes of adding more to the literature regarding health care accessibility for young children with autism and their families. The use of the open-ended questions included in this study added supplemental information to the findings of the quantitative survey. The use of open-ended questions had the potential to offer new insights into the problem of unmet needs for young children with autism.

## Barriers to Health Care Service Use

There are barriers that exist that make it difficult for individuals with autism to access health care services in the United States and result in unmet health care needs. Barriers to service use are detrimental to the child with ASD because they delay diagnosis and cause mistrust between parents and medical providers (Zuckerman et al., 2014b). Any combination of barriers to access whether it is insurance coverage, racial/ethnic disparities or low socioeconomic status makes it significantly more difficult for families of young children with ASD to gain access to therapeutic interventions in the most critical years of development for the child. The barriers to access to care have been studied using all three types of research methodologies with little variation in the conclusions drawn from the study (Crocetti et al., 2012; Magaña et al., 2012; Pickard & Ingersoll, 2015 & Szilagyi, 2012).

## Insurance Coverage

The use of mixed methods and quantitative studies has revealed that the most documented barrier to accessing care reported by parents of children with autism is insurance coverage (Pickard & Ingersoll, 2015; Vohra et al., 2014). Crocetti, Ghazarian, Myles, Ogbuoji, and Cheng (2012) noted that Hispanic children have a higher likelihood of being uninsured. African American and Hispanic children have higher rates of being uninsured for at least part of the year (Szilagyi, 2012). 10.6% of Hispanic children with special health care needs and 9.8% of African American children reported having no insurance for at least part of the year. The problems accessing health care are not limited to those using private pay health care plans and the problems exist for those on public health insurance plans as well. Medicaid reimbursements are typically so low that providers refuse to provide care to patients with Medicaid insurance (Thomas et al., 2016). Despite the lack of availability of providers in the Medicaid health care network, parents report higher levels of satisfaction with their child's health insurance coverage when the child is enrolled in Medicaid (Thomas et al., 2016).

The specific barriers that impacted Latino and African American families have been clarified through the use of mixed methods and qualitative research studies (Magaña et al., 2012; Zuckerman et al., 2014b). Specific barriers existed for parents of children eligible for programs such as Children's Health Insurance Program (CHIP) and Medicaid (Kenney, Haley, Anderson & Lynch et al., 2015). Parents noted increased challenges finding information about health care programs as the gap in coverage increases (Kenney et al., 2015). Schools and mental health centers did not adequately link families that indicated that they had Medicaid to appointments or referrals for an appointment (Williams, Perrigo, Banda, Matic, & Goldfarb, 2013).

Research has demonstrated that service use among Latino children has been lower than among Caucasian children (Magaña, Lopez, Aguinaga, & Morton, 2013). Hispanic children received less rehabilitative health care services such as Speech Language Therapy (SLT) and Occupational Therapy (OT) than Caucasian children (Irvin, McBee, Boyd, Hume, & Odom, 2012). It is possible that the deficits caused by delayed entry into therapy may result in increased use of rehabilitation, residential and vocational services over the course of the lifetime of the individual with autism.

The increased number of parents reporting barriers may have been attributed to policy changes including the implementation of the ACA, the passage of autism mandates and transitioning Medicaid recipients to private payer systems (Cheng, Wise, & Halfon, 2014; Chiri & Warfield, 2012; Devoe et al., 2015; Kenney et al., 2015; Leininger & Levy, 2015). It is unclear whether barriers would only be temporary as a result of the changes in policy legislation related to health care and autism or if those barriers would be permanent.

Zhang and Baranek (2016) completed a multivariate logistic regression analysis of the National Survey of Children's Health (NSCH) dataset to assess access and utilization of health services amongst children with autism. The findings produced by Zhang and Baranek (2016) revealed gaps in access and utilization specifically as a result of whether the child had private or public insurance coverage. Children with private health insurance had access to less services with their parents paying more out of pocket for their health care services. Parish, Thomas, Williams, and Crossman (2015) reported a similar finding with the parents of children with autism utilizing private insurance reporting significantly higher out of pocket expenses. The types of out of pocket expenses appear to be similar such as outpatient services and prescription medications (Parish et al., 2015).

### Strengths and Limitations

The literature on the topic of barriers to health care accessibility addressed the problem from a variety of angles. Qualitative and mixed methods research addressed the problem specifically for African American and Latino individuals using quantitative studies with open-ended qualitative questions and focus groups to gain as much information as possible from the participants enrolled in the study. The problem of barriers to health care access was considered a social justice issue with researchers creating a socio-cultural framework to guide the direction of future research on the topic (Lopez, 2014).

Zuckerman et al. (2014b) described several limitations related to qualitatively studying barriers to health care access for Latino families. Most notable is the recognition that accessibility to health care changed rapidly with the implementation of ACA. Medical home models were likely to offset barriers to health care access following the implementation of ACA (Cheak-Zamora & Farmer, 2015). Lopez (2014) suggested that the use of longitudinal studies in future studies because longitudinal research has the potential to capture the effects of health care policy changes over time.

The benefit of quantitative studies was limited for African American and Latino participants because there was a lack of African American and Latino participants in the literature related to autism. Qualitative studies on the topic shared a weakness with quantitative studies in that participants were grouped together, and this limited the exploration of within group differences (Jo et al., 2015; Zuckerman et al., 2014b). There were differences within the Latino population that should be acknowledged when grouping participants. For example, Latino's originating from Mexico may have different outcomes than Latino's originating from Latin America (Zuckerman et al., 2014b).

## Autism and Legislation

### The Affordable Care Act (ACA)

The implementation of the ACA was anticipated to reduce the financial burden for adults with high medical needs and those receiving health care through Medicaid (Blumberg, Waidmann, Blavin, & Roth, 2014). Researchers predicted that an indirect benefit of ACA would be an increase in the uptake of insured children but reducing uninsured children was never the primary intention of the ACA legislation (Harrington, 2015; Kenney et al., 2015). Policymakers believed that programs like the Children's Health Insurance Program (CHIP) would continue to provide health insurance coverage to children and it would not be necessary to be overly concerned about ACA covering uninsured children.

In the short term, ACA had the potential to disrupt access to health care services for children (Cheng et al., 2014; Devoe et al., 2015; Leininger & Levy, 2015). Cheng, Wise and Halfon (2014) noted that Latino children were particularly vulnerable to ACA changes. There was the potential for fluctuations in parent income levels to cause churn which causes detrimental gaps in health care coverage for children. In the long-term, there was funding allocated through ACA for PCMH and school-based health care clinics which were likely to improve the quality and the accessibility of health care services for children (Devoe et al., 2015; Leininger & Levy, 2015; Thomas, Parish, Rose, & Kilany, 2012).

**School based clinics.** The proximity of the school to the child's home made it an important resource for parents trying to access services for the child with autism spectrum disorder (ASD) (Gourdine et al., 2011). Schools were an important link for families unable or unwilling to seek support from physicians (Gourdine et al., 2011). Educating professionals in the school regarding services for the ASD in the community is important. The funding provided by the ACA to create school based medical clinics stood to benefit children with ASD in the areas in which finding a culturally competent physician was difficult.

Additionally, schools offered an opportunity to screen children for ASD within the early childhood years. Janvier et al. (2015) described the potential effectiveness of early childhood providers as screeners ASD in low-income and resource lacking communities. Studies such as the one completed by Janvier et al. (2015) demonstrated that professionals in the community are capable of effectively screening for ASD in underserved areas

**Express Lane Eligibility.** Express Lane Eligibility (ELE) made it easier to enroll children in health insurance programs such as the CHIP and Medicaid. ELE is a temporary policy that allows each state to enroll children in Medicaid or CHIP by using another program such as Supplemental Nutrition Assistance Program (SNAP) (Crocetti et al., 2012; Harrington, 2015). The temporary status of the ELE policy inhibited states from moving forward with automating the application process for Medicaid and CHIP programs (Harrington, 2015; Hoag, 2015).

An automation of the application process stood to benefit children who experienced gaps as a result of frequent changes between Medicaid and CHIP programs. Decreasing the amount of time waiting for health care coverage was likely to benefit children and families affected by autism spectrum disorder (ASD) attempting to access therapeutic interventions. Gaps in coverage of over one year resulted in increased barriers to enrollment as parents perceived more challenges in knowing where and how to enroll their child in a Medicaid or CHIP program (Kenney et al., 2015).

The economic savings of ACA were likely to be seen over a lifetime rather than in a span of a year (Blumberg et al., 2014). Research has demonstrated that changes in the delivery of health care service such as the implementation of a PCMH take a considerable amount of time to show an effect (Leininger & Levy, 2015; Marcu et al., 2014). The continuation of research associated with pilot projects is essential to demonstrate the long-term outcomes of the ACA (Friedberg, Rosenthal, Werner, Volpp, & Schneider, 2015). Specific areas to examine in long-term studies would include program evaluation, accessibility to care, and out of pocket expenses. Additionally, efforts should be made to include vulnerable populations in long-term efforts to assess the effectiveness of ACA programs such as ELE’s. Colby and Natzke (2014) reported that they left children with disabilities out of their study to maintain a homogenous sample, therefore, future research should be mindful of the need to monitor the long-term benefits of the ACA on children with disabilities.

While ELE's are designed with the purpose of increasing enrollment in public insurance programs, PCMH's are designed with the intention of reducing health care cost and improving the quality of health care for those with chronic conditions (Miller, Nugent, & Russell, 2015). Research findings demonstrated that PCMH can reduce the unmet health care needs of children with special health care needs (CSHCN) (Miller et al., 2015).

*Patient centered medical home (PCMH).* The PCMH model showed promise concerning improved access to health care for children and reducing unmet health care needs. Despite the promise, children with autism living in the United States had decreased odds of having access to a PCMH (Cheak-Zamora & Farmer, 2015; Farmer et al., 2014). Park et al. (2014) indicated that disparities existed regarding the access that Hispanic and African American children had to PCMH and that the odds of a Hispanic or African American child receiving access to a PCMH model dropped if they had comorbid conditions such as ADHD and or a developmental disorder (Park et al., 2014).

*Family Centered Care and Care Coordination.* The Family Centered Care (FCC) and Care Coordination (CC) are key components of the PCMH model that are considered instrumental in improving access to care for children with ASD but are often underutilized (Christon & Myers, 2015; Miller et al., 2015). FCC encourages a positive relationship between clinicians and families and CC centralizes the patients care with the primary care physician. The usage of PCMH for children with autism has been shown to significantly reduce unmet health care needs and FCC and CC are key factors in the success of the PCMH model for children with autism (Cheak-Zamora & Farmer, 2015). Increasing utilization of the PCMH components presented challenges, but the literature demonstrated that the FCC and CC components were valuable in reducing unmet health care needs within the autism population (Christon & Myers, 2015; Farmer et al., 2014).

Insurance companies rarely reimbursed for CC and FCC services (Christon & Myers, 2015; Hyman & Johnson, 2012). As a result, practitioners were not typically reimbursed for these services unless they sought grant opportunities to cover the expenses associated with providing the service (Hyman & Johnson, 2012). A systems barrier to the development of FCC component of the PCMH was funding (Christon & Myers, 2015). Providing reimbursement for care plan oversight would have encouraged practitioners to engage in more collaboration with educational and behavioral health professionals leading to improvements in FCC (Hyman & Johnson, 2012). Collaboration among professionals had the potential to improve outcomes for ASD children (Hyman & Johnson, 2012; Christon & Myers, 2015). It was important to incentivize the use of the PCMH model for professionals working with the ASD population.

Programs that incorporated shared savings among the providers offered an incentive to providers to manage utilization and cost effectively (Friedberg et al., 2015). An established PCMH model resulted in less unmet health care needs and reduced the time caregivers spent on care coordination (Farmer et al., 2014; Miller et al., 2015). Fueyo, Caldwell, Mattern, Zahid, and Foley (2015) indicated that lost productivity is a significant portion of the cost associated with caring for children with ASD. Caregivers make life changing decisions to care for the child such as deciding to stay at home full time or change jobs (Moodie-Dyer et al., 2014). The use of the PCMH had the potential to reduce the amount of time caregivers spend coordinating care for the child.

An option for improving accessibility was locating the PCMH for individuals with autism within a behavioral health setting (Fueyo, Caldwell, Mattern, Zahid, & Foley, 2015). 2017 PCMH recommendations supported the identification and coordination of behavioral health needs (NCQA, 2016). The location of the PCMH within the behavioral health setting would have provided families with access to needed services in one location. The primary needs of ASD individuals were often behavioral and social, so locating the services within this framework helped to connect the individual and the family to the provider that is likely to be of most assistance (Fueyo et al., 2015). The Center for Autism and Developmental Disabilities in Pennsylvania was an example of health model that was located in a behavioral health setting (Fueyo et al., 2015). Fueyo et al. (2015) noted that two important aspects of the model, cost effectiveness, and clinical effectiveness had yet to be evaluated. Some studies indicated that there was more work that was needed to reap the full range of benefits that the PCMH could provide to children with ASD. According to Christensen, Zickafoose, Natzke, McMorrow, and Ireys (2015) enrollment in a PCMH did not increase health care utilization among children with Medicaid.

*Autism mandates.* The combination of the ACA and autism mandates resulted in improved access to care for children with ASD. The use of health care exchange plans led to increased access to services for the child and reduced out of pocket expenses for families in the long-term (Baller et al., 2015; Blumberg et al., 2014).

The available literature on the topic suggested that there was variability between states regarding access to health care for children with ASD (Parish et al., 2012b; Price & Eibner, 2013; Thomas et al., 2012). Southern states typically had the highest rates of uninsured children (Parish et al., 2012b). Florida was among one of five states that contributed to almost half of the uninsured children in the United States (Crocetti et al., 2012). A contributing factor in state to state variation was the passage of autism mandates.

The passage of autism mandates was thought to contribute to the variation in quality of care between states. The literature provided an example of a positive outcome from the implementation of an autism mandate in Pennsylvania. The mandate enabled more families to seek coverage through private insurance (Stein, Sorbero, Goswami, Schuster, & Leslie, 2012). There was concern in the literate that the mandates resulted in increased problems with accessibility because there was not enough infrastructure in place to support an influx of children seeking therapeutic interventions (Baller et al., 2015). The literature supported regulation to ensure that providers were adequately incentivized to treat individuals with ASD to avoid accessibility problems (Baller et al., 2015).

*State to state variability*. Disparities between states were exacerbated by the frequency of required Medicaid eligibility renewals and the rate of reimbursement for physicians (Parish et al., 2012b; Price & Eibner, 2013). These factors reduced the continuity of care which impacted the quality of health care (Parish et al., 2012b). The children living in states with higher reimbursement rates experienced fewer challenges when accessing services (Price & Eibner, 2013; Thomas et al., 2012). It should be noted that some studies assessing access to health care had limitations in that the estimates of children that were eligible but uninsured were inaccurate because there was state to state variation in income ineligibility for public insurance programs (Crocetti et al., 2012). It wasis difficult to make state to state comparisons when the states did not have similar guidelines for Medicaid programs.

There was considerable variation among states regarding the services that Medicaid covered (Havens, 2015; Semansky, Xie, Lawer, & Mandell, 2013). Havens (2015) reported that Medicaid programs did not endorse one specific treatment modality for ASD, so each state was able to define the therapeutic interventions that were to be considered “medically necessary.” Children with ASD living in neighboring states had very different outcomes as a result of differing interpretations of “medically necessary”. Semansky, Xie, Lawer, and Mandell (2013) reported that only six states in the United States provided access to the four core therapeutic interventions for ASD that were physical therapy, occupational therapy, speech/language therapy and Applied Behavior Analysis (ABA).

*Service delivery transitions***.** States such as Florida that were transitioning Medicaid recipients to managed care programs to save money exacerbated the issue of state to state variation. States were looking to reduce health care expenditures by shifting Medicaid recipients to managed care systems to manage cost (Crossley, 2014). States such as California and Florida experimented with transitioning vulnerable populations such as those with disabilities to managed health care plans (Crossley, 2014; Marcu et al., 2014). To date, there was no comprehensive examination of the outcomes of changing Medicaid service delivery models for individuals with disabilities especially children with ASD. There were several aspects of changing service delivery models such as customer service and education that have been explored with mixed results (Hall et al., 2014; Knapp, Madden, Sloyer, & Shenkman, 2012; Peterson & Hyer, 2015).

Several pilot projects have documented the impact of a transition to a managed care system in Florida. A transition to an Integrated Care System (ICS) found improvement in parent reported customer service for those enrolled in the Florida ICS. Knapp, Madden, Sloyer, and Shenkman, (2012) noted that ICS did not positively or negatively affect parent perceptions of quality of care and that the transition to ICS did not worsen the quality of care as expected by previous researchers (Knapp et al., 2012).

The focus of the Hall et al. (2014) study was the patient and parent experiences with the Medicaid demonstration project. The data collection tool used in the study was the Consumer Assessment of Health Providers and Systems Survey (CAHPS). Ordered logistic regression models revealed that the plan type was not a factor that significantly impacted patient health status.

Findings from Knapp et al. (2012) included decreased levels of satisfaction amongst participants that did not speak English or Spanish and as a result, the researchers suggested improvements in the health care literature disseminated to participants. Peterson and Hyer (2015) also examined the materials distributed to consumers during the transition to a managed care system for those receiving long-term care within the state of Florida. The materials distributed to consumers were examined to determine the adequacy of the information. Peterson and Hyer (2015) indicated that the materials lacked clear explanations about the change. The materials also were lacking in regards to explaining the choices that consumers had regarding what would best meet their individual needs (Peterson & Hyer, 2015).

Efforts have been focused on understanding the transition for those individuals consuming long-term care and support services in a managed care system (Hall et al., 2015; Moodie-Dyer et al., 2014; Peterson & Hyer, 2015). Less was understood however about the transition to managed care for those individuals with disabilities that consumed community-based therapeutic services. More research was needed to understand how the transition affected service delivery specifically for children with ASD utilizing community-based services.

## Overcoming Methodological Challenges

This section of the literature review addressed the common methodological limitations noted in previous research on the topic of health care accessibility for children with autism spectrum disorder (ASD). It also discussed the ways in which the current methodology can be designed to contribute to the preexisting literature on the topic.

### Limitations of Secondary Data Sources

Within the meta-analysis, there were numerous studies that used secondary data collected from the National Survey of Children with Special Health Care Needs (NS-CSHCN) between the years 2005 and 2012 (Crocetti et al., 2012; Jo et al., 2015; Johnson et al,. 2014; Lin & Stella, 2015; Litt & McCormick, 2015; Magaña et al., 2012; Parish, et al., 2015; Semansky et al., 2013; Strickland et al., 2015; Thomas et al., 2012; Thomas et al., 2016; Vohra et al., 2014; Zuckerman et al., 2014a). A large number of studies utilizing the NS-CSHCN data underscores the wealth of data available to researchers. The data available to researchers is invaluable because it is a low cost option to explore the problem of health care accessibility for children with ASD.

Three studies used questions from the NS-CSHCN to create specific follow-up questionnaires (Farmer et al., 2014; Oswald, Haworth, Mackenzie, & Willis, 2017; Zablotsky et al., 2015). One study used three datasets to diversify the information gathered from the data analysis (Lavelle et al., 2014). Many of these studies noted generalizability as a limitation and that directionality of relationships was not interpretable. Furthermore, these studies are limited in that the researcher was not able to follow up with families regarding responses.

Additionally, the NS-CSHCN and other national surveys relied on parent report of diagnosis and parent perception of the problem which could be affected by the parent's ability to recall information accurately (Chiri & Warfield, 2012). The diagnosis of ASD may not be accurate as a result of not having input from a medical record in addition to that of parent report (Chiri & Warfield, 2012). The NS-CSHCN provided a wealth of useful information for those seeking to understand the problem of health care accessibility for children with ASD, but there remain inherent limitations in the use of secondary data that limits the findings from the subsequent studies.

Of particular interest to this study was the use of the Consumer Assessment of Health Providers and Systems Survey (CAHPS) survey to examine the quality of the health care experience for children from the parent perspective. A small number of studies included in the meta-analysis used the CAPHS as part of their research design (Hall et al., 2014; Knapp et al., 2012). The survey was available online for individual researchers to use within the framework of their research study. The benefit to this was that researchers had access to a valid and reliable survey tool for the Medicaid population and the private insurance population. The tool enabled researchers to collect data that more closely matched the research question. The researcher also had access to the participants for any additional follow up questions and clarification of responses as needed. The use of the CAHPS questionnaire was likely to generate some of the same limitations as the NS-CSHCN in that the survey is heavily dependent on parent recall of information. An additional source of information such as a records review would provide a verification of parent responses.

### Increasing the Diversity within Sample Populations

A specific limitation relevant to the current study was the limited participation of African American and Latino children in studies focusing on the autism spectrum disorder (ASD) population. Large national surveys tended to have predominantly Caucasian participants (Benevides, Carretta, & Lane, 2016; Emerson et al., 2016). Findings from these larger studies must be reviewed with caution with greater than 60% of the sample being Caucasian (Emerson et al., 2016). Many of the studies related to ASD had non-diverse samples regardless of the size of the study. More needs to be done to attract a more diverse participant pool in ASD studies. Efforts to decrease the tension between the medical community and African American and Latino parents of children with ASD may increase the likelihood of their participation in research in the long-term.

The disproportionate ratio of Caucasian to African American and Latino individuals in studies related to autism is common (Benevides et al., 2016; Emerson et al., 2016). With the parents of African American and Latino children with autism reporting differences in their health care access experiences, it is important to ensure that each group is adequately represented in research studies assessing issues surrounding health care accessibility for children with autism.

## Rationale for a Mixed Methods Design

To date, the research completed on issues surrounding health care and the autism spectrum disorder (ASD) population have been completed through the use of primarily secondary data analysis. The analysis of large datasets provided much of the available information about accessibility to health care within the population of young children with autism. As a result, there were a limited number of studies using primary sources of data to address the issues. There were even fewer mixed methods studies in the literature. The limited number of mixed methods studies available however did add a greater depth of knowledge to the topic of health care accessibility for children with autism. Furthermore, children with autism from Latino and African American backgrounds are typically underrepresented within large datasets. The use of a primary data source enabled the researcher to recruit a sample of participants from African American and Latino backgrounds.

### Summary

An analysis of the literature revealed that understanding the problem of health care accessibility for young children with autism from the perspective of their parents was needed. Moreover, transitioning large populations of individuals with developmental disabilities to private Medicaid programs was such a novel endeavor that it was unclear how young children with autism that required intensive therapeutic interventions in the first three years of life would fare. The findings of the literature review supported the development of a research project designed to understand the impact of the transition to a private Medicaid payer system. Furthermore, the use of a mixed methods study was supported by the promising findings of the limited number of mixed methods studies related to the topic. Chapter 3 discussed the mixed methods research plan for the project.

## Chapter 3: Research Method

### Introduction

The purpose of this chapter was to discuss the collection and analysis of the data required to address the research questions. The central phenomenon under investigation in the study was accessibility to therapeutic health care services for young children with ASD under the age of eight living on the west coast of Florida. Accessibility is defined as a parent’s ability to acquire therapeutic health care services in a prompt manner for their young child diagnosed with ASD.

A mixed methods embedded design was used within the framework of this study to best address the research questions. The mixed methods design provided a thorough analysis of the problem of health care accessibility representative of Caucasian, Latino and African American children. The mixed methods approach helped to address some of the limitations of using either a qualitative or quantitative methodology. Some of those limitations include lack of diversity within the sample and the researcher's inability to tailor the research questions specific to the ASD population as a result of working with large national datasets. Furthermore, a mixed methods approach such as this one presented an opportunity to assess the needs of the target population while simultaneously giving caregivers an opportunity to express their thoughts on the topic in a confidential manner. The use of the mixed methods design was intended to generate data supporting the future direction of research and the development of research tools specifically designed to measure accessibility to health care services for children with autism.

## Restatement of the Problem

There was a considerable amount of evidence supporting the assertion that children with autism have unique challenges in accessing health care services and, in particular, therapeutic health care services. Furthermore, children from African American and Latino backgrounds face additional obstacles accessing health care services in general. The difficulties in accessing health care services delay diagnostic and therapeutic treatment services for young children with ASD (Siller et al., 2013). Transitions to managed care health care systems for children with disabilities in the state of Florida was not thoroughly explored in the literature prior to the privatization of Medicaid. The state of Florida was one of the first states to transition children with disabilities to a private payer Medicaid system. There was a gap in the literature related to how young children were affected by this transition in the state of Florida. African American and Latino children are at greater risk of experiencing challenges in accessing health care services in general. The problem was that young children with autism who did not receive health care services were at a significant disadvantage compared to their same age peers because they did not have access to therapeutic health care services in the first three years of life (Dababnah et al., 2011; Mandell et al., 2009). If the issue of health care accessibility is not addressed, there is likely to be economic consequences for the state government. The cost of caring for individuals with autism will rise as a result of the need for increased health care services over the course of the lifespan.

## Research Design

### Mixed Methods Design

Following approval from the Walden Institutional Review Board (IRB), the data collection process began (IRB Approval #10-13-16-0367112). In this study, an embedded mixed methods design was used. A cross-sectional survey with additional qualitative open-ended questions was the data collection method. The inclusion of qualitative and quantitative components strengthened the research design for several reasons. For one, the quantitative component offered an opportunity to sample a large number of families with autism in an efficient manner to determine how the change to private Medicaid has impacted access to health care services for children with autism. The use of multiple choice questions made the survey easy for participants to complete in a short amount of time. Furthermore, the addition of open-ended questions helped to examine if there was evidence indicating whether there were any unique challenges faced by those from diverse backgrounds when attempting to access therapeutic health care services for their child.

The inclusion of qualitative open-ended questions provided an opportunity to develop root definitions and rich pictures on the topic of health care accessibility (Hodges et al., 2012). The inclusion of the qualitative question increased the real-world applicability of the findings by making it possible to take those findings directly from the participants who were affected directly by the problem of health care access. The inclusion of the qualitative aspect of the study strengthened the suggestions related to the direction of future research on the topic. Additionally, utilizing a CCM approach ensured that positive outcomes were replicable for a broader range of children with autism.

## Restatement of the Research Questions

Quantitative:

*RQ1:* What are the differences in accessing therapeutic health care services for children with ASD based on insurance type?

$H_o1$: There are no differences in accessing therapeutic interventions for children with ASD based on insurance type.

$H_a1$: There are differences in accessing therapeutic interventions for children with ASD based on insurance type.

*RQ2:* What are the differences in delays reported by caregivers of children with ASD in terms of accessing therapeutic services based on insurance type?

*$H_a2$:* There will be no difference in delays in accessing therapeutic services based on insurance type.

*$H_a2$:* There will be differences in delays in accessing therapeutic services based on insurance type.

Qualitative:

*RQ3:* What are the unique challenges, if any that African American and Latino families face when accessing services for young children with ASD enrolled in a Medicaid program?

## The Setting

For this study, the setting was a recreational gym for children with autism and a children's autism center located within an outpatient medical clinic. A recreational gym for children with ASD and related developmental disabilities was an example of one of the locations used in the project. The gym was chosen because it provided open play and group therapy catering to children from all socioeconomic backgrounds who use all types of insurance. There were therapeutic group sessions provided at a discounted price for children not able to afford private therapeutic services. With the gym open 7 days a week there were ample opportunities to reach families.

## The Role of the Researcher

As an employee of a hospital system, I felt that I may have had a potential bias within this study. Several steps were built into the design of the study help to mitigate researcher bias. Several measures such as choosing a predeveloped survey instrument, and utilizing an expert/peer review process helped to reduce the chances of biased wording in the questions. Additionally, the inclusion of open-ended questions allowed participants to describe their experiences with health care accessibility in a confidential manner. Blinding the researcher and using a study team member during the recruitment process reduced potential bias. Participants were not offered a tangible incentive to participate to reduce potential bias even further.

## Methodology

### Population

The study looked to investigate the health care accessibility for children with autism spectrum disorder (ASD) living on the west coast of Florida. The specific population from which the sample was drawn was children under the age of eight years old with ASD living in the metropolitan area of Tampa Florida and the surrounding communities. The sample originated from local organizations that provided services to children and families affected by developmental disabilities such as ASD. Families learned about the opportunity to participate through recruitment flyers posted at support group meetings and gathering places such as the sensory and recreational gym and from a study member. Interested persons contacted the researcher or approached the study team member to receive the survey. The collection of data stopped when there were sufficient participants to determine statistical significance and there was saturation associated with the qualitative open-ended question.

By reaching out to organizations in the community supporting children and families with ASD, I hoped to reach participants with diverse ethnic and socioeconomic backgrounds. I sought out organizations offering free or discounted services to children with ASD. Participants with young children under the age of eight years of age were the target of the study. I sought to enroll the caregivers of children who experienced the transition to private Medicaid that occurred in 2014. A control group of children with ASD that used private insurance was also sought.

### Assumptions Testing

The assumptions associated with the chi-square test were that the population distribution of X was normal, the X's were a random sample from the population and the null hypothesis was true (Kirk, 1999). The assumptions related to the Mann Whitney U test were that there were independent observations and that the shape of the sample distributions was identical (Green & Salkind, 2011).

### Sample Size Justification

The sample size for the t-test was determined using g- power analysis. The power analysis was set to a priori. The effect size was set to detect a large effect size of 0.8 and the alpha level was set to .05. The necessary sample was size was 84. The sample size for the Mann Whitney U test was also determined using g power analysis. The power analysis was a priori. The effect size was set to detect a medium effect size of 0.5 and the alpha level was set to .05. 57 participants were needed to determine statistical significance using the Mann Whitney U test. To complete the chi-square analysis a sample size of 55 participants was needed. The statistical test to be used is the goodness of fit, contingency tables. The type of power analysis is a priori. The effect size was set to detect a moderate effect size of 0.5. The alpha level was set to .05.

## Instrumentation

Hall et al. (2014) studied the experiences of parents in the trial phase of the privatized Medicaid program in the state of Florida. Data was collected using the Consumer Assessment of Health Providers and Systems Survey (CAHPS) (Hall et al., 2014). The study did not look at specific groups within the population with special health care needs. Hence, Hall et al. (2014) noted the need for future research to assess the needs of special health care populations as the cost of caring for these special needs populations continue to increase. Thus, the CAHPS survey is to be used in the proposed study to determine the differences in health care accessibility based on insurance type.

The CAHPS 4.0 version has the option of adding specific questions that can address the needs of young children enrolled in Medicaid programs (Agency for Healthcare and Research Quality, 2017). The survey questions are answered by participants in either in a yes/no format or by the use of a Likert scale (Agency for Healthcare and Research Quality, 2017). The question on the survey that will be used to answer the first research question about whether or not there is a difference in accessibility based on insurance are answered in a yes/no format. The second research question about delays in accessibility to health care services will also be answered using the Likert format and the yes/no format. The instrument also has several questions relating to the child and caregivers demographic information such as the age of the child and the caregiver as well their gender and race (Agency for Healthcare and Research

Quality, 2017). As a result, the survey appears to have the necessary items needed to determine differences in health care accessibility and to determine the delays in access to care.

Lee Hargraves, Hays, and Cleary (2003) established the reliability of the 2.0 version of the CAHPS adult version. The measure had high internal consistency on two of the five composites. Cronbach's alpha was >. 75. Chong, Damiano, and Hays (2012) established the reliability of the adult 4.0 version of the CAHPS. The median internal consistency was .078. Agency for Healthcare and Research Quality (2017) notes that the survey measures have been thoroughly tested to ensure reliability and validity. I was unable to locate any research studies that specifically addressed the Psychometric properties of the CAHPS 4.0 version for children. Furthermore, there are no studies investigating the psychometric properties of the survey for use with children with ASD. Agency for Healthcare and Research Quality (2017) establishes the reliability and validity of the CAHPS through psychometric testing and cognitive testing. The combination of psychometric and cognitive testing is deemed sufficient for establishing the reliability and validity of the measure for use with general populations such as commercial health care users. The reliability and validity of the tool have not been established for specific populations of individuals such as young children with ASD. The reliability for using the tool for assessing the health care accessibility needs of young children with ASD will be assessed within the context of the current study.

## Recruitment

Participants were recruited from businesses serving children and families with autism spectrum disorder (ASD) on the West Coast of Florida. The commercial version of the Consumer Assessment of Health Providers and Systems Survey (CAHPS) 4.0 questionnaire is to be given to all participants because Medicaid in Florida is now a private payer commercial system.

### Establishing Reliability and Validity

Cronbach's coefficient alpha was used to determine the internal consistency reliability. A coefficient of >.70 was desirable (Lee Hargraves, Hays, & Cleary, 2003). A reliability index for individual items was also computed (Allen & Yen, 2002). The qualitative questions were assessed for readability using the Flesch-Kincaid Readability Formula (Petkovic et al., 2015). Being that there were limited instruments available that assessed health care accessibility for children it was not feasible to determine the construct validity. The determination of construct validity was beyond the scope of this project. The goal of the project was to determine the differences in access and if there were any differences in delays between two groups rather than to assess whether the survey instrument measured what it was intended to measure.

## Data Analysis Plan

### Quantitative Component

All the descriptive and inferential statistics for the project were to be analyzed using the SPSS program licensed by Walden University. Descriptive statistics were to be used to determine the mean, median, and standard deviations for each group in the study. The use of inferential statistics was necessary to determine whether the differences between the two groups (private payer Medicaid; traditional commercial private payer insurance) were statistically significant. The quantitative research questions were to be analyzed using nonparametric tests if the assumptions for the t test were not met.

### Qualitative Component

The qualitative data collected was to be analyzed within the Nvivo software program purchased by the researcher. The qualitative data was analyzed until a point of saturation was reached, and no new information was generated from the continuation of the analysis. The conceptual framework of the literature review was the basis for the development of preconceived themes for the qualitative data analysis. The conceptual framework supported the idea of looking for what was working in the system so that it could be replicated for others.

All data was to be stored in a locked storage box when not in use by the researcher. Data stored electronically was kept on a hard drive that was password protected. Only the researcher had access to the key to the storage box and to the password for the hard drive where the electronic data was kept.

## Data Cleaning Procedures

For the quantitative data, the data cleaning procedures consisted of regularly checking the data set for typing errors and column shifts. Descriptive statistics were to be graphed to find any data outliers that were not otherwise noticed through consistent data checking. Any detected errors would be coded as missing data. The qualitative data was carefully sorted and analyzed on an ongoing basis. Photocopies of participant responses ensured that no data was lost or distorted to the point that the data is rendered uninterpretable. The use of the Nvivo software was to be an asset when attempting to keep the data organized.

### Quality of the Qualitative Data

The quality of the qualitative data was ensured using journaling and a peer review process. I used a journal to reduce researcher bias in the data analysis portion of the project. After each data entry, I would write in the journal and those entries were shared with the peer reviewer. In addition to reviewing the journal entries, the peer reviewer also reviewed the data set to ensure that the data was organized and there was no blatant bias. I shared the findings of the project with participants to ensure that the views of the participants were not distorted or misrepresented.

### Integration of Data

The data from the quantitative and qualitative components of the study did not undergo a formal integration. The data was analyzed separately to answer the specific quantitative and qualitative research questions. I intended to keep the data sets separate and not to allow one set to influence the analysis of the other set. The qualitative data was analyzed first which reduced potential bias when coding the data. There was no process of integration that occurred to infer conclusions and determine potential future directions for research on the topic.

## Threats to Validity

There were viable threats to the internal and external validity of the study. The threats to the internal validity of the study made it difficult to discern whether the independent variable of insurance type was truly the cause of the differences or delays in accessibility. The internal validity of a study was threatened in part by the instrument. There were no known instruments that had been previously deemed reliable and valid measures of assessing health care accessibility for young children with autism spectrum disorder (ASD). The instrument selected for the project was modified in order to discern differences between the two groups in the study. As a result, the potential of the study was limited in that it was difficult to determine whether the independent variable was the clear reason for the changes in the dependent variable based on the results of the modified use of the instrument. Additionally, relying on caregivers as historians also threatened the internal validity of the project. Future research using mixed methods and qualitative methodologies would reduce threats to internal validity by triangulating the data to reduce internal threats to validity.

The external validity of the study was threatened by an inability to generalize the study to a larger population. Assessing the modified the Consumer Assessment of Health Providers and Systems Survey (CAHPS) tool for reliability and validity within the framework of the current study provides opportunities for future research to work toward generalizing the findings to larger target populations.

## Informed Consent

By completing the modified the Consumer Assessment of Health Providers and Systems Survey (CAHPS) survey and answering the open-ended questions, participants provided their consent to participate in the study. Completed surveys were an indication that participants gave their consent to participate in the study. Participants exited the study when they completed the survey instrument in its entirety. Each participant received a list of local counseling services in the event that the completion of the survey caused them to feel distressed in any way.

## Summary

A mixed methods embedded study was proposed to address the problem of health care accessibility for young children with autism spectrum disorder (ASD). There were few survey instruments available to researchers interested in studying health care accessibility for the ASD population. The instrument used in the study was a modified version of the commercial the Consumer Assessment of Health Providers and Systems Survey (CAHPS) 4.0. Additional open-ended questions added to the survey addressed the specific challenges that individuals from diverse backgrounds faced when accessing therapeutic health care services from a private Medicaid system. Additional attention focused on the needs of the African American and Latino populations because of a history of challenges in accessing health care. The additional open-ended questions explored the problem of health care access from the perspective of a group of individuals that traditionally were underrepresented in social science research (Benevides et al., 2016; Emerson et al., 2016). The credibility of the data was ensured through the process of member checking and peer review. Chapter 4 describes the research findings of the study.

# Chapter 4: Results

## Introduction

The results of the qualitative and quantitative data analyses that addressed the research questions are presented in this chapter. The qualitative and quantitative data was analyzed separately as the two types of data answered two different research questions. This chapter is divided into several sections, including a review of the purpose statement for the study, a review of the research questions, the overview of the sample, the results of the data analysis, and a summary of the chapter.

## Restatement of the Purpose

The purpose of the quantitative phase of the study was to determine whether there were differences in access to therapeutic health care services for young children with autism based on insurance type. The purpose of the qualitative phase of the study was focused on determining whether non-Caucasian children and their family experienced additional challenges in accessing health care based on race or ethnicity. Caregivers of young children from birth to 8 years of age using private and public insurance provided the information necessary to answer the research questions.

## Restatement of the Research Questions

### Quantitative:

Quantitative:

*RQ1:* What are the differences in accessing therapeutic health care services for children with ASD based on insurance type?

$H_o1$: There are no differences in accessing therapeutic interventions for children with ASD based on insurance type.

$H_a1$: There are differences in accessing therapeutic interventions for children with ASD based on insurance type.

*RQ2:* What are the differences in delays reported by caregivers of children with ASD in terms of accessing therapeutic services based insurance type?

$H_a2$: There will be no difference in delays in accessing therapeutic services based on insurance type.

$H_a2$: There will be differences in delays in accessing therapeutic services based on insurance type.

Qualitative:

*RQ3:* What are the unique challenges, if any that African American and Latino families face when accessing services for young children with ASD enrolled in a Medicaid program?

## Settings

There were no traumatic events or experiences that occurred during the time of the data collection that appeared to influence the participants. The data was collected at local businesses that provided services to families affected by autism. The local children's hospital was one of the locations that was used for recruiting participants for the study. To ensure recruitment was completed without coercion from the researcher, a study team member handled the recruitment for the participants recruited through the children's hospital. The hospital's IRB worked in conjunction with the Walden

University IRB to ensure the protection of the research participants in the study. The data for both the qualitative and quantitative analysis were collected over a 12-month period. The Walden IRB was granted copies of any documents that were requested during the data collection process.

## Demographics

Participants were the caregivers of young children between the ages of birth and 8 years of age diagnosed with ASD. Each participant who met the inclusion criteria for the study completed a survey that yielded quantitative and qualitative data for the final analysis. Participants were asked to provide demographic information about themselves as well as their child with autism. Eighty-six participants consented and met the inclusion criteria for participation in the study. One participant who consented and participated was excluded because the child was too old. The data for this participant was excluded from the both the quantitative and the qualitative data analysis. Demographic information related to the children in the study is provided in Table 1. Information pertaining to the caregivers is included in Table 2.

Table 1

*Individual Characteristics of the Children in the Sample*

|  | n | % | M | SD |
|---|---|---|---|---|
| Age | 86 |  | 4.64 | 1.23 |
| Gender |  |  |  |  |
| Male | 67 | 77.9 |  |  |
| Female | 19 | 22.1 |  |  |
| Race |  |  |  |  |
| White | 60 | 69.8 |  |  |
| Afr American | 11 | 12.8 |  |  |
| Asian | 3 | 3.5 |  |  |

| | | |
|---|---|---|
| Other | 4 | 4.7 |
| Mixed | 7 | 8.1 |
| Ethnicity | | |
| Hispanic | 15 | 17.4 |
| Non-Hispanic | 71 | 82.6 |

Table 2

*Demographic Characteristics of the Caregiver of the Child with Autism*

| Characteristic | N | % |
|---|---|---|
| Parent Gender | | |
| Male | 10 | 11.6 |
| Female | 75 | 87.2 |
| Relationship to the Child | | |
| Mother/Father | 84 | 97.7 |
| Grandparent | 1 | 1.2 |
| Education Level | | |
| Some high school, but did not graduate | 4 | 4.7 |
| High School Graduate/GED | 4 | 4.7 |
| Some college or 2-year degree | 36 | 41.9 |
| 4 year college graduate | 16 | 18.6 |
| More than 4 year college | 24 | 27.9 |
| Age range | | |
| 18-24 | 1 | 1.2 |
| 25-34 | 36 | 41.9 |
| 35 -44 | 39 | 45.3 |
| 45-54 | 7 | 8.1 |
| 55-64 | 2 | 2.3 |

The majority of the caregivers who completed the survey reported their gender as female (*n = 75)*. 88.4% of caregivers reported that they had at least some college experience. The demographic profile of the participants in this study is similar to a study that analyzed results from the Medical Expenditure Panel Survey (MEPS) (Parish et al., 2015). The MEPS is designed to oversample low-income and minority populations.

## Consent Process

Caregivers of young children aged birth to eight years with autism who were approached by the researcher or a study team member for recruitment into the study at a specific location were approached following a specific protocol. Participants recruited from the local hospital were only recruited to participate by the study team member to avoid any potential for participants to feel pressured into participating. Additionally, contact information was collected separately for participants wishing to participate in the member checking process following the completion of the data collection. Keeping the data separate from the contact information further assured participants that the information provided would not affect their care at the local hospital. The information about the study was shared with each potential participant. Interested caregivers were given a document to review. The document indicated that by completing the survey that they were consenting to participate in the study. The informed consent document provided information regarding the purpose of the study and the measures that the researcher would take to protect the confidentiality of the participants. The document also emphasized the voluntary nature of the study. Additionally, the document provided assurances that the participant's information was not to be used for other purposes and that the data would be secured by the researcher.

Participants who chose not to participant returned the clipboard with the research documents in the same manner that participants who completed the survey returned the clipboard with the documents. Participants were treated in the same manner regardless of whether they chose to complete the survey or not. Some participants omitted specific questions such as the questions pertaining to demographic information or the qualitative questions. All of the information that the participants did provide was factored into the analysis.

## Data Collection

The qualitative data was categorized using Nvivo software purchased by the researcher. The qualitative data was sorted by race/ethnicity to determine observable differences between the race/ethnicity on each of the open-ended questions. A text count in Nvivo quantified the number of times each theme was categorized for each race/ethnicity in the study.

## Assumptions Testing

The assumptions related to the t test were violated because the data was ordinal, therefore, the Mann Whitney U test was used in place of the t test. The assumptions of chi-square were tested by creating a frequency table to determine if the expected frequencies count were at least five or greater. The Fisher's exact test was used in the one case in which the expected frequency was less than five (Cochran, 1954). The assumptions testing was performed with SPSS software.

### Reliability and Validity

Cronbach's coefficient alpha was used to determine the internal consistency reliability. A coefficient of >.70 was desirable (Lee Hargraves, Hays, & Cleary, 2003). The coefficient value for all test items on the survey was $\alpha = .611$ indicating that there was less than ideal internal consistency among test items. However, prior assessments of the CAHPS survey indicated strong reliability for the measures total score (Co, Sternberg, & Homer, 2011).

A reliability index for individual survey items was computed (Allen & Yen, 2002; Mitra, Nagaraja, Ponnudurai & Judson, 2009) and the results are summarized in Table 3. A response of less than .30 indicated that the item was difficult to answer whereas a response greater than .80 indicated that a response was easy to answer for the participant.

Table 3

*Item Analysis*

| Item | N | Item Difficulty |
|---|---|---|
| 2 | 85 | .46 |
| 3 | 40 | .8 |
| 4 | 85 | .82 |
| 5 | 71 | .54 |
| 6 | 86 | .87 |
| 7 | 74 | .16 |
| 8 | 85 | .6 |
| 9 | 51 | .18 |
| 10 | 84 | .79 |
| 11 | 65 | .20 |

The qualitative questions were assessed for readability using the Flesch-Kincaid Readability Formula (Petkovic et al., 2015). The Flesch-Kincaid Readability for the qualitative open-ended questions was 5.9 indicating that the questions were appropriate for our sample with no caregivers reporting their education level to be less than eighth grade.

## Quantitative Analysis

To answer the first research question pertaining to differences in access to therapeutic health care services based on insurance type, the ordinal data was analyzed using the Mann Whitney *U* test. The results indicated no significant differences in responses between the private group (*M*=1.98, *SD*= 1.022) and the public group (*M*=2.25, *SD*= 1.175) for question seven (*U*=567, *p*=.367). The results indicated no significant differences in responses between the private group (*M*=2.21, *SD*= 1.122) and the public group (*M*=2.24, *SD*= 1.033) for question nine (*U*= 280, *p*=.851). The results indicated no significant differences in responses between the private group (*M*=2.62, *SD*= .962) and the public group (*M*=2.65, *SD*= .885) for question 11 *(U*= 472, p=.880). The categorical items were analyzed using a chi-square analysis. The results indicated no significant differences in responses between the private group (*M*=1.11, *SD*= .320) and the public group (*M*=1.15, *SD*= .364) for question six ($x^2$(1) =.268, p=.605). The results indicated no significant differences in responses between the private group (*M*=1.35, *SD*= .480) and the public group (*M*=1.48 *SD*= .508) for question eight ($x^2$(1) =1.618, *p*=.203). The results indicated no significant differences in responses between the private group (*M*=1.17, *SD*= .382) and the public group (*M*=1.28 *SD*= .457) for question 10 ($x^2$(1) =1.377, *p*=.241). The null hypothesis was accepted for research question one.

The second research question pertaining to delays in access to care was analyzed in the same manner as question one with the same statistical tests. The ordinal data for the question was analyzed using the Mann Whitney *U* test. The results indicated no significant differences in responses between the private group (*M*=3.95, *SD*= .213) and the public group (*M*=3.56 *SD*= .616) for question three (*U*=129.5, *p* =.062). The results indicated no significant differences in responses between the private group (*M*=3.31, *SD*= .811) and the public group (*M*=3.38 *SD*= .820) for question five (*U*=578, *p*=.689). The results indicated no significant differences in responses between the private group (*M*=1.21, *SD*= .412) and the public group (*M*=1.12, *SD*= .331) for question four ($x^2(1) = 1.133$, *p*=.287). The null hypothesis is accepted for research question two.

A paired samples t test was conducted to determine significant differences between items on the CAHPS survey measuring access to health care versus access to therapeutic health care services. Significant differences were found between question 2 and question 6 (t (84) = 6.748, p = 0.00) and between question 3 and question 7 (t (36) =-8.338, p = 0.00) indicating that the participants in the study struggled more to access to therapeutic services for their child than to access basic health care services.

## Qualitative Analysis

The qualitative analysis revealed that the parents of non-Caucasian children utilizing the health care services for their child with autism in the sample did not indicate that race, culture, or ethnicity impacted their ability to access health care services for their child. Race, culture, and or ethnicity did not create more challenges for participants when attempting to access therapeutic health care services for their young children with autism. This finding is contrary to what was indicated in the literature and what was initially hypothesized, as some non-Caucasian parents indicated positive experiences accessing health care for their child with autism but there is still cause for concern because some participants were proactive in their efforts to avoid problems with race, ethnicity, and culture.

One caregiver of a mixed race child indicated that there were no problems as a result of race, culture or ethnicity because she always chose Caucasian when completing demographic information on the child. This may indicate that there are in fact problems with race, culture, and ethnicity affecting health care access still in the system but that caregivers are savvy and being proactive in their efforts to avoid potential problems in the best ways that they know how to do that.

The analysis brought to light the fact that all participants of all races, cultures, and ethnicities had challenges in accessing therapeutic health care services for their child with autism. The challenges were noted by all participants regardless of demographic characteristics. Participants from both groups offered a range suggestions as to what has worked for them in terms of accessing health care services for the child and suggestions for improving the system. The results were analyzed using Nvivo software. A combined text frequency count was analyzed for the questions *"Is there anything that worked well for you in terms of getting your child access to health care in a timely manner?"* and *"If you could offer advice to other families struggling to gain access what would you suggest for them?"* The results indicated that the most common response for both Caucasian and Non-Caucasian groups was *"to call."* Participants within the Caucasian group indicated that calling the insurance company was most beneficial whereas the participants in the Non-Caucasian group indicated that calling their providers was most helpful when attempting to access health care services.

## **Quality of the Qualitative Data**

The quality of the qualitative data was ensured by using a researcher journal, a peer reviewer, and member checking. The peer reviewer reviewed the data and indicated that were no signs of bias in the way that the qualitative data was analyzed. The peer reviewer made several insightful comments that are to be included in the social change section of Chapter 5. The participants who chose to share their contact information received a copy of the summary of the research findings. They were given a two week period to make comments. The comments and suggestions were also incorporated into the final analysis of the data.

## Summary

The quantitative research questions examined access to therapeutic health care services and delays in access to therapeutic health care services. The researcher failed to reject the null hypotheses for differences based on insurance type. Upon item analysis, it was determined that participants, on the whole, found it harder to access therapeutic health care services than general health care for their child with autism. The qualitative analysis of the study indicated that there were challenges in terms of accessing therapeutic health care, but that those differences were not based on race, culture or ethnicity. Identifying that there are struggles in both groups in terms of accessing therapeutic health care services will help children and families with autism to gain access to the care they need in a more efficient and timely manner regardless of whether they have private or public health care insurance.

# Chapter 5: Discussion, Conclusions, and Recommendations

## Overview

As the cost of health care continues to rise and an increasing number of children and families are affected by autism, there is an urgent need to address the problem of therapeutic health care access for young children with autism. Therapy has the most benefit for individuals with autism when provided in early childhood (Estes et al., 2015; Jaffee, 2013). Therefore, time is of the essence on the issue of therapy access for young children with autism. Individual states in the United States such as Florida have privatized their Medicaid programs in an effort to reduce costs (Knapp et al., 2012). Privatizing Medicaid programs reduces costs (Knapp et al., 2012; Marcu et al., 2016). There are questions that remain such as: How does a reduction in cost affect the quality of care that children, in particular children with chronic conditions such as autism, receive?

The purpose of the present study was twofold. The study quantified the problem of access to therapy for young children with autism while also exploring qualitatively any additional challenges faced by African American and Latino families. The findings from this study indicated that participants regardless of their insurance type found it difficult to access therapeutic health care services for their child with autism. Participants in the study of all races, ethnicities, and cultures indicated frustration with access to therapeutic health care services for their child with autism. Caregivers struggled equally in their attempts to get therapy for their young child with autism. As a result of the willingness of the participants to share their experiences about access to therapy, a significant amount of information was generated from the open-ended questions on the survey. The participants offered advice to other parents on what has worked for them, and they provided suggestions to improve the overall system to increase access to therapeutic health care services for children with autism. Following the analysis of the study results, the participants were also provided an opportunity to give input on the findings. The remainder of this chapter is dedicated to understanding the findings of the study in the context of the conceptual framework and exploring ways in which the findings can be used to improve health care access for those affected by autism.

## Conceptual Framework

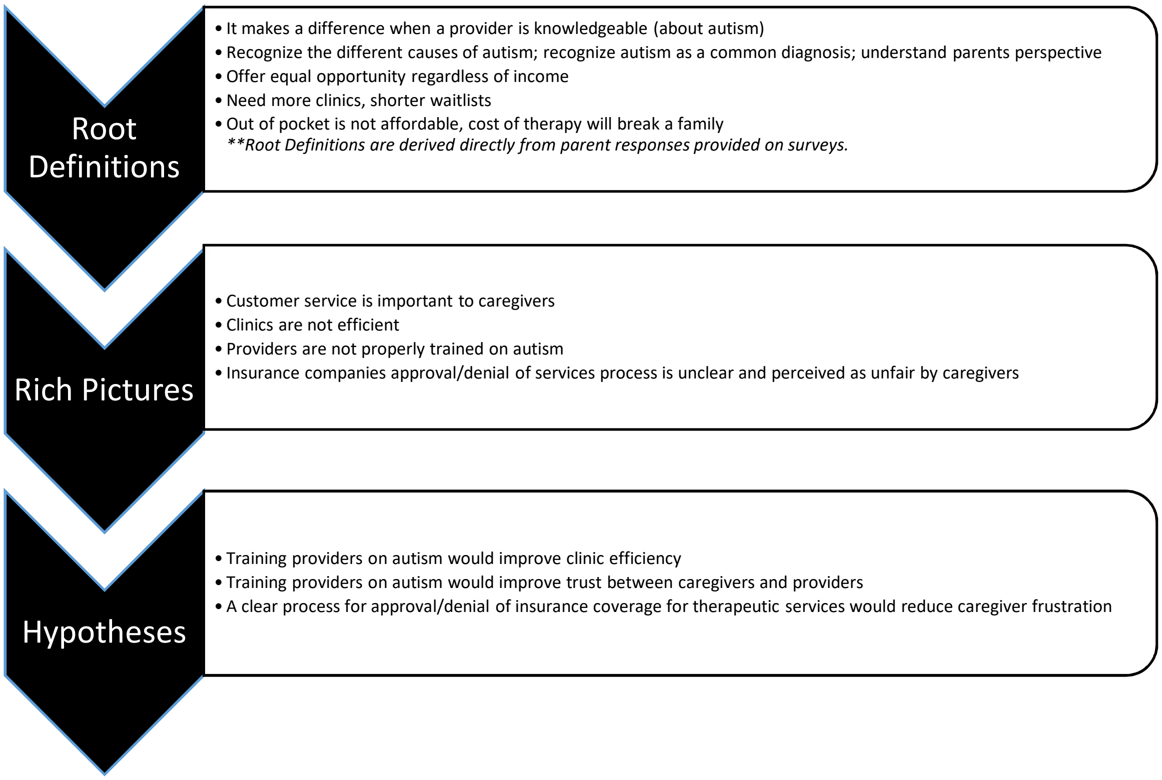
The conceptual framework for this study included elements from four different theories. In review, those theories were Aday and Andersen's BHM, social model of disability, CCM, and SSM. All four of the theories helped contribute to the interpretation of the findings in the study. Through the lens of the BHM model, it is clear that barriers continue to exist that prevent children with autism from accessing therapeutic care within the health care system in Florida and there is a high degree of caregiver dissatisfaction upon entrance into the system. This study found that regardless of insurance type or race/ethnicity, there were struggles to enter into the health care system and to find a high quality of care once in the system. Barriers to access such as churn impede individuals with autism from reaching their full potential in adulthood as predicted in the social disability theory.

To develop solutions that increase access to health care for young children with autism, CCM and SSM are essential to ensure that solutions have real-world applicability. SSM generated qualitative data for the researcher to use to follow up with participants on their thoughts regarding the findings of the study. Participant thoughts and comments are incorporated in the final analysis and the development of the rich pictures and root definitions.

## Interpretation of the Findings

Findings from the study indicated that there is a problem accessing therapeutic health care services for children with autism, but the problem is not related to insurance type. Item analysis of the survey questions indicated that it is easier for caregivers to access general health care services for the child with autism than therapeutic health care services. Through the item analysis of the survey questions, it is evident that caregivers attempted to access therapeutic health care services for their child but found it very difficult to actually get those services. It is evident that caregivers experienced high levels of frustration due to the lack of access to therapeutic health care services for their child with autism.

The development of root definitions made it possible to develop rich pictures associated with the caregiver's perspective on the problems with the system. From these rich pictures, a better understanding of the problem emerged. Figure 1 is a diagram of the progression from root definition to hypotheses for this study. The participants in the study provided the root definitions that were then used to develop the rich pictures and hypotheses. The hypotheses developed from this process can be used to formulate a plan to address the problem of access to therapeutic health care for children with autism.



- It makes a difference when a provider is knowledgeable (about autism)
- Recognize the different causes of autism; recognize autism as a common diagnosis; understand parents perspective
- Offer equal opportunity regardless of income
- Need more clinics, shorter waitlists
- Out of pocket is not affordable, cost of therapy will break a family

***Root Definitions are derived directly from parent responses provided on surveys.*

- Customer service is important to caregivers
- Clinics are not efficient
- Providers are not properly trained on autism
- Insurance companies approval/denial of services process is unclear and perceived as unfair by caregivers

- Training providers on autism would improve clinic efficiency
- Training providers on autism would improve trust between caregivers and providers
- A clear process for approval/denial of insurance coverage for therapeutic services would reduce caregiver frustration

*Figure 1.* Figure depicting hypotheses development.

Caregivers from the private insurance group mentioned the need for ABA more times than caregivers in the Medicaid group. It appeared as though ABA was more of a pressing concern for the private insurance group but recent changes in the processes for authorization of services for Medicaid patients in Florida makes it likely that ABA will become a pressing concern for all families affected by autism living in Florida (Agency for Health Care Administration, 2017). The new authorization process for ABA requires preauthorization and frequent reassessments to determine the need to continue the ABA services (Agency for Health Care Administration, 2017). Changing the authorization process for Medicaid patients seeking ABA services is likely to impact caregiver perceptions of access to service for ABA within this population. This supports the notion that the problem is less related to a specific insurance type and more related to the policies and procedures put in place by insurance companies to determine eligibility for therapeutic health care services.

## Recommendations

Participants in this study frequently mentioned a lack of providers and therapists and long waitlists as important aspects of the health care system that need to be improved to increase access to therapy. Austin et al. (2016) used a systems analysis approach to improving access to care at Autism Treatment Centers and through this approach, each of the clinical teams in the study were able to find sources of delay in their system and use information gained from their analysis to reduce the delay, resulting in significant reductions in the number of patients on waitlists and delays for ongoing care appointments. Waitlists were significantly reduced by using data analysis tools such as mapping of the clinic flow (Austin et al., 2016). The use of mapping can help to reduce waitlists, thereby improving access to therapy services. Providers can help to meet the demand for access to therapy by ensuring that their clinics are running as efficiently as possible. Improving the efficiency of clinics will likely result in less frustration on the part of caregivers, leading to more trust and better relationships between providers and caregivers. This will likely benefit the child with autism.

The next step in the process identified by Austin et al. (2016) is to study the impact of the changes on stakeholders such as caregivers. As demonstrated by the current study, caregivers are acutely aware of the problems in the system interfering with their ability to gain access to therapy for their child. More mixed methods research studies are recommended to take into account how changes in the system are impacting access to care from the caregiver's perspective. Many participants in this study commented on the complexity of the system and how it was impacting access to care for their young child with autism, so researchers should continue to give a voice to caregivers in future studies. This will help to ensure that quality of care is not compromised as clinic productivity demands increase.

Participants in this study reported that a relationship with providers was beneficial to their ability to access to care for their children. Participants reported that what was helpful to them was when providers would go the extra mile for them and make calls or referrals for their child. Participants also reported that the system would be improved if providers were more knowledgeable about autism. A study by Mazurek, Brown, Curran, and Sohl (2017) indicated that physicians themselves do not feel educated enough about autism. Mazurek et al. (2017) demonstrated the effectiveness of a pilot project called the Extension for Community Health care Outcomes (ECHO) to improve physician training in autism. It is recommended that physicians be trained in autism using evidenced based curriculum. This is an important step in improving access to therapeutic health care for young children with autism. Increasing provider knowledge about autism may increase trust between caregivers and physicians thereby strengthening the relationship and leading to better outcomes for the child with autism.

To further build trust between provider and caregiver, modules in the curriculum should encourage providers to be mindful of cultural differences when working with the families of children with autism. Misunderstandings related to culture between provider and caregiver may result in delays in enrollment in therapy services (Durkin et al., 2010; Gourdine et al., 2011; Janvier et al., 2015; Mandell et al., 2009; Parish et al., 2012a). Indications from participant responses in this study are that there is a need for cultural awareness training for providers. Participants indicated that they avoided any potential problems with race by indicating that the child was Caucasian on medical intake forms.

Recent research studies support a trend indicating that race is becoming less of a factor in the care and treatment of autism (Emerson et al., 2016; Jo et al., 2015). Larger studies accessing data from providers and from caregivers is necessary to truly understand whether the issue of race is affecting therapeutic access to care. It appears evident from this study that the primary issue affecting therapeutic access to care for the children with autism in this study was related to the policies and procedures set in place by both insurance companies and medical facilities.

## Social Change Implications

The results of the study can provide implications for social change on the issue of access to health care for children with autism. Researchers and clinical providers can make social change by working together to develop effective clinical models that include the use of evidenced based training curriculums. The result will be efficient clinics that are run by empathetic and knowledgeable providers and staff. By improving clinical care models, children can get diagnosed quicker, and caregivers can begin the process of working with their insurance carrier to get access to necessary therapies. By researchers, and providers working together this will ensure that the quality of care is as important as reducing cost and improving efficiency.

Changes to the insurance process are necessary to ensure that access to therapy is not delayed or denied when it has been deemed medically necessary by a trained and informed provider. Stakeholders in positions of authority and power can ensure that changes are made to legislation that prevents insurance companies from denying access to therapeutic health care in the critical early years for the child with autism and their family. Caregivers and autism advocates alike can help to ensure that those in positions of power and authority hear their voices on issues about therapy access for children with autism through calling and writing their elected representatives.

The research findings may also make social change by empowering the voice of the caregiver to be heard in autism research. Through the inclusion of open-ended questions and providing an opportunity to give feedback on the findings, caregivers have an opportunity to feel as though their voice on this issue is being heard. Despite parents indicating frustration with the system, they indicated that they were not going to give up and that they would keep fighting for their child with autism. I hope that the findings generate social change in that future researchers will choose to incorporate the caregiver perspective into their methodology.

## Limitations of the Study

Several limitations are present in this study. Several are related to the instrument that was used in the study. There was a threat to internal validity from the lack of an established instrument specifically normed to assess the health care access needs for children with autism. The survey tool used in this study was modified by adding open-ended questions impacting its ability to be considered a reliable tool.

The direct upfront nature of the question of race affecting access to therapeutic care may not have been the best way to assess whether race is affecting access to therapeutic health care services. There may have been issues of unconscious bias that caregivers are not aware of that affect their access to care. A multi modal approach involving a series of questions and engaging providers in the discussion may lead to a better understanding of how race is impacting access to care for this population.

Additionally, there were challenges in accessing low-income patients due to an inability to share the study information at locations where it would be likely that these patients would be receiving care. The challenges gaining access to patients contributed to a small sample size.

## Conclusions

There is a great deal at stake both in regards to financial cost and the human cost of not acting quickly on this issue.  The number of children diagnosed with an Autism Spectrum Disorder (ASD) is rising, and the best treatment outcomes occur when therapy is provided in the early years, so delays in access are only costing taxpayers money and limiting the potential for children with autism to become independent adults capable of contributing to society.

Early diagnosis and treatment of autism are crucial to getting children on as close to a normal developmental trajectory as possible. It is clear from the findings in this study that caregivers of young children with autism are having difficulty accessing therapeutic health care services for the child. The difficulties in access to therapeutic care occurred across insurance groups and were not solely the result of race, ethnicity or culture. It appeared to be more difficult for caregivers to access therapeutic health care services than it was to access health care in general. Social change efforts can be focused specifically on improving access to therapy services for children. As per the research conducted by Austin et al. (2016) and Mazurek et al. (2017) it is possible that simplifying clinic flows and educating clinicians on autism could have significant impacts on access to care in general for children with autism. Increasing access to therapeutic health care will make a positive impact on the lives of children and families affected by autism.

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# Appendix A: Title of Appendix

Our records show that your child is now in {INSERT HEALTH PLAN NAME}. Is that right? ____________

What is the name of your child's health plan? Please print: ______________

When responding to the questions do not include care your child got when he or she stayed overnight in a hospital. Do not include the times your child went for dental care visits.

In the last 6 months, did your child have an illness, injury, or condition that needed care right away in a clinic, emergency room, or doctor's office?
Yes ☐
No ☐

In the past six months, when your child needed care right away, how often did your child get care as soon as you thought he or she needed?
☐ Never
☐ Sometimes
☐ Usually
☐ Always

In the last 6 months, not counting the times your child needed care right away, how often did you get an appointment for health care at a doctor's office or clinic as soon as you thought your child needed?
☐ Never
☐ Sometimes
☐ Usually
☐ Always

In the last 6 months, did you get or try to get special therapy such as physical, occupational, or speech therapy for your child?

Yes ☐
No ☐

In the last 6 months, how often was it easy to get this therapy for your child?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always

In the last 6 months, how often was it easy to get this treatment or counseling for your child?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always

In the last 6 months, did you try to get any kind of care, tests, or treatment for your child through his or her health plan?

Yes ☐
No ☐

In the last 6 months, how often was it easy to get the care, tests, or treatment you thought your child needed through his or her health plan?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always

What is your child's age? ☐ Less than 1 year old

______ YEARS OLD (write in)

Is your child male or female?
☐ Male
☐ Female

Is your child of Hispanic or Latino origin or descent?
☐ Yes, Hispanic or Latino
☐ No, not Hispanic or Latino

What is your child's race? Please mark one or more.
☐ White
☐ Black or African-American
☐ Asian
☐ Native Hawaiian or other Pacific Islander
☐ American Indian or Alaska Native
☐ Other

What is your age?
☐Under 18
☐ 18 to 24
☐ 25 to 34
☐ 35 to 44
☐ 45 to 54
☐ 55 to 64
☐ 65 to 74
☐ 75 or older

Are you male or female?
☐ Male
☐ Female

What is the highest grade or level of school that you have completed?
☐ 8th grade or less
☐ Some high school, but did not graduate
☐ High school graduate or GED
☐ Some college or 2-year degree
☐ 4-year college graduate
☐ More than 4-year college degree

How are you related to the child?
☐Mother or father
☐ Grandparent
☐ Aunt or uncle
☐ Older sibling
☐ Other relative
☐ Legal guardian

Did someone help you complete this survey?
☐ Yes ☐ No

Thank you. Please return the completed survey in the postage-paid envelope.

Please respond to each question. Write N/A if it doesn’t apply to you or your child. You can use the back of the paper if you need more room to write your responses.

How have your experiences with gaining health care services been affected by the child’s race, ethnicity or culture?

Is there anything that worked well for you in terms of getting your child access to health care in a timely manner?

If you could offer advice to other families struggling to gain access to health care services for their child what would you suggest to them?

In what ways can the health care system improve to better meet your child’s needs?